Human Rights of People Living with HIV, Men with Diverse Sexualities and Transgender Women in PNG

Tim Leach

February 2021

A thesis submitted for the degree of Doctor of Philosophy
at The Australian National University

Declaration

This thesis is my own work. All sources used have been acknowledged.

17 February 2021

Abstract

My thesis is an exploration of how human rights are understood and experienced by Papua New Guinean people living with HIV, men with diverse sexualities and transgender women. I examine the emergence and progress of two organisations established by these communities: Igat Hope and Kapul Champions. I consider the ways these organisations have, while still pursuing their missions to limit the impacts of HIV on their members and all Papua New Guineans, been used to help promote the human rights of constituents. Through this examination, I reflect on my own history with these organisations and the community movements which have built them, and on my roles as advocate and researcher.

I find that the human rights of people with HIV, men with diverse sexualities and trans women in PNG are regularly violated across many areas of life. I find these communities have an understanding of human rights and support their promotion, particularly rights analyses that recognise the value they place on community connection and that emphasise their inclusion. I see human rights in PNG as a dynamic space, with an indigenisation of the rights framework that will facilitate its application. I find both Igat Hope and Kapul Champions to have significant records of achievement, including in human rights. I also find a way to be comfortable in my multiple roles, suggesting some ways in which my research might support local advocacy efforts.

Acknowledgements

I am forever indebted to the 72 people living with HIV, men with diverse sexualities and transgender Papua New Guineans who shared their stories with me as I conducted my research. These stories were great gifts, generously bestowed, although some of them must surely have been hard to tell. I am profoundly grateful to the past and present boards, employees and members of Igat Hope and Kapul Champions. These are critically important organisations which have been both led by and produced some remarkable human rights advocates. I have had extraordinary, ongoing support from both organisations and I could not have done this research without this help. I have had the great privilege of working with some true human rights champions in PNG and I feel very lucky not only to have known them, but to have had so many of them agree to participate in this research.

I am deeply indebted to my supervisory panel, chair Professor Margaret Jolly and doctors Katherine Lepani and John Rule, all such clever and supportive people. I've greatly valued the rolling conversations we have had about my research over many years, conversations which have sustained and encouraged me as I plodded away through the writing process. Thanks also to Dr Carolyn Brewer for her excellent editing work on my thesis. I am grateful to the National Association of People With HIV Australia and the Australian Federation of AIDS Organisations for entrusting to me the responsibility of helping deliver their development programs in PNG. These have been among the most enjoyable moments of my professional life. I've worked with some amazing people in PNG and, in writing this, I have recalled them all at various points, admiring their efforts and musing on our shared experiences, occasionally chaotic and often hilarious. It sometimes felt very hard, but it was also a privilege. In particular I thank my dear friend Elizabeth Reid for taking me on my first trip to PNG and changing my life forever.

And thanks to my family, who have listened patiently, thoughtfully and sometimes confusedly to my stories of PNG. I hope to take you all there one day.

Table of Contents

List of Illustrations

Pseudonyms

The following list provides the status and names of people who are quoted in this thesis or to whom direct reference is made, but, according to assurances of anonymity, all are referred to by pseudonyms as below.

People Living with HIV (PLHIV):
Alani, Bosai, Caleb, Elsie, Juvelyn, Kutan, Matilda, Miriam, Moia, Rachel, Ruth, Serah, Toby
Men with Diverse Sexualities (MDS):
Obi, Justin, Lionel, Sam, Thomas
Trans women:
Chris, Dau, Elizabeth, Jara, Jasmine, Jonah, Jonny, Kiteni, Magda, Marta, MaryAnne, Natasha, Rita, Rossa, Therese, Veronica
Stakeholders:
Angela, Anthony, Damien, Dante, Esther, Jamie, Laurel, Victor

However, the dedications at the start of each chapter refer to high-profile public activists whose achievements relating to human rights and their communities are well known and have been documented elsewhere—some have now passed.

Chapter One
Introduction and Context

I have dedicated each chapter of my thesis to a different human-rights champion with whom I have been privileged to work in Papua New Guinea (PNG). Each has been a leader, a courageous defender of the human rights of people living with HIV, men with diverse sexualities (MDS) and trans women in PNG. There is not necessarily a link between the person and the content of their dedicated chapter, but each person has been a major contributor to the community movements I document through my thesis.

This chapter is dedicated to Jason Lavare. Jason worked for Save The Children in PNG's Poro Sapot Project (PSP) for many years during the 2000s, coordinating programs for men who have sex with men. No story about the rights of men with diverse sexualities and trans women in PNG is complete without reference to PSP, and no story of PSP is complete without reference to Jason. Jason coordinated PSP's HIV awareness programs for MDS, supervised outreach to MDS across the National Capital District and ran the drop-in service for MDS, the first and last of its kind in PNG. He was an early spokesperson for the MDS and transgender community in PNG — a public face when there were few on offer. He was forever cheery and helpful, and key to building the relationship between PSP and the Australian Federation of AIDS Organisations (AFAO) that enabled the establishment of the Leadership Development Group, of which Jason was a member. This group then went on to establish Kapul Champions. Nearly every research report of the emerging MDS and transgender response in PNG acknowledges Jason's contribution, as an interviewee, informant, contributor, guide. He was very generous with his knowledge and was articulate and persuasive. He died a young man in 2010.

*

My thesis is a story, itself comprised of several stories. First, it is the story of three communities in Papua New Guinea (PNG): people living with HIV (PLHIV); men with diverse sexualities (MDS); and transgender (or trans) women. This story explores the way they understand, embrace and experience human rights, as well as the way their rights, and observance of them, are shaped by HIV. Second, it is the story of two organisations set up by and for these communities: Igat Hope (for PLHIV) and Kapul Champions (for MDS and trans women). Third, it is my story, of my work and aspirations as a development worker, researcher, advocate and activist. The telling of these stories has been shaped in turn by the stories of my 72 interviewees, shared with me over several years. So, there are lots of interwoven stories with each impacting on the others.

My thesis is, in a sentence, an exploration of the human rights of PLHIV, MDS and trans women in PNG. I hope this thesis will contribute to knowledge by documenting the views of Papua New Guinean PLHIV, MDS and trans women on human rights, and their experiences of rights violations. It will tell the story of work that has been done in PNG over the last 20 years to advance and protect the human rights of these communities and look for learnings from this work. The thesis will explore the connections between international, constitutional and legal rights in PNG, and consider a range of factors that shape the ways rights are conceptualised in the country. Given the demonstrated link between protection of the human rights of marginalised groups and the prevention of the spread of HIV within these communities (more of this later), the study will also generate public-health insights. Any evidence that can be assembled to show how the human rights of marginalised groups in PNG might be best protected will be useful not only for PLHIV, MDS and trans women, but for the broader public health of the country.

In embarking on this research, I set the following key research questions.

1. How do the people who self-identify or are described as PLHIV, MDS and transgender think about their HIV status, their sexuality, their gender or their membership of these groups? Is there a shared notion of community amongst the members of these groups, such that might support a community response to HIV or any other issue?
2. How do members of these groups think about human rights? Do they think there are commonalities between their experiences of human rights and the experiences of other members of their group/s?
3. How are the human rights of group members observed in PNG?
4. How have Igat Hope and Kapul Champions conceptualised and approached human rights? What efforts have Igat Hope and Kapul Champions undertaken to promote the rights of their constituents?
5. How have the PLHIV, MDS and trans-women communities in PNG experienced these efforts to promote their rights?
6. What, if any, impacts have these efforts had?
7. What can past efforts teach us about what might be done in the future to promote the human rights of PLHIV, MDS and trans women in PNG?

A guide to the chapters

This opening chapter acts as a general introduction before exploring three issues in detail. The first relates to the names and labels used to describe PLHIV, MDS and trans women in PNG, including by members of these communities and the organisations that represent them. This discussion necessarily involves questions of identity and the influence of external forces, including the global HIV epidemic. Second, I describe the international and local legal frameworks shaping how rights are understood and experienced in PNG. Third, I explore the interconnectedness of HIV and human rights. I have chosen to explore these three issues at the outset as they are so critical to the framing of the stories that are told over subsequent chapters.

Chapter 2 begins with a reflection on my work history and identity. It canvasses my work in PNG with the communities and organisations that are the focus of this research. I explore my role as an outsider and the question of whether I am sufficiently external to be impartial. This chapter also explores the role of the activist researcher. Reflecting again on my own past and motivations, I consider the challenges and benefits associated with being politically invested in my research, the connections between a researcher’s motivations and the goals of a community being researched, and whether and how research can reflect collaborations between researchers and their subjects. I settle on an understanding of my role that is sufficient for me to give myself permission to write this thesis.

The chapter concludes with a description of my methodological approach: qualitative interviews, participant observation and analysis of documentation. I describe how my research interviewees can be divided into four main groups: PLHIV, MDS, trans women, and then a group of people I have collectively described as ‘stakeholders’. This last group includes people whose views were sought because they work in HIV and/or development in PNG and/or Australia, they have knowledge of PLHIV, MDS and trans women in PNG, and because they were likely, in my view, to have an interesting perspective on the issues I was researching. Sometimes I consider and report issues or views group by group, while at other times I canvass an issue as it relates to all groups.

In Chapter 3, I explore the notion of human rights and how it is understood in PNG. The views of PLHIV are presented separately from those of MDS and trans women. I start with an analysis of how PLHIV conceive of their human rights and where they think their rights come from. I describe which rights are most commonly cited by PLHIV and consider the practice of understanding and articulating human rights by reference to unfair or discriminatory treatment. I then consider how MDS and trans women conceptualise their rights and where they think the source/s of their rights might be located. The chapter also explores the perceived interrelationship between rights and responsibilities in PNG, a major theme to emerge in my research. The chapter moves on to a consideration of stakeholders' views on rights and their origin before contextualising group knowledge of rights: many interviewees felt very strongly that this knowledge is only part of the picture. While observing that knowledge of rights is important, many interviewees argue this knowledge must be supported by appropriate domestic laws, by a capacity to enforce laws and by a willingness to do so, even where enforcement is said to ‘go against culture’.

In Chapter 4, I relate the stories shared by my interviewees when asked how their human rights are observed in PNG. All-in-all, it is a rather grim read. My interviewees’ voices are heard sharing examples of their rights having not been respected or having been intentionally violated. My interviewees frequently utilise the notion of ‘stigma and discrimination’, a phrase imported to PNG, but which now has great domestic currency. This affords an opportunity to reflect on HIV discourse more generally, and its impact on the communities with whom I have been working.

I begin with the experiences of PLHIV and interrogate the proposition that life has improved for them in PNG. I document the enduring experience of stigma and discrimination for PLHIV, focusing on the areas of health care, employment and education. I consider the experience of being discriminated against on multiple grounds, sometimes referred to as ‘double discrimination’ (although it can involve discrimination on more than two grounds), before exploring the notion of class in PNG and whether this may affect PLHIV experiences of stigma and discrimination. I consider the role of anti-retroviral therapy (ART) and its inseparability from the experience of stigma and discrimination in modern PNG. Having reported on the range and frequency of rights violations, I explore how PLHIV feel about their avenues of redress before making a couple of observations on the burden of responsibility for HIV prevention.

The chapter then moves on to document the experiences of MDS and trans women. I begin by sharing interviewees’ observations on whether their rights are respected generally, before focusing on the rights that MDS and trans women say are most frequently violated. The chapter explores the interconnectedness of these rights and what it might mean, in the PNG context, for a trans woman to ‘be herself’. The chapter considers research done with trans communities across the Pacific, as well as broader explorations of non-normative Pacific experiences. Interviewees share stories of being excluded from community (but often building communities of their own), police brutality and discrimination in the areas of education, health care and employment. The chapter details interviewees’ thoughts on *why* their rights are not respected, focusing on the ‘place’ of MDS and trans women with reference to PNG history and culture and the role of Christianity. This section considers the roles of class and HIV in shaping the lives of MDS and trans women, the views of trans women on how their ‘special nature’ constitutes a strength, and views on seeking redress for rights violations. This section of the chapter concludes by looking at Kapul Champions’s documentation and other research that might usefully contextualise interviewees’ stories. The consideration of Kapul Champions’s documentation introduces the notion of the organisation as an advocacy agency, as a documenter of experiences and charter of reform. The chapter concludes by comparing the experiences of PLHIV, MDS and trans women. The chapter finds commonalities in the experiences of violence, stigma and discrimination. It also notes important differences.

Chapter 5 shifts gear to focus on Igat Hope and Kapul Champions as organisations. I begin by discussing the community-based organisation model used by Igat Hope and Kapul Champions before embarking on the task of telling the organisations' respective stories. Each organisation is considered separately, and for each the story begins with a focus on the 'what', that is, the recounting of what the organisation has done in its years of operation. This is followed by a discussion of what the organisations might claim to have *achieved*, particularly in relation to the building of community voice, self-determination, visibility, legitimacy with stakeholders, peer connection, community pride, and success in combining rights, health and community development.

Following this reflection on the organisations' work and impact, in Chapter 6 I ask whether the community-based model utilised by Igat Hope and Kapul Champions is in fact fit for purpose in PNG. Concluding that the model can indeed be useful in the PNG context, given the right factors and a degree of good fortune, I then suggest what might have been done differently to enhance the success of the two organisations. In the second part of this chapter, I focus on the organisations' human-rights work. After considering what measures might be used to assess achievement, I explore how effectively the organisations promoted the human rights of their constituents.

Chapter 7 explores the overall usefulness of human-rights advocacy in PNG. It draws on interviewees' perspectives on the appropriateness of a human-rights framework for advocacy. The chapter revisits the question of how Papua New Guineans' interest in human rights can be most effectively aroused and whether the source of these rights impacts on their importance in the minds of the public, before reflecting on the high degree of commitment to the organisations' roles in promoting human-rights approaches. At this point I share my confusion — the strong support from interviewees seems at odds with criticisms of human-rights approaches made by these same people. But, by digging deeper into the stories of my interviewees, I recognise that this criticism of human-rights approaches is best understood as criticism of a particular *kind* of human-rights approach, not human-rights approaches per se. Interviewees are, in fact, highly supportive of a *different* kind of approach, one that is tailored for PNG. This emerges as another major theme — that there is a human-rights approach that is appropriate for PNG and that reflects an indigenisation of the Universal Declaration of Human Rights.

In describing a human-rights approach that is appropriate for the PNG cultural context, the chapter necessarily explores what we might mean by Papua New Guinean 'culture'. Resisting conceptualisations of culture as monolithic and unchanging, the chapter acknowledges research on non-heteronormativity in the Pacific and the way that interviewees can be, simultaneously, both deeply embedded within, and subversive of, local culture. The chapter notes research on the dividuality (divisibility) of Papua New Guineans as individuals and the vernacularisation of human rights in PNG, and the way many human-rights interventions have tended to isolate their intended beneficiaries, when what these beneficiaries seek is the opposite. The chapter then returns to an exploration of how human-rights interventions can be made culturally appropriate for PNG, and how elements of culture can facilitate human-rights programs, with culture viewed as a positive force for human rights.

My conclusions are set out in Chapter 8 in the form of a series of advocacy tools. Chapters 2 to 7 will make clear why I have chosen this format for my final chapter.

Identity and naming

In my work, I am talking about sexuality and gender, although my work is not a focused study of either. While I have been interested to explore how sexuality and gender are conceptualised by the communities I work with in PNG, there are many things I have *not* explored. For example, I did not ask my interviewees to explain what they understood terms like sexuality and gender to mean. I was interested in the degree to which they identified with being transgender or non-heterosexual and I almost never needed to pose the question. Interviewees understood the focus of my research and understood that their sexuality and gender identity were relevant. They freely and generously shared with me information about their gender identity and sexuality, but I did not probe beyond this.

I would like to share a story about the terms ‘men with diverse sexualities’ and ‘TG’. I will begin with the work of Wilo Muwadda (2012) who, having conducted interviews with 21 people in Port Moresby and Lae who self-identified as being non-heterosexual, found a broad range of terms being used to describe his interviewees. These terms included *girly girl, palopa, palo, man stret* and *meri stret,* MSM, transgender, TG, bisexual, homosexual and gay. Muwadda describes how these names may be used in various combinations — someone may, for example, identify as a *meri stret* transgender. Muwadda’s interviewees had experienced these names in different ways, from owned and affirming to derogatory. Then, on 12 November 2013, there was a small gathering in Port Moresby of Papua New Guineans who, to that point, had been commonly referring to themselves as MSM (Men who have Sex with Men), a term introduced into PNG as part of HIV awareness and prevention programs in the late 1990s. I was present at this gathering and observed a fascinating conversation. Group members decided that they no longer wanted to be known as MSM and from now on they would refer to themselves as men with diverse sexualities, or MDS for short. After further discussion they decided that, given many of the group’s transgender members did not identify as men, they would refer to themselves as MDS and transgenders, or MDS and TG, and that they would ask others to refer to them in the same way.

This was a very interesting decision but not without precedent. People who work for any time in HIV understand that the way in which groups are described is important. The history of the epidemic is full of stories of ‘AIDS victims’ becoming ‘people with HIV’ and ‘prostitutes’ becoming ‘sex workers’. In country after country, marginalised groups have demanded they be referred to in terms that reflect the way they see themselves rather than ways in which they are perceived by others. And so, the group’s call to be referred to as MDS and TG was interesting and significant, but not all that surprising.

The choice of MDS may have been influenced by the Pacific Sexual Diversity Network, a forum known to group members. But whatever the origin, it was taken up as a clear rejection of the term MSM. The discussion that led to the rejection of MSM was triggered by a story told by one of those present, whose permission has been given for me to share it here. He told of how he had recently attended a large meeting in Port Moresby of agencies engaged in the national HIV response. At the forum he and his peers were mostly referred to as ‘MSM’, but he also learned they constituted a ‘MARP’ (Most-At-Risk Population), a ‘KAP’ (Key Affected Population) and a ‘stigmatised group’. He had never imagined himself as such a ‘problem’, so completely ‘other’. The term MSM, he felt, reduced him to a sexual act, and a problematic one at that (an unlawful one, a potentially infectious one). He argued, and the 12 November gathering agreed, that the term MDS, by contrast, is about a person who *possesses* something rather than a person who *does* something. And by using the word ‘diversity’ to acknowledge a range of sexualities, Papua New Guinean MDS place their sexuality alongside others — same but different — in this country that is so very proud of its cultural diversity. This ‘same but different’ positioning is another theme to emerge in my research.

While the men of this story largely rejected the MSM label, the term is still frequently applied to them. The appropriateness of the term MSM has been widely debated. Tom Boellstorff (2011) writes about the three transformations of the term: from a category excluding other notions of sexuality and gender to a category that includes them; from a category describing behaviour to one describing identity; and from an American term to an international one. He documents that the term was primarily the creation of public-health workers, epidemiologists and other HIV professionals, and that its original and fuller expression was ‘MSM but who do not identify as gay’. This fuller expression, writes Boellstorff, evidenced an acceptance of ‘men’ and ‘sex’ as stable but conceptualised ‘gay’ as a social construct. It was all about what you do, not who you are. Boellstorff writes that MSM offered a way of sidestepping identity, leading to a more scientific understanding of the location and transmission of HIV.

There were, and are, considerable problems with the term. It technically includes trans women, although trans women often reject being referred to as men and do not see their sex with men as homosexual. At the same time, it excludes trans women (and trans men) who identify as gay. And it assumes that the male partners of trans women are also MSM, when many would categorically reject this label. And yet, writes Boellstorff, this flawed term has not only survived but evolved into an identity, the very thing the phrase was coined to avoid. ‘MSM’ has become a group rather than individuals with risk behaviour. It has morphed further into a ‘community’ rather than a ‘risk group’, in that community organisations around the world have taken up the term and helped contribute to a notion of group consciousness. And if MSM ‘communities’ can exist, then, by definition, members of these communities must have MSM identities. In the end, large amounts of HIV programming have been implemented around the notion of MSM identity, even though many people supposedly included within the term utterly reject it. This can lead to an increased alienation from HIV-prevention strategies on the part of intended targets, concludes Boellstorff. In charting its rise, Boellstorff notes continuing reservations relating to the term and that the Yogyakarta Principles (2006 and 2017), an important international framework for thinking about sexual identity and rights, does not include the term at all. He observes a continuing evolution, and indeed it is hard to say whether MDS will continue to be the descriptor of choice in PNG. Perhaps MDS will revert to MSM or morph into something else, but for now, it is the term MDS that is preferred and endorsed by Kapul Champions. Out of respect for Kapul Champions and the communities it represents, for the purposes of this thesis I have gone with the term MDS.

Kalissa Alexeyeff and Niko Besnier (2014) reflect on the different labels that might be applied to non-heteronormative people across the Pacific and ask what is gained by this labelling: ‘Frequently, terminological discussions conflate description and enactments, words and meanings, and fail to account for the instability of categories across time, context, and place’ (16). Alexeyeff and Besnier observe how people in the Pacific might perform one kind of identity while at home and take on a very different persona when they migrate; they might enact gender and be gendered differently in formal environments as compared with informal ones. The authors see that terms are not just descriptive but performative and note that with the performative comes the political. They observe that:

> The terminology used to describe non-heteronormativity by both scholars and those who identify with this identity is temporally and contextually unstable … Terms may thus be unstable over time, just as they are at any given moment the focus of contestation … Ultimately, ad nauseam debates about whether categories are similar or different, or assertions to the effect that a term is in and others are out, are unproductive. (8–9)

I agree it is possible to get bogged down in the analysis of names and words, yet the decision in PNG to adopt MDS over MSM does seem to me to be significant, and to be consistent with the way this community has been pursuing its agenda. It is also worth noting that, in my experience, trans people in PNG most commonly refer to themselves as ‘transgenders’ or ‘TG’. Most of the trans women I interviewed for this research did not describe themselves as trans women, instead they used the term ‘transgender’ or ‘TG’ to describe themselves and their community, and earlier drafts of this thesis used these descriptors. Yet I have often found my use of these descriptors corrected by people outside PNG, who consider it disrespectful in emphasising the transgender status and ignoring the person. It is a fair point, so while noting that the transgender Papua New Guineans with whom I have worked routinely use ‘transgenders’ or ‘TG’ to describe themselves, I will refer to them as transgender people, or trans people. All my transgender interviewees were living or identifying as women or trans women rather than as men or trans men, so in this thesis I mostly use the term ‘trans women’. I did not set out to exclude trans men from my research; they exist in PNG and Muwadda (2012) interviewed trans men in his work. However, trans men did not present for research interviews and, in my experience, are not represented in the membership of Kapul Champions (although they would be eligible for membership; a matter discussed in detail in Chapter 5).

MDS and trans women are both represented by the organisation Kapul Champions. In my experience, and based on my interviewees’ stories, both communities feel an ownership of the organisation and the links and bonds between these two groups are acknowledged by each. But MDS and trans women are not the same, and at different times the differences were clear and the subject of comment. I observed with interest how some members of Kapul Champions might identify as MDS at certain times and in some contexts, and as trans women at other times and in other contexts, thus evidencing the ‘instability of categories’ to which Alexeyeff and Besnier (2014) refer. But again, this was not the focus of my research. I was interested in listening to interviewees talk about identity issues where they chose to do so, but I did not interrogate them as to why they identified one way or the other. Still, it is apparent that context is relevant to the ways in which MDS and trans women identify, and interviewees were very clear that MDS and trans women are different from each other, even while individuals might assume both labels at different times depending on context.

My work is about sexuality and gender in multiple ways, not least because it is a study of the HIV response in PNG. As is the case in so many countries, any analysis of the PNG HIV response requires particular emphasis on the heightened vulnerability to HIV of gay men and transgender people. My work is not a study of the PNG HIV epidemic, but some key points about the epidemic will provide useful context. When I first began working in PNG in the early 2000s, the expectation was that the country was heading for a generalised epidemic of disastrous proportions. And then, after several years, the emphasis was suddenly shifted to MARPs and KAPs, only to be recalibrated again a decade later towards a kind of hybrid epidemic, with epidemics within some populations and generalised epidemics in some locations. In summary, we might say that this ‘shape shifting’ epidemic in PNG is now understood as not one single epidemic, but several, experienced differently depending on which part of the country you live in and the sub-population of which you happen to have membership. While there are certainly geographically defined clusters of infection, the epidemiology also bears out an observation that the PNG epidemic has important dimensions that relate to being homosexual or transgender. For example, Avi Hakim and others (2019) report HIV prevalence among men who have sex with men and transgender women to be 8.5 per cent in Port Moresby and 6.9 per cent in Lae, compared with separately collected data on general population infection showing national prevalence at less than 1 per cent. See also Angela Kelly-Hanku and others (2018), upon whose research Hakim and others draw. Kelly’s bio-behavioural survey focused on two groups: women and girls who sell and exchange sex (more than 650 people in this category were surveyed), and men who have sex with men and transgender women (400 surveyed). In addition to the finding of 8.5 per cent prevalence among men who have sex with men and transgender women, the team found HIV prevalence among female sex workers in Port Moresby to be 14.9 per cent.

Katherine Lepani (2016) offers another perspective on the epidemic in PNG that affirms its changing shape over time. Lepani observes how changes in surveillance data over time have shaped the way the epidemic has been described. Rapidly escalating numbers of confirmed cases nationally from 1997 to 2004 prompted warnings of an ‘African-style’ generalised epidemic with UNAIDS in 2002 describing the epidemic as generalised. Subsequent data led to the epidemic being described in 2010 as ‘levelling off’, with data from 2012 showing a much more regionalised experience, with higher infection rates in the Highlands. From her 2016 perspective, Lepani looked ahead to the generation of more specific data via a planned bio-behavioural survey, wondering where ‘the persistent drive to measure the epidemic numerically, and pin down prevalence to the decimal point’ might lead (2016:181), and suspecting ‘the orthodoxy of statistical evidence will now hold the national response — and people’s sexuality — accountable like never before’ (2016:182). The Papua New Guinea National STI and HIV Strategy 2018–22 also provides a brief but useful overview of the county’s ‘mixed’ epidemic. The strategy notes that national prevalence hovers around 1 per cent, the figure used by many to indicate a generalised epidemic, but that HIV is also concentrated in particular populations (sex workers, men who have sex with men and transgender people) and particular parts of the country (notably the Highlands region) (2018:58). And so the epidemic resists the binary of generalist versus concentrated.

The cultural influence of Australia, particularly via aid and very particularly via PNG’s HIV response, is also relevant. In my experience, much of the community response to HIV in PNG has been facilitated, fostered and funded by donor agencies with experience of HIV as an epidemic disproportionately impacting on sub-populations, notably gay men. This is certainly true of the Australian Department of Foreign Affairs (DFAT) in PNG (and its former international development agency, AusAID), and true of many other aid agencies as well. I have worked in PNG with many gay men from around the world whose own views of how to respond to the epidemic have been informed by gay epidemics elsewhere. This cultural influence has been significant, but it has not been unchallenged. The earliest phases of the PNG national response sought to foster a broad-based community response through awareness and peer education and included efforts to dispel perceptions about HIV being all about homosexuality. Instead, there were efforts to emphasise HIV as a social and economic development issue that affects everyone regardless of sexual identity and practice. But the subsequent contributions from donor and aid agencies have added their own dimensions.

Gary Dowsett (2003) questions the adequacy of 'sexual identity' as a means of understanding sexual behaviour and uses an engaging example: the story of gay bashers that lure victims by engaging with them (at least to a point) in homosexual activity. He reminds us of the difference between the 'I am' question and the 'I do' question. Dowsett recalls Michel Foucault's observation that what bothers most non-gay people about gayness is not the sex acts themselves, but the gay lifestyle; the idea that gay men might create new kinds of relationships that destabilise the mainstream. Dowsett observes that this may well be true, but that it is not only this that causes people to take offence. Dowsett posits that it is also the actual sex taking place that counts:

> Gay men denote and define physical possibilities, pleasures foregone, refused or delayed … maybe even remembered. There is an element of 'reciprocity' here, a 'uniquely masculine moment' that suggests that gay men may not, after all, symbolise the 'other' but rather the 'proximate'. (2003:128)

Dowsett resists binary categorisation and suggests a blurring at the level of practice and bodily sensation that confounds categorisation, and that indicates an instability in heterosexual masculinity. He suggests: 'This might explain, at least in part, the fear of those living with HIV/AIDS as the fear of the proximate, of one's own penetrable body and the dangers implicit in one's own desire' (2003:128).

Dowsett goes on to observe that there is considerable evidence of less-uniform heterosexual masculinities and more varied sexual cultures in the developing world, and that these support any challenge to the western notion of 'sexuality'. He looks closely at the *kothis* (young men who sell sex) and *hizra* (biological males, perhaps castrated, who dress and live as women and sell sex to men) in Bangladesh. Dowsett documents how the *kothis* and *hizra* are affected terribly by HIV and notes that some of the stigma and discrimination to which they are subjected flows from their association with female sex workers, already regarded by many of their fellow citizens as unclean and the source of disease. Dowsett observes that the *kothis* and *hizra* will be damaged more by local sexism than by local homophobia. But Dowsett argues that the West will be culpable for the damage that flows from its efforts to 'colonise' *kothis* as gay rather than recognising their legitimate sexual culture. Dowsett sees this as generating a dilemma for the *khotis.* They have established an organisation to represent their interests, but the fledgling entity employs many western ideas and images, borrowed from western HIV organisations. This makes sense on one level — why reinvent the wheel? — but it potentially undermines the sexual authenticity of these ideas and images as a result. If the *khotis* claim the space occupied by 'gay' in the international HIV response, they will confront the entrenched homophobia that comes with it. If they model their organisation on sex-worker organisations, their sexual desires and pleasures will risk being erased. Dowsett warns that international HIV agencies, keen to help, risk causing the *kothis* and their organisation to become inauthentic and ultimately invisible.

PNG is a long way from Bangladesh, but Dowsett's story has application to Kapul Champions. There is a risk, always, that in seeking to become part of an international, funded HIV response, community organisations in developing countries will be pressured to conform. Where willingness to adopt language familiar to western funders enhances access to money and other supports, the pressure to do this will be significant. I do not see the decision to adopt the descriptors 'MDS' and 'TG' as succumbing to pressure — indeed the decision was a specific rejection of the terms more familiar to funders; that is gay and MSM. But I have wondered what other trade-offs may have been made as Igat Hope and Kapul Champions have sought, quite reasonably, to access the benefits of being part of a global response to HIV. This is a question explored in subsequent chapters.

While my work is not about sex workers per se, the issue of terminology relating to sex work deserves noting. Christine Stewart (2014) addresses the matter in detail, noting different opinions. Friends Frangipani, the community organisation that advocates for sex worker rights in PNG and which is comprised of members who engage in sex for money or other reward, uses 'sex worker'. Stewart argues that this term is shaped by foreign cultural assumptions regarding the purpose of selling sex and the degree of agency that sex workers possess in the process. In many developing countries, Stewart says, sale of sex does not equate to a profession but to a means of survival. She suggests 'survival sex' or 'transactional sex' might be more appropriate for PNG (29). Stewart considers how others have made sense of women's engagement in sex for return, citing Holly Wardlow (2001) who argues that, while the Huli women of her research may indeed sell sex, their initial motivation is not material necessity but rather anger and resistance. Stewart (2014:30) also canvasses the view that calling these women sex workers is an essentially middle-class liberal response that confuses the subject of the hostility — which is selling sex — with a word, and that fails to properly recognise that if a ‘sex worker’ is still selling her body, she is still stigmatised (Macintyre 2009).

Stewart goes on to say that the terminology in respect to male-to-male sexuality is similarly problematic. She notes that the West has long debated the connections between the social constructs of ‘sex’, ‘gender’ and ‘sexual orientation’, and that these categorisations continue to change and evolve. Stewart notes (like Muwadda 2012) a range of terms used to describe those engaged in non-heterosexual sex: *manmeri* (man/woman), *geligeli* (girlie-girlie), *askan* (arse-cunt), suckers, *vavine* or *kekeni* (local language terms for woman or girl). Stewart confirms that the term MSM has been imported into PNG as part of the HIV discourse, and that while it may originally have been used to describe a practice, is now commonly used to describe an identity. She notes that many of her informants preferred the term gay (although my interviewees, as a rule, did not). She also reports use of ‘sister-girl’, which I note is the term used by Aboriginal and Torres Strait Islander trans women. In this thesis I have used the term ‘sex workers’ out of respect for Friends Frangipani and the community it represents. But I acknowledge that the situation is fluid when it comes to language, descriptors and identity.

Angela Kelly and others (2011) sought to manage issues of terminology in their research on HIV risk for women engaged in the sale or transacting of sex in Port Moresby. They intentionally use language of inclusion rather than judgement, informed through consultations with the women of their study. They talk of gender rather than sex, so as to be inclusive of trans people and resist the acronyms FSW (female sex worker) and MSW (male sex worker), not only to encompass transgender research participants but also because their subjects did not always identify as sex workers.

All this can start to feel a little confused. On the one hand, names and language are important and how we describe people matters. And on the other hand, we can get bogged down in the nuance of language and expend vast energy agreeing on labels and categories only to find communities have moved on to new ones. Perhaps it is enough to listen to others, particularly the marginalised, when they tell us what does and does not feel respectful, and to be more generally attuned to the evolution of terminology.

And yet a final caution from Dennis Altman and Jonathon Symons (2016) seems apt. They write of the challenges in linking human-rights activists from western nations with activists in the developing world. They ask the question I have asked myself many times: ‘Is it possible for outsiders (be they governments or activists) to promote acceptance of sexual diversity in communities of which they are not members?’ (132). Indeed, I have tried hard to exercise caution when thinking about the struggle of MDS and trans women in PNG through the lens of my own activism in Australia. Altman and Symons write that, although international campaigners are likely to misunderstand the precise changes required within a developing country to affect the outcomes local activists want, they can still play an important role by focusing on universal prevention of criminalisation and violations of personal safety. Beyond this, there will need to be an openness to difference. Altman and Symons observe that in many societies in which the extended family is central, negotiating sexuality can happen only with reference to a person's broader family:

> The western concept of coming out as the essential ingredient of liberation may not have the same meaning in societies where there are different notions of kinship and community, and is a further reason for scepticism about the constant invocation of LGBT community. (2016:135)

This negotiation of sexuality and gender identity with reference to family and community emerged as a major theme in my work.

Ultimately, I see the labelling and identification of MDS and trans communities in PNG as a highly dynamic space. Terminology is evolving and who can say what its endpoint might be, if there ever is to be one. Dynamic also in terms of context — people may identify in one way in one context and differently in other environments, depending on a variety of factors. At different times there will be an adoption by these communities of terms familiar with the structures of HIV responses and aid programs, but this may be as much a matter of pragmatism or convenience as anything else. Importantly, my interviewees, and their organisations, are active players in naming and labelling; they are showing agency and participating in terminological evolution. Acknowledging all this fluidity, I have had to settle on an approach for now, and so in this thesis I use the terms 'MDS', 'trans women' and 'sex workers', although, for the reasons outlined, I do so with more comfort in relation to the first term than the last two.

International and local legal frameworks

Human rights are articulated in international agreements, have been subject to judicial interpretation over decades and have been given further meaning through national legislation. Before we can talk about rights in PNG, a basic understanding of what international law says about the rights of PLHIV, MDS and trans people is required. Here I consider international declarations and covenants and canvass what some scholars have had to say about their applications to the communities of my interest. This section deals briefly with the Constitution of the Independent State of Papua New Guinea (PNG Constitution), which is rich in statements about the human rights of PNG citizens, and with specific laws that have application to PLHIV, MDS and trans women (primarily criminal laws and HIV-related laws).

HIV status: The rights of PLHIV under international law

A core element of the Universal Declaration of Human Rights (1948) is that people's entitlement to enjoy their human rights, and to have those rights respected by the state, should not be impacted by irrelevant characteristics ('distinctions of any kind'). The declaration lists examples of these kinds of characteristics: race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. The list is not exhaustive, and it has long been understood that disability is an 'other status'. In the early 1990s, the Australian Government recognised this international obligation to prevent discrimination based on disability as sufficient basis for enactment under its constitutional international obligations power of the Disability Discrimination Act (DDA) 1993. HIV has long been considered a disability and the DDA's definition of disability makes clear that it includes HIV.

In 1996, the Office for the High Commissioner for Human Rights and UNAIDS adopted the International Guidelines on HIV/AIDS and Human Rights, recognising a broad range of human rights likely to be infringed by HIV-related discrimination and providing a framework for a rights-based response. The relative success of the HIV response in those countries that can rightly claim success owes much to the acceptance of human-rights principles, particularly recognition of the equal dignity and worth of all persons, as well as the meaningful involvement of affected communities. The United Nations has made this assessment based on national responses worldwide and the conclusion is prominently asserted via its website.

In 2006, the United Nations adopted the Convention on the Rights of People with Disabilities, further articulating and extending the human rights of people with disability. PNG has signed and ratified the Convention.

Sexuality: The rights of MDS under international law

When the Universal Declaration was being developed, there was no public discussion of sexuality. It simply was not addressed in consultations that led to the declaration. Sexuality is similarly absent from the two major international covenants that give meaning to the declaration, the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic and Social Rights (ICESCR), both adopted in 1966. Yet in 2020 a strong argument can be made that sexuality is clearly covered by human rights.

Sexual rights were first articulated in a UN document in 1995, the Beijing Declaration and Platform for Action, an outcome of the Fourth World Conference on Women, although to the extent that sexual rights emerged from an articulation of reproductive rights, perhaps the real starting point is the International Conference on Population and Development (ICPD) in 1994 (CREA 2006).

The Beijing Platform for Action described sexual rights (at paragraph 96) as being amongst the human rights possessed by women everywhere to have control over and decide freely on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence. Understandings of sexual rights have evolved since that time; they can be thought of in different ways with no single universally accepted definition. Diane Richardson (2000) notes the different ways sexual rights might be conceptualised. They can be thought of as rights to different forms of sexual practice, such as the right to participate in sexual activity, the right to sexual pleasure, and the right to bodily autonomy and integrity. They can be thought of as rights relating to sexual identity, including the right to self-expression and to develop diverse sexual identities. Or sexual rights might be thought of in the context of relationships, including the right to engage in sexual practice within relationships, to freely choose sexual partners, and the right to public recognition and validation of sexual relationships.

Kate Sheill (2008) has observed that since its original articulation, the notion of sexual rights has travelled a rocky road through international forums and been the subject of sustained attack by conservative forces worldwide, both religious and governmental. It appears, then, that sexual rights might not be as universally palatable as rights more specifically referenced in international covenants. So perhaps it is not surprising that Kapul Champions has not built its advocacy around such a notion. (Here I am focusing on the relevance of sexual rights to the constituency of Kapul Champions, for obvious reasons, but it is important to note that the sexual rights of PLHIV are also routinely infringed. Subsequent chapters will detail the denial and control of PLHIV sexuality.) Of course, to some extent, Kapul Champions already *does* talk about sexual rights. It already focuses on a range of rights that have a direct impact on sexual health and sexual expression: MDS interviewees shared with me stories of ways in which these rights have been infringed and upcoming chapters are constructed around many of these stories. In different forums, MDS and trans women have spoken of how their rights to liberty and security have been violated by being imprisoned or beaten by police for expressions of their sexuality or gender (a contravention of the International Covenant on Civil and Political Rights (ICCPR) Article 9.1). They have spoken also of their right to freedom of expression, including the right to attain and share information (ICCPR Article 19), their right to marry and found a family (ICCPR Article 23) and the right to health (International Covenant on Economic, Social and Cultural Rights (ICESCR) Article 12).

Richardson (2000) observes that one advantage to Kapul Champions in taking up the fight to promote sexual rights more generally is the opportunity to forge alliances with other groups whose sexual rights are consistently violated. Women are the most obvious of these groups, but others include sex workers and people with disabilities. Kapul Champions’s alliance with Friends Frangipani is already well established. But as Jaya Sharma (2008) observes, there are dangers in employing sexual rights arguments in that the language of rights can be limiting rather than liberating. There is a tendency to articulate sexual rights as they apply to specific groups (women, sex workers, sexual minorities) and, in this sense, the term perpetuates a sense of otherness that can be unhelpful. There is a risk that categorising people into different marginalised groups will result in inflexible categories that fail to accommodate the real diversity of sexual desire and expression. And while the language of sexual rights offers a safe way of dealing with homosexuality at arm's distance from the rights of others, this can also be counterproductive.

Paul Boyce and ashkay khanna (2011) discuss these issues in their reflection on the tension between advancing rights for the sexually marginalised, and the potential alienation and misrepresentation of those in whose name the claims are advanced. This is an interesting challenge for Kapul Champions. Just how separate does the organisation want to be in its efforts to promote a more just world for its constituents? As I detail in the following pages, the answer seems to be *not very much at all*. Kapul Champions seems keen to emphasise the extent to which its members constitute a part of PNG society, not their otherness. My MDS and transgender interviewees were very keen to emphasise their connectedness to and inclusion within a community and were suspicious of any advocacy that might undermine this message. They did not support advocacy strategies that emphasised a set of distinct entitlements.

Altman and Symons (2016) track development in sexual rights thinking, noting two critical developments: the establishment of the European Court of Human Rights in 1959 and the creation of an individual complaint's mechanism under the 1976 First Optional Protocol to the ICCPR. The European Court of Human Rights 1981 decision in *Dudgeon v United Kingdom (Article 50)* found that laws prohibiting consensual homosexual sex between adults constituted a breach of the European Convention on Human Rights and subsequent decisions strengthened this finding. Holning Lau (2004) writes of the key international law cases that deal with sexual rights, beginning with the 1994 decision of the UN Human Rights Committee in the matter of *Toonen v Australia.* In that matter the Committee determined that laws prohibiting homosexual sex between consenting adults constituted a violation of Nick Toonen's ICCPR right to privacy on the basis of sex. Lau emphasises the importance of *Toonen:* while the ICCPR does not even mention sexual orientation, *Toonen* clarifies that sexual orientation rights are embedded in the treaty's language. Lau also notes two other important cases, *Young v Australia* and *Lustig-Prean & Beckett v United Kingdom.* In *Young*, the UN Human Rights Committee found that Young was entitled to a government pension because of his status as the same-sex partner of an Australian veteran. On a proper analysis of Article 26, the Committee held, Australia had no right to refuse same-sex partners the same government benefits as were offered to heterosexual partners. In *Lustig-Prean* (1999) the European Court of Human Rights found that the United Kingdom's ban on gays in the military violated the European Convention on Human Rights. While not an international tribunal in the strict sense, Lau writes that the decision of the European Court of Human Rights has been persuasive in judicial decision making around the world.

Lau writes that, following *Toonen*, four other human-rights treaty bodies declared that their treaties should be considered to protect sexual minorities: the ICECSR, the Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW) (1979), the Convention Against Torture (in force from 1987) and the Convention on the Rights of the Child (in force from 1990). Lau also documents that six UN High Commissioners for Human Rights Special Rapporteurs now include sexual orientation in their agendas. Lau acknowledges progress, albeit patchy, in recognition of sexual rights in domestic legislation in many parts of the world before noting that this trend is not being followed everywhere. There has been little or no progress in many parts of the world and some regions are going backwards. A special report in *The Economist*, 'The gay divide,' (14 October 2014), documents how victories in some parts of the world have provoked backlash elsewhere. Its 'then and now' map of laws prohibiting homosexual acts shows that homosexuality remains illegal across vast swathes of Africa and Asia (and PNG), with some countries (in Africa) having introduced new laws criminalising homosexuality against the international trend.

The Yogyakarta Principles on the Application of International Human Rights Law in relation to Sexual Orientation and Gender Identity reflect the collaborative efforts of some very highly regarded international jurists. Declared initially in 2006 and supplemented in November 2017, the principles, while never endorsed by the United Nations, have been affirmed by the Council of Europe and superior courts around the world. Principal 1 declares: 'All human beings are born free and equal in dignity and rights. Human beings of all sexual orientations and gender identities are entitled to the full enjoyment of all human rights.'

In a 2006 report, the World Health Organization (WHO) documented its amendment of working definitions of sex, sexuality, sexual health and sexual rights. These significant changes had been agreed at a 2002 gathering of technical consultants, meeting in response to the global HIV pandemic. Among other things, the consultants succeeded in encoding a definition of sexual rights, aligning it firmly with human rights. The WHO working definition of sexual rights established it in a way that facilitated its subsequent use internationally. A second WHO meeting, this time in 2012, and its 2015 report, analysed these matters in the context of the interconnection of international conventions and law with national constitutional and statute law. This gave the notion of sexual rights even more authority.

Altman and Symons's (2016) history of the emergence of gay rights begins with a reflection on the development of a new language of human rights in the 1970s combining with the second wave of feminism as a major force to give birth to a new notion of sexual rights. They observe how sexual rights are considered in different ways, including the right to determine and declare sexual and gender identity. Altman and Symons document how sexual rights continued to be debated through international forums including UN conferences on Human Rights (Vienna 1993), Population and Development (Cairo 1994) and Women (Beijing 1995). They record how, throughout the 1990s, important human-rights non-government organisations (NGOs), such as Human Rights Watch and Amnesty International, added homosexuality to their agendas, and that in 2008 the UN High Commissioner for Refugees adopted a guidance note on refugee claims relating to sexual identity and gender identity, although nation states have had very different responses to this guidance.

Altman and Symons write that the emergence of the HIV pandemic linked rights with sexuality in new ways. In its global response to HIV, the UN has consistently emphasised the connection between the human rights of marginalised populations and the spread of the epidemic. They quote the lead essay (Mann et al. 1994) in the inaugural issue of *Health and Human Rights:* 'The evolving HIV/AIDS pandemic has shown a consistent pattern through which discrimination, marginalization, stigmatization and, more generally, a lack of respect for human rights and dignity of individuals and groups heightens their vulnerability to becoming exposed to HIV' (1994:20–21).

The rights of trans people to protections under international human-rights law

Trans people and their advocates point to the Universal Declaration as clearly, if not specifically, indicating that trans people should enjoy the full enjoyment of their human rights without discrimination based on the other status of gender identity. Key human-rights mechanisms of the UN have affirmed the responsibility of member states to protect citizens from discrimination based on sexual orientation or gender identity (Amon and Sun 2019). UN human-rights instruments provide protection for people on the basis of sexual orientation, gender identity and intersex status, writes Maria Castro-Peraza and others (2019), who point also to Article 8 of the European Convention on Human Rights which enshrines the right to respect for privacy. What is a more intimate, private aspect of a person's identity than gender identity, the authors ask? They defend the right of trans people to development and personal identity, as well as to the physical and psychological integrity of the person and argue that pathologisation of trans people threatens the integrity of their person, undermining their right to health. The authors also note the importance to trans people of the Yogyakarta Principles, and that advocates for trans rights also refer to the United

Nations Human Rights Council resolution on human-rights violations based on sexual orientation and gender identity (L.9/Rev.1), the first resolution to bring specific focus to such violations.

The Office of the United Nations High Commissioner for Human Rights has conducted high-profile campaigns calling for the elimination of discrimination against trans people and published campaign material making clear that: ‘A person’s sexual orientation, gender identity and sex characteristics is a status, like race, sex, colour or religion. United Nations human-rights experts have confirmed that international law prohibits discrimination based on sexual orientation, gender identity and sex characteristics’ (3).

The Office’s website describes a history of UN General Assembly and Human Rights Council statements on sexual orientation and gender identity, including Council resolution (17/19) expressing concern over the violence and discrimination to which people are subjected based on sexual orientation and gender identity. The Office declares that UN Human Rights treaty bodies have repeatedly confirmed that sexual orientation and gender identity are included as prohibited grounds of discrimination, including via decisions and general guidance notes.

While the Universal Declaration does not mention sexual rights, or homosexuality, it is clear to me that a person’s human rights include their sexual rights. MDS are entitled to invoke these rights by reference to the growing international academic and legislative acknowledgement that sexual rights are many and varied, and that homosexuality is one of those ‘any other distinctions’ which must not be allowed to impede access to and enjoyment of human rights.

The PNG Constitution and PLHIV, MDS and trans women

For a rights advocate like me, the PNG Constitution can be a rewarding read. The Constitution includes powerful statements regarding the rights of all Papua New Guineans. The Constitution makes clear that rights are not subject to the irrelevant factors — race, tribe, place of origin, political opinion, colour, creed or sex. The Constitution declares that national goals include freedom from oppression so that each citizen may have the opportunity to develop as a whole person, and equal opportunity to participate in and benefit from development. The Constitution sets out a set of basic rights, including rights to life, liberty, security and protection of the law; the right to engage in politics; the right to freedom from inhuman treatment and forced labour; the right to freedom of conscience, of expression, of information, assembly and association; the right to freedom of employment and freedom of movement; and the right to protection of privacy of home and from unjust deprivation of property. The Constitution then sets out a series of basic social obligations, establishing at constitutional level a link between rights and responsibilities. This link was another major theme to emerge in my research.

The Constitution provides that in determining the application of, and entitlement to, human rights in PNG, courts may have regard to the Universal Declaration of Human Rights and other UN instruments.

Domestic laws relating to PLHIV, MDS and trans women

There are several PNG laws of relevance to PLHIV, MDS and trans women. The *Criminal Code* was imported from Australia, specifically by way of the then *Queensland Criminal Code 1889*. The PNG *Criminal Code* came into effect in 1975 following PNG's independence, replacing versions of the *Queensland Code* which had been operating separately in Papua and New Guinea (Ottley and Zorn 1983). The PNG *Criminal Code* makes it a criminal offence to have anal intercourse. This does not make it illegal to be homosexual but it does make the practice of anal intercourse, associated most closely with homosexual men, a criminal act. The code also makes it unlawful to live off the earnings of a 'prostitute' (the statutory term). Oddly, this has been interpreted in PNG as applying to sex workers themselves rather than pimps when it was surely intended as a means of pursuing the latter. These laws and their impacts on PLHIV, MDS and trans women are considered in detail by Stewart (2014).

The *HIV/AIDS Management and Prevention (HAMP) Act 2003* (drafted by Stewart) is an important piece of legislation for PLHIV, MDS and transgender Papua New Guineans. For its time, the Act was a very progressive piece of legislation. The Act covers a broad range of HIV-related matters, including intentional transmission of HIV, entitlements to HIV information, and protection from discrimination based on actual or perceived HIV infection. These last two elements are potentially very important tools in the protection of PLHIV, MDS and trans women, although the experience of *HAMP's* application has been a little mixed (addressed in greater detail in Chapter 3).

Repeal of those sections of the *Criminal Code* criminalising sodomy and sex work is a key objective for Kapul Champions, and it is part of a coalition of forces keen for reform. An alliance has been formed by UNAIDS, community organisations, researchers, international NGOs, health practitioners and departmental bureaucrats, particularly from the Ministry of Health, to chart a way to reform. This work is loosely described as relating to the 'national dialogue', a reference to important work spearheaded by Dame Carol Kidu from 2010–12 when she was a member of parliament (for Moresby South, elected 1997) and Minister for Community Development. This group has, among other things, overseen the development in 2016 of a draft bill intended to decriminalise homosexuality by making PNG law silent on the practice of anal sex. A second bill was also developed that would have decriminalised sex work. In 2016, there had been some hope that at least the sex-worker bill might be advanced, however the bill never made it the floor of the parliament and has since lapsed.

Interconnectedness of health and human rights

I have spent much of my life in that bit of the Venn diagram where health intersects with human rights, so-much-so that I often mistakenly assume people understand the connection. To avoid this mistake here, I will make some observations on the interconnectedness of health and human rights, leaning heavily on the work of Daniel Tarantola and several of his co-authors, and on the early observations of Jonathan Mann.

Sofia Gruskin, Edward Mills and Tarantola (2007) observe the ongoing impact of human-rights violations on the health of individuals and populations, noting that the continuing and foreseeable absence of access to effective care for most people living with a high burden of disease in poor countries can also be viewed as a violation of human rights. Human rights should, therefore, be imperative in the delivery of care and in the implementation of public-health programs. The authors identify three main relationships between health and human rights: the positive and negative effects on health of the promotion, neglect or violation of human rights; the effects of health on the delivery of human rights; and the effects of public-health policies and programs on human rights. While acknowledging that interest in the interconnectedness of health and rights dates from the very establishment of the UN, the authors credit the HIV epidemic with focusing attention on the way these interact.

Mann and Tarantola (1998) describe how the first worldwide public-health strategy to explicitly engage with human rights occurred via the Global Programme at the World Health Organization (WHO) in the late 1980s. The inclusion of human rights was motivated by different factors, but two in particular: the moral outrage at the abuses being experienced by PLHIV, and evidence that discrimination was driving people away from HIV prevention and care. Mann and Tarantola observe that the right to health is most closely associated with ICESCR Article 12 but see that all forms of rights are relevant to health: economic, social, cultural, political and civil. They turn their focus to the international HIV response and summarise the global strategy as relying on people coming forward to access prevention, treatment and care. For this to happen, people have to feel able to (read ‘welcome to’) access these supports. The strategy was set first by WHO as the international agency with responsibility for the promotion of health rights. By having this as the de facto UN policy, governments were made publicly accountable for their public health and human-rights actions or inactions.

Mann and Tarantola (1998) outline how human rights may be applied to health, noting three ways in particular: advocacy, application of legal standards, and programming (including service delivery). As an example of advocacy (or 'bearing witness'), the authors point to the effectiveness of advocacy in bringing down the costs to developing countries of antiretroviral therapies (ARVs). This, they suggest, is a fine example of the way health and human-rights arguments have been combined in public campaigns to impact on public-health policy. In an observation highly relevant to Igat Hope and Kapul Champions, the authors see risks for organisations in trying to combine sustainable health action with the documentation and criticism of human-rights violations. The latter can quite easily impact on the former, threatening relations with government and placing health workers at risk. By application of legal standards, the authors refer to the use of internationally agreed norms, standards and accountability mechanisms within health-care systems and in the work of national and international health, economic and developmental policy makers. Individuals, whose rights have been violated in the course of accessing (or trying to access) public-health programs, have legal mechanisms for redress. An example has been the use of national constitutions to enforce rights to ARVs. With regard to delivery of care and programming, the authors focus on rights-based service delivery, while noting some confusion as to what this exactly entails. The authors suggest rights-based service delivery involves the following: concern for delivery of services to vulnerable populations; examining laws and policies under which programs take place; systematically integrating into all programs core human-rights principles such as participation, non-discrimination, transparency and accountability; and focus on key elements of the right to health including availability, accessibility and quality. The authors conclude with a note of concern for the future. Government roles and responsibilities are increasingly delegated to non-state actors, such as biomedical research institutions, health-insurance companies, health-management organisations, the pharmaceutical industry and care providers. To this we might add, if they are not already included by implication, donors, development agencies and international NGOs. The authors worry that, while the responsibilities of governments to safeguard human rights are clear, the accountability of these other players is ill defined and inadequate.

Writing in 2008, Loren Hallgarth and Tarantola summarise a rights-based approach to health as follows: 'A rights-based approach to health includes taking the core principles of human rights and using them as a framework for developing and evaluating health policies and programs' (157). The authors offer four basic or core principles of human-rights law: non-discrimination, particularly where distinctions are made on the basis of those factors listed in international covenants; participation, the active and informed participation of individuals and communities in decision-making that affects them; accountability and transparency, crucial to the realisation of all human rights, particularly those subject to progressive realisation, there can be no accountability without government transparency and the capacity to monitor government performance; and attention to vulnerable populations (158–59). The authors argue that states have a responsibility to respect rights, protect rights and take steps to ensure this responsibility is met, including by engaging non-state actors where necessary. This responsibility impels states to take such steps as may be required, individually and through international assistance and cooperation, to move towards the full realisation of rights, including the right to health. The authors note this right is subject to progressive realisation but make the point that the principle of progressive realisation does not apply to those rights enshrined in the ICCPR — the right to non-discrimination, among others. These impose immediate obligations. Therefore, when it comes to citizens' rights to health, countries are entitled to have their national health-service delivery capacity considered. They must strive to achieve the best attainable health for citizens given context and the resources available. They get no such leeway, however, when it comes to disproportionate impacts on sub-populations based on irrelevant grounds. The authors return to the idea of the right to health as involving availability, accessibility, acceptability and quality. Availability is straightforward, you can either access something or you cannot. By accessibility, the authors are referring to four internal elements: services must be available to people without discrimination, they must be physically accessible, economically accessible, and information accessible. Acceptability refers to health that is respectful of medical ethics and culturally appropriate, while quality denotes that care must be scientifically and medically appropriate and of good quality. A rights-based approach to health draws attention to principles such as participation, attention to vulnerable populations and non-discrimination. It involves an acknowledgement that major determinants of health are increasingly understood to lie outside the health system and include fulfilment of an array of rights — indeed nearly every human right has implications for health.

Before moving on to Chapter 2, it is worth reiterating three key points from this chapter. First, the naming and labelling of PLHIV, MDS and trans women in PNG — and their ownership of these different descriptors — has shaped the HIV response in PNG. A range of external influences has played a role in this naming and labelling: western advocacy movements driven by PLHIV, gay men and transgender people; donor culture, particularly Australian donor culture; and the global HIV response, particularly its interest in identifying, categorising and apportioning risk. But internal factors are at play also, notably local desire to access donor benefits. This is an evolving space, but it is best understood where these multiple influences are acknowledged. Second, consideration of the rights of PLHIV, MDS and trans women in PNG requires reference not only to international human-rights law, but also to the PNG Constitution and domestic legislation. These different components combine to shape the ‘human-rights framework’ considered in this research. As subsequent chapters, particularly Chapter 3, will demonstrate, these components are interconnected, indeed they overlap in many ways. Critically, the Constitution and local protective laws such as the *HAMP Act* echo international human-rights laws, making them less ‘other’. Papua New Guineans also hear another echo, this time of values embedded in Papua New Guinean community life that predate the Universal Declaration and colonisation. Third, there is a correlation between effective HIV responses and responses that respect the human rights of marginalised groups.

With these observations, we are ready to move on to hear stories from the people I interviewed for my research. I conducted qualitative interviews with a purposive sample of 72 members of PLHIV, MDS and transgender communities in Port Moresby. Given my focus on HIV and the way people’s experience of human rights is shaped by the virus, it should be no surprise that half my interviewees were PLHIV. The experience of PLHIV is also critical to my story about the emergence and efforts of Igat Hope, another focus of this work. Similarly, my story of Kapul Champions requires emphasis on the stories of its constituents, men with diverse sexualities and transgender Papua New Guineans. I am interested in the human rights experiences of the marginalised, noting again the way that HIV often reserves its harshest impacts for those communities which are the most marginalised. I explore the interrelationships between HIV, human rights, sex and gender, and it is notable that I do not seek to do this through a focus on the experience of women. While I do consider the particular impacts of HIV on women in PNG, women are not the focus of my research. Instead I focus on MDS and transgender women. I do so partly because these are the perspectives needed to understand the story of Kapul Champions, and also because these communities have been central to my work over decades and, as I detail in the next chapter, this history is part of the story I am telling in this work. I also consider the experience of MDS and transgender women in PNG to illuminate the experience of marginalisation more generally, and to offer critical insights into the transferability of some of the HIV responses favoured by NAPWHA, AFAO and the broader development sector in PNG. The experiences of MDS and transgender Papua New Guineans also help us understand how human rights are being understood with reference to identities and practices associated (however inaccurately) with modernity and Western influence, another theme in my work.

Interviews were conducted over three field trips from December 2015 to September 2017. Of the 72 interviews, 35 were conducted with PLHIV, six were conducted with MDS and 31 with trans women. I also interviewed nine other stakeholders. Chapters Three to Eight are constructed around these 81 stories. But first, a short detour. Before I could write this story, I needed to understand my position in relation to the stories I was hearing and the work I was documenting. Chapter 2 is about this positionality.

Chapter 2

Insiders and Outsiders, Advocates and Researchers

This chapter is for Maura Elaripe. Just about anyone who has worked in HIV in PNG knows Maura or knows of her. She was one of the very first people with HIV in PNG to speak openly about her status and so became, in many respects, the face of the positive community as PNG came to learn about HIV. She has held governance positions with Igat Hope, was a member of its first board and served as acting president at critical times during Igat Hope's earliest years, including in the lead up to the organisation's inaugural AGM. She has worked for Igat Hope, for UNAIDS and UN Women in PNG, and has been a leader across Asia and the Pacific through her work with APN+. She has been a passionate HIV-treatments activist and a vital and influential community voice in local Global Fund forums. She has been a strong advocate for positive women and helped establish Women Affected by HIV/AIDS.

*

In this chapter, I reflect on my role in my research, seeking to understand my own biases and the ways in which interviewees may have been influenced in the sharing of their stories, especially by my subject position as friend, colleague and advocate. I explore what it is to be an insider or outsider, think about how roles of researcher and advocate can be balanced, and reflect on my own motivations in approaching this research. To facilitate this reflection, I consider what a range of researchers and scholars have had to say on the best strategies for managing these challenges. The chapter concludes with a description of my methodology, and here I make some observations on the strategies that I used and whether the challenges were subsequently met.

Insider/outsider, dichotomy or continuum?

I feel like I have spent my entire professional life as a bit of an outsider. I began my career as a community legal centre lawyer in Sydney's west, circa 1990. In the community legal sector, we often described our area of practice as poverty law. I had a commitment to helping disadvantaged communities seek justice, but I was not really *of* the communities I was servicing. At the end of each day, I hopped on a train (and another train or bus) to my home in Sydney's east, far from the disadvantage of my centre's community.

True, as a (then) young gay man, I did imagine myself to have some understanding of disadvantage and marginalisation. I imagined some affinity with people whose experience of justice was shaped by factors beyond their control, by their involuntary membership of a group. And I felt (somewhat foolishly in retrospect) that my politics somehow connected me with my clients — I assumed they would all be left-leaning and seeking structural social change. (They were not.) But I also knew that this ‘connection’ with my clients would not accommodate me being open about my sexuality; I observed a lot of homophobia in the community being serviced by my centre, and in quite a few of my clients as well.

After three years I went to work as a legal research officer for the AIDS Council of NSW, later to be rebranded as ACON, and so began my life of work in HIV as an HIV-negative man. It has been my observation that the HIV sector is acutely attuned to the conversation about membership versus non-membership. The notion of ‘peer’ is keenly understood — there is awareness that people’s connection with HIV can be similar depending on their experiences or characteristics and that responses to the epidemic can and should be tailored around these peer groupings. The sector’s acceptance that people with HIV should speak and decide for themselves is one of its defining characteristics and greatest strengths. The sector sometimes challenges HIV-negative people who work in the sector to reflect on their insider/outsider status, and this is the same challenge (in Australia at least) that confronts sector workers who are not gay men. I have heard many women working in HIV also talk about this.

After a couple of years, I went to work as a policy officer in the Disability Discrimination Unit of what is now the Australian Human Rights Commission. Again, as a person who did not have a disability, I was an outsider. The Disability Discrimination Unit included a number of employees with disabilities and their lived experience of disability was critical to the unit’s success. Their perspectives were highly valued. The Commission consulted extensively with the broader disability sector and the perspectives of leaders of these communities were similarly valued. Again, it was clear that people who did not have disabilities would need to respect the views of those who did, and our role was to facilitate, to give effect to these insights. Interestingly, it was my connection with HIV that gave me some legitimacy at the commission, even though there were many disability advocates at the time who were reluctant to accept HIV as a disability.

When I started to work in international development in the late 1990s, initially through HIV but since then in a range of different areas, my role as outsider became even clearer. There is a lot that I do not have in common with a Papua New Guinean man having sex with other men, for example. In relation to my role as an international development worker, I am more obviously an outsider, yet there is still a connection that affects my work. Again, as a gay man, I think I know something about the experience of gay men in PNG (and I will come to the question of whether ‘gay’ has meaning in PNG in due course). It is possible that I do not, but I believe I do. This is relevant to my role as a researcher; this confidence that I understand some things about homosexuality in PNG, and my expectation that my research will validate these understandings. For example, it would take a lot to convince me that gay men do not care about the way the law regards their sexual practices. It would take a lot to convince me that gay men in PNG do not want equal rights and social acceptance and places to gather and safe opportunities for sexual engagement and the chance to build loving unions without fear of violence or community rejection. So, while I appreciate that I am an outsider, I purport to know what insiders want. I get the contradiction.

One of the reasons I originally chose a 'human-rights' framework for my research was because (somewhat naïvely) I wanted to be *inside* again. I wanted to write about a cause which was undeniably my own. I imagined I would be talking legitimately about *my* rights, not as a committed outsider but as an insider. I wanted to speak for a cause without constantly questioning my entitlement to do so and without the need to be seen to be deferring to others who have more right to speak for it than I do myself. I wanted to speak for myself. But, as I will explain, things turned out to be a little more complicated than I had planned.

Of course, my situation is complicated by all sorts of factors, including my involvement in the work I am documenting. I have been privileged to be witness to much of Igat Hope's history. I was not present when it was set up in 2001, but I was one of the first consultants that the National Association of People Living With HIV Australia (NAPWHA) dispatched to work with Igat Hope in 2004, and I have continued to work with the organisation off and on since that time. I was the Chair of Igat Hope's first AGM in 2005, and its second and its third. So, I have seen its democracy in action. I have been a technical adviser to the organisation, supporter, advocate and critic. In reflecting on Igat Hope's work, I am reflecting, in part, on my own.

I was around for the birth of Kapul Champions. I was in the room when the relevant resolution was passed to establish the organisation and I counted the votes at the election of its Inaugural Board in 2011. I have been a technical adviser to the organisation, and I have been engaged by the Australian Federation of AIDS Organisations (AFAO) to support it over many years. I have formally reviewed it. Again, in reflecting on the organisation's work, I am reflecting on my own.

I understand that my contribution has been a small one. I appreciate that the two organisations have been built not by development workers from Australia but by the constituencies themselves, and especially by those brave Papua New Guineans who have taken up leadership roles in their organisations. I have, however, been at least a part of the story of these organisations. My challenge has been to recognise my place in this work and to try to consider it critically, while recognising that this is only one component of the overall picture. This research is not just about my work; my work is a small part of the story of Igat Hope and Kapul Champions, and an even smaller part of the story of community movements of PLHIV, MDS and transgender women.

I have felt a particular connection with the MDS and trans women with whom I have worked in PNG. I have a long history of collaborating with queer community organisations in Australia, as a Gay and Lesbian Rights Lobby Board member, as convenor of the Lesbian and Gay Legal Rights Service and as a delegate for NSW to the Australian Council for Lesbian and Gay Rights. My work at ACON, and later AFAO, was situated heavily within queer communities. During the 1990s and 2000s, this was taken to include the trans community as well. I appreciate there is a longer story about the degree to which trans people have been truly included in the work of these organisations but, suffice to say, a lot of the work done by ACON and AFAO (at least while I was an employee/consultant) was done in the expectation that it applied to trans people. All this meant that, when I arrived in PNG and began working with MDS and trans women there, I felt a degree of understanding of their issues, if not their experience. I believe that the willingness of Kapul Champions's members to share their stories with me has been shaped in part by my sexuality.

An equally important factor shaping the willingness of interviewees to participate in my research has no doubt been my history with AFAO and NAPWHA. I believe this history contributed to a degree of trust on the part of interviewees, and the fact that I reached most interviewees through these organisations supports this. Feedback from many interviewees confirmed that I am trusted. I also understand that my links to these organisations represent 'opportunity' to many of my research interviewees. I am seen, rightly or wrongly, as a possible conduit to travel and training opportunities, perhaps even to employment. I am seen by some as a potential source of money, either directly or through the Australian organisations for which I have worked. And while I have sought at every opportunity to be clear that my research brings no material benefits for individual interviewees, it is understandable that some interviewees might still have thought participation in the research study might lead to a personal gain.

More broadly, I believe I am seen as an advocate for Igat Hope and Kapul Champions, so community members committed to these organisations may see participation in my research as likely to aid the organisations' future. And it is true that I *do* believe that community organisations are important, and I hope my work *does* assist marginalised groups to sustain representative voices, so I have had to monitor my efforts to ensure I am genuinely impartial in my analysis of these organisations. I like to think my experience as an independent consultant reviewer of organisations and programs has been useful training for ethical objectivity.

I had already done a lot of thinking about the insider/outsider question before I formally started my research, trying to determine my entitlement to do this work. I have since been interested to learn how other people have explored the insider/outsider question and, in particular, how researchers balance their academic and activist motivations. I began my reading with an exploration by Sonya Corbin Dwyer and Jennifer Buckle (2009) of the strengths and weaknesses of undertaking qualitative research from within and outside the researched community. Corbin Dwyer had conducted insider research on white parents of adopted children from Asia, while Buckle undertook outsider research on bereaved parents. As the authors note, postmodernist research emphasises the importance of understanding the researcher's context as part of narrative interpretation, and researchers are increasingly declaring their subject position. The authors observe that 'whether the researcher is located within or outside, the personhood of the researcher, including her or his membership status in relation to those participating in the research, is an essential and ever-present aspect of the investigation' (55).

One of the most obvious strengths for the insider is acceptance. Membership of the researched group brings a degree of trust and openness. Subjects may be more likely to share their stories in the expectation they will be understood. This aids in getting subjects to participate — membership gives a degree of validity to the process. While I am not a member of the PLHIV community I researched, I have been a (small) part of a group of development workers and activists who have supported and helped maintain Igat Hope. Membership of this group did facilitate access to research subjects, and it did, I feel, contribute to a degree of trust and openness. This was evidenced by the significant number of PLHIV interviewees who discussed 'old times' with me or talked about friends and associates we had in common, or said things like, 'You remember, Tim?' as they shared their stories.

When it came to MDS and trans women my connection felt a little different. Again, I am not Papua New Guinean and I am not trans, but I am an MDS and have a shared knowledge of life as a man who has sex with men. I am confident that this was highly relevant for many of my MDS and transgender interviewees. Interviewees often joked with me about homosexual sex or shared quite intimate details of their sex lives or relationships (jokingly or otherwise), and I believe they felt comfortable in doing so partly because they knew me to be a gay man. But the relevance of my sexuality was indicated more by what was *not* said than by what interviewees said. Many things were not explained because it was assumed I would, as a gay man, understand them. At this point I should emphasise that I understand MDS and trans are different and that my connections to each community differ. However, the communities are connected, socially and politically, so I frequently refer to 'MDS and trans' together.

Returning to the issue of assumed knowledge, Corbin Dwyer and Buckle (2009) note these assumptions can be a downside of insider status. Subjects may assume too much insider understanding. Researchers may assume too much knowledge, applying their own understandings instead of truly hearing what is being said. Here is a possible example of subjects assuming too much. While I certainly have personal experience of sex with men, I actually do not have any experience of homosexual sex in PNG. I hold a political and professional view of this practice that it would not be compatible with me being a development worker, but I think many of my interviewees assumed that I have had sex in PNG, and with Papua New Guinean men. In fact, over the years I have heard more than one rumour of my alleged sexual relationships with members of Kapul Champions. I did wonder whether my lack of PNG-based sexual experience might suggest a kind of barrier, established on my part, which could limit my understanding of my interviewees' world. Might it even constitute a 'hang up', I wondered. Andrea Waling (2018) offers some interesting reflections on researcher comfort zones and asks what the responsibility is of the researcher to go beyond this comfort zone. In particular, she asks this in relation to the notion of the erotic within anthropological and sociological research, observing that researchers have traditionally been positioned as objective and neutral where the sexuality and sexual desire of the researcher remains a subtext that is systematically erased. She explores 'erotic subjectivity', the practice of focusing on the desires and sexuality of researchers in the field whereby researchers are encouraged to acknowledge their own sexual identities/desire. This, Waling posits, can then help them explore the embodied researcher, enhancing data collection, analysing and theorising. But it is not just about recognising the impact of your own sexual identity label on the research communities, but about the practices of desire in everyday interactions in the field — simple touches or ways of communication. These can generate a shared self-connection that is also political when considered against broader social dynamics. Waling sought to research the erotic men's dance troupe, Manpower. She had imagined her role as researcher and feminist with a negative view of this kind of entertainment (as low-brow, possibly sexist and not particularly entertaining) might afford her some power in the dynamic but ended up being more conflicted than she had anticipated. Instead of feeling empowered as the researcher, she was impacted upon by insecurities.

Of course, outsiders do not know what they do not know. I will never know how much my interviewees did not tell me because I am not HIV-positive or because I am not a trans woman or because I did not share their ethnicity or nationality. But being an outsider has its advantages. Corbin Dwyer and Buckle (2009) describe four potential strengths associated with outsider research (observed earlier by Fay 1966): distance can give perspective not available to people enmeshed in the researched setting; outsiders can sometimes make sense of the overlapping, mixed and occasionally contradictory perspectives of others in ways those individuals cannot; externality might enable researchers to see the bigger picture; and external observers may be able to see past the self-deception of the researched (Corbin Dwyer and Buckle 2009:59). I recognise these potential strengths, and yet wonder if this analysis slightly exalts the outsider, as if locals cannot see the big picture. And the notion of self-deception does not sit entirely comfortably with the clarity of interviewees' accounts.

Corbin Dwyer and Buckle (2009:55) note that 'membership' of a researched group may have different levels. Citing work by Patricia Adler and Peter Adler (1987), the authors canvass three levels of observational research: peripheral (where researchers do not participate in the core activities of the group), active (researchers are involved in the central activities without necessarily committing to the members' values and goals) and complete (researchers are members of the group or become fully affiliated during the course of the research). This analysis did not seem useful for me because, as peripheral, I am theoretically left claiming the objectivity of a complete outsider when that does not truly feel like a legitimate claim.

The authors acknowledge there may be levels beyond these three. They go on to canvass a range of challenges, including the conflict that might arise between different loyalties, where researchers feel a loyalty to their subjects or the subject material that impacts upon the degree to which they would be comfortable critiquing them/it, yet are committed to the integrity of the research. They refer also to the challenges of role confusion where the researcher is familiar with the research setting or participants through a role other than that of researcher. This was certainly the case with me. I know the setting and, in many cases, the interviewees, through my paid work. Some of the interviewees had become my friends so I had heard at least some of their stories in social settings.

Corbin Dwyer and Buckle ultimately posit (2009:59) that what is most important is not insider or outsider status, but 'an ability to be open, authentic, deeply interested in the experience of one's research participants, and committed to accurately and adequately representing their experience.' They agree that it is wrong to see the situation as an either/or. Researchers can be insiders and outsiders. This conclusion resonated deeply with me.

Nationality, ethnicity and empathy

Researchers Ayça Ergun and Aykan Erdemir (2010) reflect on their insider/outsider status in relation to their field work in Azerbaijan and Turkey respectively. Each researcher had some link with the community being researched, yet each was also an outsider to some degree. Ergun is Turkish and conducted research in Azerbaijan, where she observed that Turks and Azerbaijanis share many cultural characteristics and that many research subjects considered her one of their own. Erdemir is a Turk and conducted research with Turks while living in the United States. The authors write that, for researchers in the field, insider/outsider identities are not set in stone. They are fluid, non-static, permeable and dialectic. They are shaped by factors such as cultural, social and linguistic affinities, ideology and political preferences, age, gender, marital status and profession. Ergun and Erdemir suggest that for field researchers there is neither a comfortable insider status nor a comfortable outsider status, and that data will be best obtained through a dialectical process involving constant negotiation of status and relationship with informants. Ergun and Erdemir observe that researchers must have consideration for neutrality with concerns regarding the preservation of neutrality stemming from scholarly, pragmatic and ethical motivations. A certain level of distance from subjects must be preserved. While researchers will want to immerse themselves in the community of research to grasp the emic perspective, the perspective from within, and understand what the locals think, this must not result in the loss of etic (observer) insight. They must be able to distinguish what the *locals* think from what *they* think.

Lauren Breen (2007) conducted research on the grief experienced by people who have lost loved ones in car accidents. Her partner was one such person, having lost his sister in an accident. Breen was a step removed from this experience of grief and considered herself a researcher somewhere in the middle between insider and outsider. Breen’s own review of the literature prompted her to observe that it is becoming increasingly important for social researchers to clarify their personal motivation for undertaking research. She notes, like others, that insider status brings superior knowledge of the researched community and its context and an ability to interact naturally with the group’s members, while it can have costs in terms of loss of objectivity, in particular a tendency to make erroneous assumptions based on prior knowledge and experience. In her research she observed how the insider/outside position impacts on subject recruitment and finding informants. For example, Breen found it hard to find interviewees amongst those whose roles might impact on road safety, because potential interviewees suspected that her proximity to a road death meant she could not be impartial.

Breen writes that her outsider status prompted her to immerse herself in her subject area in a way she may not otherwise have done and argues it contributed to assumptions that she was independent and unbiased. She chose to apply four strategies to maximise the rigour of her research: multiple sources of data and methods of data collection, maintenance of a daily journal, checking data interpretations with informants to determine accuracy, and dissemination of result summaries to participants for comments and clarification. As I will explain in my methodology section, with the exception of the diary, I used these same approaches.

I used a paper by Roger Vallance (2007) on Melanesian research to further reflect on my status as a white Australian. The paper was written by an expatriate academic living and working in PNG, so I had imagined he may have struggled with some of the same insider/outsider questions that have troubled me. In exploring the question of whether there might be a Melanesian way of researching, Vallance asks the question whether there might be a Melanesian perspective or view of reality relevant to research. He notes that others have written about a Melanesian worldview, often described as holistic with connections between the natural world and the people who inhabit it. This worldview is grounded in relationships, which are primarily communal and active among research participants, and between the participants and the researcher. Vallance sees that a Melanesian ontology would encourage research questions that are holistic and integrated and that respect the cultural dimensions of participants and stakeholders (7).

Vallance references work done by Karl Franklin (2007) listing 10 values which he believes underpin the Melanesian world view, these being the values of land, clan, reciprocity, food, ancestors, ritual, leadership, education, compensation and work (7). Vallance concludes that Melanesian methodology does not rely upon Melanesian ethnicity but Melanesian values and worldview, although I appreciate there are many (in PNG and elsewhere) who would maintain that ethnicity is critical. It is also a hard claim for a non-indigenous person to credibly make, that being indigenous is not a criterion for Melanesian methodology.

Vallance adds that issues of authenticity and trustworthiness are also pertinent to Melanesian research and that researchers are subsequently required to pay close attention to how initial contact is made, ownership of knowledge, prolonged engagement, persistent observation, the need to ‘check in’ regularly with the community, language and the interview process. Vallance suggests that six criteria must be satisfied to claim the use of a Melanesian methodology: the research must be grounded in a Melanesian world view; the research program must respect and focus upon the Melanesian experience; the research must share Melanesian values and demonstrate this in data collection and analysis; the research must be grounded in Melanesian community experience and consolidate that life-force integration; the research must reflect an understanding of the lived experience of Melanesian culture; and research outcomes must be developed, publicised and actioned in ways that foster the life of Melanesian community. On this analysis, in significant ways, my research is not Melanesian; to begin with, my experience in PNG does not constitute lived experience of Melanesian culture. I also conducted my work in English and not in Tok Pisin. So perhaps the best I can do is have some understanding of the ways in which my research is *not* Melanesian, and at least have regard to Vallance’s criteria as I write this thesis.

Having considered an expatriate’s writings on Melanesian culture, I felt the need to consider a Melanesian’s writings on the matter. In his ground-breaking work, *The Melanesian Way*, Bernard Narokobi (1980) explores issues of Melanesian identity, voice and way. He observes that while Melanesians have lived in PNG for thousands of years, the way they are viewed, and indeed their self-perception, is disproportionately shaped by recent history and the views of outsiders: ‘For far too long we have known ourselves through books written by others' (3). He observes that Papua New Guineans have subsequently come to see themselves as they are understood and written up by foreigners. He writes, 'Melanesians are walking in the shadows of these Western analysts, living under dreams and visions dreamt and seen by Westerners' (9). Not surprisingly, this prompted me to reflect on my entitlement to write a story of Igat Hope and Kapul Champions. Having cautioned against trying to understand Melanesians by reference to outsider views, Narokobi shares his own insights into Melanesian identity. He talks about foundational understandings that characterise Melanesians:

> [F]rom creation, every person of a human community, be it called a village or a nation, is endowed with a sense of good and bad by the Divine Source, however conceived or named. Accordingly, the inherent good or evil in Melanesia is in some respects unique to ourselves; while in others we share them with other communities the world over. (3)

Narokobi writes of Melanesians as an ancient people born to liberty and to ancient culture and civilisation. He sees them as spiritual with a right and responsibility to call upon the wisdom of ancestors. From this spirituality Melanesians have a vision of totality and cosmic harmony. They are non-exploitative, non-acquisitive and non-colonialist, inherently capable of giving and taking, of cooperation and mutual support, especially in times of crisis. Minimisation of confrontation and competition are also core, he observes. He describes a village as a cultural unit: 'an organ of civilisation, technology, agriculture and enterprise, with people applying their talents at their own pace, working without incentive or higher pay or overseas travel but because it's right to work' (1980:13). He sees a spirit of self-reliance.

Having made some observations about Melanesian culture, Narokobi also points out that Papua New Guineans are never slaves to their cultural practice, being able to evolve and cast off traditions where they become obstacles. This is possible because they are united by a common vision, he says. Melanesian civilisation, laws and values are not derived by others. Given the inherent strengths of Melanesian culture, and the ability of Melanesians to see all that has succeeded around the world, as well as all that has failed in other countries, he wonders what paths Melanesians will choose as they chart their future. In confronting these choices, he observes what Melanesians share with people worldwide but also the unique nature of the Melanesian.

These themes — cultural practice and its evolution and absorbing and resisting influences from outside — were to arise frequently in my interviews as people reflected on what is Papua New Guinean and what is alien. This came up often as interviewees talked about the origins of human rights and whether they matched up with Papua New Guinean 'values' or were consistent with Papua New Guinean 'culture'. Many interviewees referenced sources of human dignity beyond an international instrument — speaking of indigenous understandings of good and evil, of birthright and traditional values. Some interviewees sought to both claim the international protections provided by declarations and covenants — the protections that come with being citizens of the world — while simultaneously reinforcing the unique nature of being Papua New Guinean. Most fascinating of all were interviewee observations on how the external has been indigenised, and cultural practices changed as a consequence, consistent with Narokobi's reflections on the capacity of the Melanesian culture to evolve and adapt, by choice rather than as a result of force.

Finally, Narokobi also makes important points about western framing of community service and volunteerism, another recurring theme in my work in PNG. He is critical of the way 'service organisations' encourage community service and volunteerism, as if it is novel to Papua New Guineans. (This, in my experience, is true also of most donors and development agencies whether or not they see themselves as 'service organisations'.) As if this is not what happens every day in community life with people voluntarily supporting extensive family networks without expectation of government or other support, because it is required by tradition and because they consider it the right thing to do. Gratitude cannot be forced out of people, he says. Foreign aid is no more than sharing the resources of the world with its people (Narokobi 1980:16). Forty years on from the publishing of his *The Melanesian Way*, Narokobi's observations remain relevant. Writing in a special commemorative issue of the *Journal of Pacific History*, Lise Dobrin and Alex Golub (2020) note his enduring status as a great theorist of Oceanic modernity and identity and as the author of a decolonisation philosophy that remains highly relevant. His work, they argue, stands as a continuing guide to Melanesian people committed to Christianity, cultural unity-in-diversity, regional connection but national aspiration and non-violent resistance to colonialism.

Linda Tuhiwai Smith (2013) offers some further cautions regarding the telling of indigenous stories by outsiders, encouraging readers to understand the ways that indigenous people are discussed, researched, written about and theorised by people who are not indigenous. She asks people to consider the concepts that shape the ways that ideas of indigenous people are articulated, including imperialism and colonialism. She writes that these are concepts with multiple meanings, all of which can be problematic from the indigenous perspective: 'Words of emotion that draw attention to the thousands of ways in which indigenous languages, knowledges and cultures have been silenced or misrepresented, ridiculed or condemned in academic and popular discourses' (58). Tuhiwai Smith argues that people undertaking or documenting research relating to indigenous people must consider these issues. They must engage in a process of decolonisation, which involves having a more critical understanding of the underlying assumptions, motivations and values which inform research practices.

Tuhiwai Smith talks about ongoing research with indigenous communities around the world, with waves of researchers entering with ‘goodwill in their front pockets and patents in their back pockets’ (2013:65–66). Everything is taken, she writes — genetic codes, traditional medicines, belief systems. These researchers continue to take, but what exactly do they give back to the people they research? Tuhiwai Smith warns that the erasing or negation of indigenous histories is a critical component of colonial ideology, observing how indigenous groups argue the importance of history to any understanding of the present, and that reclaiming history is part of the decolonisation process. But she also observes that while indigenous people have struggled against a western view of history, they have also, on some level, been complicit. They have allowed their stories to be told, becoming outsiders as they heard them retold. Reading this made me wonder how my interviewees would hear their stories in my work.

Tuhiwai Smith reflects on the importance of writing for indigenous people, on how they are written about. These writings can be dangerous where they ignore indigenous people as if they did not exist, do not reinforce the culture or identity of indigenous people, speak untruthfully about indigenous people or feature them only in negative stories. This can be just as true of research writings as of any story, Tuhiwai Smith notes:

> Research is linked in all disciplines to theory. Research adds to, is generated from, creates or broadens our theoretical understanding. Indigenous people have been, in many ways, oppressed by theory. Any consideration of the ways our origins have been examined, our histories recounted, our arts analysed, our cultures dissected, measured, torn apart and distorted back to us will suggest that theories have not looked sympathetically or ethically at us. (2013:86)

Tuhiwai Smith emphasises respect for the right of indigenous people to tell their own histories, and this reminds me of the importance of constantly making this point: I am telling *a* story of these community movements with which I worked, not *the* story. PLHIV, MDS and trans people in PNG can tell their own stories.

Tuhiwai Smith talks about ‘research through imperial eyes’. Noting that indigenous people often criticise ‘white research’, ‘academic research’ and ‘outsider research’ (2013:92), Tuhiwai Smith unpacks this to explain what it is about this research which can be so problematic for indigenous people, observing that it is so often conceptualised through western, imperialist notions:

> We think about research and history and culture in ways shaped by our own histories, and this impacts on how we describe race, gender, the state of being ‘other’, the relationship between the individual and society, space, time etc. Research ‘through imperial eyes’ describes an approach which assumes that Western ideas about these most fundamental things are the only ideas possible to hold, certainly the only rational ideas, and in fact key to making sense of the world, of reality, of social life and human beings. It is an approach to indigenous peoples which still conveys a sense of innate

> superiority and a desire to bring 'progress' into the lives of indigenous people in the full range of domains — spiritually, intellectually, socially and economically. (114)

Tuhiwai Smith sees this research, completed through imperial eyes, as a form of robbery. This all made me think again about what I was taking from my research subjects: their stories, not stolen but taken all the same. Perhaps with some outcomes for them, but definitely with outcomes for me. I found Tuhiwai Smith's arguments compelling and it left me thinking that with all the well-intentioned reflection in the world I would not be able to see all the ways that my research reflects my western ways of thinking. I used some strategies to try and address at least some of the issues Tuhiwai Smith identifies. I reflected deeply on ownership of stories and data. I regularly reported back to the communities from which interviewees were drawn, checking the accuracy of my understanding and analysis. I actively sought feedback from interviewees and their communities on the ways in which I was relaying their stories. I have endeavoured to use interviewees' own words as much as possible, through multiple and extensive quotes from my 81 interviewees. I returned data in the form of advocacy materials for use by Igat Hope and Kapul Champions. In this way I have tried to be less thief and more borrower, more amplifier. And I have tried hard to respect the role of Igat Hope and Kapul Champions as the representative voices of their constituents.

Being a researcher and being an advocate

Another issue I had to reconcile before I could write my thesis was the tension between being a researcher and an advocate. The former was a new role for me whereas I have worked as an advocate for decades. My research has been clearly and overtly linked to the struggles experienced by communities of which my interviewees are members and has been strongly supported by the organisations that represent these communities. I have been keen for the process to build a consciousness of human rights among the research participants. I have allowed my personal experiences and knowledge to inform my work and I want my work to support political action. As I set out on my literature review, I had wondered what researchers and scholars might say of my struggle to reconcile my research, on the one hand, with my activist motivations, on the other.

Francesca Cancian (1993) defines activist research as aiming to challenge inequality by empowering the powerless, exposing injustice and promoting social change. She observes that this kind of research is often conducted for powerless groups, and that it involves close social ties and cooperation with these groups. She contrasts this with academic research, which she sees as being primarily for colleagues and involving emotional detachment from those studied. Cancian posits that researchers will be more successful activists when they emphasise in their research the kinds of changes that will address power imbalances, as opposed to just identifying improvements that might be achieved within existing structures. Similarly, they should incorporate collective action into their research instead of just restricting themselves to academic analysis; that is, they must include *practice* as well as *theory*. She writes that to do activist research, researchers must have strong ties to the relevant community and must hold their work accountable to both activist and academic standards. Through my research I have tried to expose injustice. Chapter 4 is full of stories of injustice experienced by PLHIV, MDS and trans women, and I have framed these by reference to power structures that need to be reformed if these injustices are to be addressed. I have drawn on my strong ties to PLHIV, MDS and trans communities and, through reporting back to communities and testing data analyses with these communities, I have sought to be held accountable. My thesis is a call for social change and my final chapter, where my inner advocate is fully unleashed, offers some tools for use in effecting some of the change required.

Cancian describes participatory research as social research over which intended beneficiaries have substantial control and in which they are heavily involved. Participatory researchers focus on power relations and work primarily with community groups rather than policy experts or academics. Cancian outlines four characteristics of participatory research: participation in the research by community members; consciousness raising and education of participants; inclusion of popular knowledge (including personal experience and feelings); and political action aimed at structural change. She approves an analysis of progressive social change (Maguire 1987) that outlines change at three levels: building confidence and critical consciousness on the part of participants (personal level), strengthening activist organisations (community level), and transformation of power structures (societal level). I found comfort in reading Cancian's work, particularly in the notion that activist research is actually a thing, and that my work could be located within a domain of participatory research that validates its emphasis on community groups.

Cancian observed the practices of a small group of academics conducting activist research, finding that while community members often heavily influence the research agenda, they rarely design or actually do the research. Cancian concludes that most activist researchers avoid a 'radical orientation to social change' that might make academics uncomfortable, although many involve some degree of collective action aimed at challenging power structures, and that most are well connected to community organisations in the field. After considering the tension between academic and activist motivations, Cancian concludes that these tensions can be managed, and that the effort involved is worthwhile. Cancian concludes that research done in association with activist organisations is more likely to produce findings that benefit the powerless. My own research was conducted in close association with, and with extensive support from, Igat Hope and Kapul

Champions, and I am very hopeful that my findings will go some way towards benefiting PLHIV, MDS and trans women in PNG.

Linda Williams (2004) undertook research on researcher/advocate collaborations aimed at ending violence against women in the United States. She observes that researcher/practitioner/advocate collaborations are not only more effective in facilitating sample identification and data collection, but they are also more likely to identify the most important research questions, find answers that are useful in the field, and reveal important steps in ending violence against women. She summarises findings from a 2001 study conducted by the National Violence Against Women Prevention Research Centre of its own research collaborations in violence prevention (based on perspectives from 130 advocates and practitioners). Williams writes that this reflection on research indicated significant frustrations on the part of both researchers and researched. Research participants complained of arrogance on the part of researchers, that researchers failed to properly consider the impact of their research on survivors, failed to solicit or adequately value advocates' ideas and opinions, seldom provided feedback on research findings and did not properly consider the costs of participation for subjects and advocates. On the flipside, researchers complained that practitioners and advocates were not truly open to some of the research findings — they were interested only in research results that confirmed their views and supported their established advocacy positions.

Williams argues that collaborations will be enhanced where researchers have better awareness of the potential impact of their work and better understand the power differentials within the relationship. After all, the researcher is usually in charge of the research and has been given the funding to conduct it. Williams refers to a set of liberating methodologies to address power imbalances. These include acknowledging the expertise that researchers, practitioners and survivors bring to each study; acknowledging that the process of knowledge production is not value free — the objectivity/subjectivity dichotomy is overdrawn as all knowledge production is political; recognising the importance of reflexivity; emphasising the voices of the subjects; and commitment to research that links activism and research. Williams observes that collaboration must be properly resourced (and funded), practitioners should be engaged (and paid for this engagement) at every stage of the process, and research reports that are accessible and jargon-free should be distributed to advocates and practitioners.

Breen (2007) also considered the position of advocate researchers. She observes that insider-researchers are sometimes criticised for being advocates rather than researchers (citing Bonner and Tolhurst 2002), and this was certainly an issue for me. I was absolutely an advocate for the cause — promotion of the human rights of PLHIV, MDS and trans women — and as my work progressed, I reflected often on my role as an advocate and activist, wondering and worrying how I might reconcile this role with my role as researcher. At one point I began to map my position against two matrices — insider/outsider and activist/researcher — as if the specific intersection point might tell me something about my place in my work. But my place on the matrix shifted every time I mapped it, depending on what work I was doing with Igat Hope or Kapul Champions at the time, so I concluded this 'moment in time' analysis would be of limited value.

Roland Stahl and Corey Shdaimah (2008) researched collaboration between community advocates and academic researchers, noting (like Cancian and others) the tension between the roles of researcher and advocate. They studied a research collaboration between a community advocacy group in the United States and a team of academic researchers, with a particular focus on the tensions generated by the distinct roles of academic and advocate. The authors were members of the collaboration's research component, so were reviewing work in which they had been key players. Stahl and Shdaimah reflect on the growth in research collaborations involving academic researchers and community groups. They speak positively of participatory action research that is driven by, and engages, people affected by a particular problem, and that has social change as a goal. They note some challenges that arise when researchers are studying a process of which they are (or have been) a part, particularly the risk that this involvement will impact on the participants' candour.

To try to balance the power they possessed as framers of the research, Stahl and Shdaimah included many direct quotes from participants. This, they argue, ensures that research includes the unfiltered voice of the community partner. They also take care not to 'erase' their own presence, to pretend they have not been central to the work being reviewed. Stahl and Shdaimah reflect on their close collaboration with the relevant community organisation, recognising that this increased the effectiveness of data gathering and analysis. But they also acknowledge that this had come at considerable cost, mostly in terms of time spent on maintaining the collaboration. They observe other challenges: insistence, on the part of the community partner, that the researchers engage with the political aspects of the problem being examined, and different assumptions about strategic considerations, the scope of the problem and underlying causes. The authors argue that, despite early agreements on research scope, as the research progresses researchers may begin to explore issues that complicate the political messages the community seeks to promulgate. They note that advocates frequently seek data that can be easily incorporated into political messaging, yet data is often complex and defies simple interpretation.

Stahl and Shdaimah conclude that this management of role expectations is critical but attainable. It does not require researchers to turn into advocates or vice versa, it requires only the respectful management of tensions and open communication. Knowledge production must be a means to an end, not the end itself. It must be informed by situated practice. Collaborative approaches are useful for studying practical social problems because researchers are forced to engage people who are directly impacted by these problems. They are forced to acknowledge the complexity and 'situatedness' of real policy problems. This all sounds right to me. I have explored these notions of collaboration in some of my earlier work, conducted with John Rule, particularly our reflections on a decade of collaboration between Igat Hope and NAPWHA (Leach and Rule 2013). Our reflections are consistent with those of Stahl and Shdaimah.

I found Igat Hope and Kapul Champions to be excellent research partners. The ways in which the organisations helped me source interviewees, and the support provided more generally, gave my work the organisations' imprimatur. There would have been a clear perception on the part of interviewees that my work was endorsed by the organisations, and this no doubt encouraged interviewees to participate. I experienced no pressure from the organisations to focus on some issues at the expense of others, or to interpret my data in particular ways. In this sense I could not have asked for more from either organisation. And yet my relationships with the organisations still add complexity to my work. In the course of my research, I have felt a strong personal desire to find data consistent with the organisations' general goals. I have always understood that my relationship with both organisations, which I have always valued and continue to value, would be negatively impacted should my work support conclusions that the organisations consider damaging. I have had to remain alert to these factors in the collection and interpretation of my data.

Valli Kalei Kanuha (2000) reflects on her experiences as a social worker researching her 'own kind' (in her case, people of colour in the United States identifying as gay or lesbian). Kanuha considers the roles and challenges of insider/indigenous/native researchers in the context of the evolution in social science from hyper-objectivity to an exploration of the space between insider and outsider. She suggests that some of the most critical analyses of this space have been undertaken by scholars who are lesbian, men of colour, international feminists and others, whose personal experiences challenge the hegemonic traditions of science, epistemology (theory of knowledge, particularly in relation to the distinction between justified belief and opinion), and ontology (nature of being). She describes her own motivations as threefold. First, drawing on her own experience of stigma she sought a greater understanding of people whose lives were similar to her own. Second, she sought a theoretical framework for comprehending what it meant to be multiply stigmatised. Finally, she wanted to contribute towards an understanding that might benefit the marginalised communities of which she was a member. While these were not exactly my own motivations, I could relate to them. Like Kanuha, I want a theoretical framework for better understanding stigma and to help marginalised communities with which I have a connection or to whose empowerment I have a commitment. Although in my case I am not researching ‘my own’.

Kanuha reflects on the challenges she faced in data collection. The stories of her interviewees so often mirrored her own life experiences that she was distracted by the similarities, struggling to retain focus on the content. Some of her efforts to establish distance were, she writes, counter-productive, generating distance from the process of her research and reducing her ability to obtain nuance and depth of insight from her interviews. She reflects also on what was *not* said in interviews, what interviewees assumed she would understand, and sees that by failing to pursue these unsaid things she missed vital data. Kanuha adopted three strategies to deal with these challenges: she consciously delved into coded responses; where a narrative appeared common across interviewees, she rigorously pursued the exceptions; and she reflected deeply on the ‘tensions’ arising in relationships with her informants as she engaged with them both professionally and as friends, noting that these relationships are not always fixed.

A concluding paragraph in her paper also had resonance for me. Kanuha confesses that the most painful work experiences of her career have involved working with clients and supervising staff who were people with social identities with which she strongly identified (for her, feminists, people of colour and AIDS activists): ‘Being an insider with clients while simultaneously an outsider who provides them with services or supervision is not an easy place to be. This is the challenge involved in exerting power over those whose struggles we are supporting’ (2000:445). It is the challenge experienced in critiquing the work of Igat Hope and Kapul Champions, as I have done in my professional roles over the years. It is the challenge involved in making ‘professional’ decisions that sometimes negatively impacted upon individual Igat Hope/Kapul Champions members, such as implementing strategic redirections that ended some project activities in favour of others and, consequently, saw some employees and constituents gain while others lost.

Cassie Earl (2017) writes about some of these challenges in being a researcher activist and notes the view that research should be part of a process that creates effective programs for change, reflecting on her own role as a researcher working both outside a social movement and in solidarity with it (in her case, the Occupy London movement of 2011–12). She observes the challenge in creating critical distance from the events being witnessed while attempting to assist the social movement as a researcher: ‘This is not an easy place to live, and this kind of work often stands at one side or the other of the interstice between hope and despair, solidarity and frustration’ (130). Earl notes the importance of fusing knowledge and action in the struggle for social change in such a way that each of these terms guarantees the truth of the other. She speaks positively of researchers positioning themselves so that the fusion of knowledge and action is achieved via action-research work. The activist researcher participates in the formation of new struggles, rather than just reporting on the struggles of others with a supposed objective distance. True, objective reporting of what is occurring has value, but all the while life for the disadvantaged fails to improve. Why wouldn't researchers who care about injustice join the struggle from their own place in academia? Earl endorses Patti Lather (1986), 'Those committed to the development of research approaches that challenge the status quo and contribute to a more egalitarian social order have made an epistemological break from the positive insistence upon researcher neutrality and objectivity' (Earl 2017:131).

Earl (2017) observes that action research can serve as a critical friend to the social movement and can be read, in close to real time, by activists as a way of understanding, from an outsider's point of view, the failures and successes of the movement. The role of the self-conscious activist, Earl writes, is to take the spontaneous learning of social eruptions and initiate a reflective and critical examination of what was imagined, what was hoped for, what occurred and what failed. Earl further observes, 'There is, all too often, an insider/outsider dichotomy in research with social movements, which needs not to be so if research with these groups and individuals is thought of by both parties as activism in and of itself' (133). Earl examined the power relationships between researcher and interviewee, noting that the former generally holds the power. She sought to rebalance this by conceptualising research as collaboration between researcher and subject in which each assists the other to make the world a better place through creative conversation and reflection.

I appreciated the observations of Christine Stewart, who reflects in her research on the motivations of many expatriates who continue to make a contribution to PNG causes in which they believe. Stewart writes about the motivations of expatriates like herself who had worked at the University of Papua New Guinea (UPNG), but her comments ring true for me also as a long-term development worker in PNG:

> Like many of those expatriate UNPG teachers, I am and continue to be involved, sympathetic and ready to offer my services to causes I consider to be just … I let those interviewed know my views on the human-rights abuses I had noted in my studies and research. I make no apology for this personal bias. In so doing I am reminded of … Nancy Scheper-Hughes's declaration that 'anthropology must exist on two fronts: as a traditional, disciplinary field *and* as a force field, a more immediate site of struggle and resistance.' (2014:5; emphasis in original Scheper-Hughes—1996:892)

Stewart's site of struggle was not so dissimilar to my own. Her site was raising public awareness of the situation of gay men (Stewart's term) and people selling sex in Port Moresby. I've no doubt that Stewart and I interviewed some of the same people, yet I feel we have shared more than just the occasional interviewee. Many of Stewart's reflections on her motivations resonate with me. Stewart was motivated by a sense of injustice, by the plight of people who had become her friends, and by a sense of what could be achieved. Like Stewart, I continue to be involved, sympathetic and ready to back social justice causes.

On friendship and not wanting to offend

My connections with the communities I was researching raised for me questions regarding my preparedness to disappoint or offend the individuals and groups involved.

Julia Brown (2018) reflects on the relationships between researcher and subjects, recalling the earlier work of Nancy Scheper-Hughes (2000), whose research on schizophrenia in an Irish community had ultimately angered her subjects. Scheper-Hughes's subjects, indeed the broader community in which they lived, felt that in the researcher's published work their weaknesses had been emphasised to the detriment of their strengths. Brown writes that the researcher had become at first a friend to the community, and then (to some at least) a traitor. Scheper-Hughes asked:

> What are the proper relations between the anthropologist and her subjects? To whom does she owe her loyalties, and how can these be met in the course of ethnographic fieldwork and writing, especially within the problematic domain of psychological and psychiatric anthropology where the focus on disease and distress, difference and marginality, over-determine a critical view? (127)

I share the interest of both Scheper-Hughes and Brown in 'disease and distress, difference and marginality'. Like the subjects of their research (people with schizophrenia), members of the communities with whom I was working have often experienced psychological trauma, ostracism and exclusion based on diagnosis, actual or imagined. Brown reflects on the challenges in inviting subjects to trust her, especially given that they have been disappointed by so many people over their lifetime. Again, this is true of the people I interviewed — many have felt let down by broken promises of partnership and support from development workers and donors. Brown observes this can be offset by an appreciation of the opportunity to have an outsider outlet for their frustrations — many appreciate being given the opportunity to share their stories; to be heard. Certainly, this has been true of my interviewees; time and again they have expressed gratitude for the opportunity to tell their stories, when many must surely have told their stories before to development workers and researchers, only to see these people disappear with these stories on laptops and dictaphones never to be seen or heard from again.

Brown also reflects on her desire for her subjects to approve of what she writes, and her concerns that what they told her was being unavoidably contextualised by her own views and interpretations. She wonders whether what she was told may not have been exactly what her subjects meant to say — people do not always say what they mean or mean what they say. This adds a complexity to research, observes Brown. We have first to consider whether we have been told the real (or whole) story, and then to reflect on the degree to which our own thinking shapes our interpretation of what we have heard. And then we have to ask if we are writing a version which we hope will garner our subjects' approval. Brown again turns to Scheper-Hughes:

> How can we know what we know other than by filtering experience through the highly subjective categories of thinking and feeling that represent our own particular ways of being … Both the danger and the value of anthropology lie in the clash and collision of cultures and interpretations as the anthropologist meets her subjects in a spirit of open engagement, frankness and receptivity. There was, I concluded, no politically correct way of doing anthropology. (Scheper-Hughes 2000:127)

Finding myself in the process and taking action

Collectively, and thankfully, the researchers, writers and academics referenced above have given me confidence to proceed with my research. It has been heartening to learn that all the issues I have found so challenging in my efforts to balance my motivations and produce 'legitimate' research have been dealt with so many times before. I have learned that some of the factors I had once thought might undermine my research are likely, if managed, to enhance it. I see that insider/outsider is a continuum, not a dichotomy. A researcher's status is not static — it might well change over time and may alter depending on who is being interviewed and what is being discussed. I have concluded that neutrality is important to the extent that the researcher must be able to distinguish between what the subjects think and what the researcher thinks. Beyond this, all kinds of immersion in and connectedness with the researched community may be appropriate provided they are authentic and mutually understood.

I have come to appreciate that the relationship between researcher and researched is negotiated. It is not for me to unilaterally declare how an interviewee should see me or feel about me. I can explain the role I seek, but an interviewee may ascribe to me another. I have come to understand that it is acceptable for me to be simultaneously an advocate/activist and a researcher. I need, however, to be clear about my advocate/activist motivations and reflect regularly on the ways in which these motivations might be shaping how my research is conducted and what interviewees say to me. I need to be mindful that data can be nuanced, complex and might not always neatly fit with established advocacy positions. It does not always lend itself to the simple sloganeering that engages communities and affects political thinking.

More fundamentally, it is acceptable for me to bring my whole self to the research process. My work will be strengthened by using my existing knowledge, based on my long history of work in this area. It is reasonable to hope that my research will benefit the communities I am researching. Of course, my subjects will be aware of my history and, whatever I say, will ascribe to me a set of views about the content area of my research. Many research participants will have some regard to their relationship with me; indeed I count many as friends. Power will be, to some degree at least, a component of all my research interactions. Here, and elsewhere in my research, self-reflection is key. My position in this research is complicated and I will navigate its complexities only if I acknowledge the factors that make it complex and reflect regularly on my motivations.

In the end, I chose to balance my motivations as follows. I sought to establish my role as a neutral researcher, in that I was open to any findings that may emerge from my research, no matter how these findings might reflect on my past work or on the organisations I have supported. I was clear that I wanted to discover more about the communities with which I have worked for so long and was open to discovering new things that might challenge my previous understandings. I made this clear in my participants' information sheet and at the beginning of every interview. I acknowledged my past work with these communities but asked interviewees to look beyond this and to see me now as a researcher. I sought to make clear that I was very comfortable hearing negative commentary about the work in which I had been involved. On occasion I prompted interviewees with examples of inputs or interventions that had (in my view) produced poor results.

I was open about my commitment to the human rights of interviewees, and to social reform that would see their rights better respected. I was open about my willingness to share my work with Igat Hope and Kapul Champions so that it might be used to support their advocacy, and about my hope that my work would ultimately deliver benefits for PLHIV, MDS and trans communities. While I did not say this to interviewees, I was not prepared to disseminate data that might negatively impact the lives of PLHIV, MDS and trans women. I imagine this ethical practice would have been assumed by most of my interviewees.

I was open about my past efforts to build and support Igat Hope and Kapul Champions (although most interviewees knew of this already). I expressed no view as to the future of these organisations and often prompted interviewees to critically reflect on the activities of these organisations, sometimes by noting the criticisms of others. In this I was drawing a distinction between my study of the human rights of researched communities (my commitment to which would not be diminished, regardless of what I heard) and my study of the two organisations (which might lead me to conclude that they were ineffective or counterproductive). While I was public about my desire to use the results of my research for the benefit of PLHIV, MDS and trans women, I was silent on whether I thought the research might ultimately be to the benefit of the organisations.

When conducting interviews, I retained an openness to letting interviewees lead me where they wanted to go (discussed further in my methodology section). Where they shared views that surprised me, I probed to understand more deeply what they were saying. In my writing I have endeavoured to give voice to interviewees by frequently using their own words, unfiltered by me. I have looked for patterns and themes in responses to give meaning to ‘community perspectives’. I have tried to acknowledge that, while all views are important, commonly shared views that might represent community perspectives have another value altogether. In this way I have looked for community perspectives that might facilitate community advocacy, so that data might be used by community activists (if they so choose) to legitimise their claims that they speak on behalf of constituencies. As my research progressed, I provided summaries of preliminary findings to both Igat Hope and Kapul Champions. Kapul Champions was keen to convert these summaries into advocacy materials, and I assisted with this process. I have included examples of these summaries in the annexures.

When I started this chapter its working title was, ‘Back inside at last’. I had imagined it would be a story about returning to a human-rights framework that would put me, as a human being, right back in the middle of my work. As I wrote the chapter it became clear that this is a story by an outsider — one who values his connections to the communities being researched and who has a personal commitment to advancing their rights, but an outsider all the same. This is a story by an outsider who played a small but not entirely insignificant support role in relation to two important community movements. And, by a researcher who remains at heart an advocate.

Unsolicited, one of the women with HIV interviewed in 2017 for my research, here given the pseudonym Martha, offered this analysis of my work:

> Okay, okay — I think, all your questions, I am happy with what you are doing and, I don’t know, like this is the research that you are coming and I am just giving a little bit of input and then someone might give you input and you can take it back to where you are going and how you are going to help us with that or some of this real life challenges we are facing here in PNG and … looking into and with the research that you are doing, I hope that you might be coming with the clear picture of what we are doing and, in the future, we might be having a good improvement to the work that we are doing and also I would like to — since you guys are coming back like this and like others to Igat Hope and being a partner of Igat Hope too, and coming and going and all that, we are proud about what Igat Hope is doing with … partnering with this research … this [research] … along the way, it’s a good networking thing that they are doing and good benefits for the patients and young generations to come through.

I like this observation on my research. Martha understood she was offering a perspective, and that others would offer theirs, and that I would use these stories to help the storytellers address the many challenges experienced by them on a day-to-day basis. I like that she was proud of the way that Igat Hope was supporting the research and I like that she understood I would be returning. I really like that she imagined my work might potentially have benefits for future generations.

Methodology

I conducted qualitative interviews with a purposive sample of 72 members of PLHIV, MDS and transgender communities in Port Moresby over three field trips, which took place in December 2015, April 2016 and September 2017. Of the 72 interviews, 35 were conducted with PLHIV, six were conducted with MDS and 31 were conducted with transgender women. A number of interviewees held membership of more than one of these communities. For convenience, they have been categorised according to whether they were interviewed during the field trip involving MDS and transgender Papua New Guineans (organised with the help of Kapul Champions in December 2015) or the two field trips involving PLHIV (organised with the assistance of Igat Hope in April 2016 and September 2017). For example, where an HIV-positive transgender woman was interviewed during the first field trip, she has been listed as one of the 31 transgender women interviewed.

The first field visit focused on interviews with MDS and transgender women, and 36 interviews were conducted. I sought and received assistance from Kapul Champions in reaching interviewees. Kapul Champions's staff contacted members and constituents they thought might be interested in participating in an interview. Kapul Champions's staff also posted an open invitation to potential interviewees at the Poro Sapot clinic in Port Moresby — the clinic favoured by MDS and transgender people. I also used my own contacts to identify interviewees. Having worked with MDS and transgender communities in PNG for over a decade, I know many members of these communities in Port Moresby and was able to secure interviews with many of the contacts I have established through my work. Over the course of the week of interviews, additional interviewees presented themselves having been alerted to the research by friends and colleagues. This introduced a snowballing element to the research. Overall, around half of all interviewees were reached via Kapul Champions with the remainder sourced via personal contacts, Poro Sapot or word of mouth. Most interviews were conducted at the National AIDS Council, where Kapul Champions has its office. Some were conducted in the lobby of my hotel or at restaurants and cafés around Port Moresby.

On my second field trip I focused on PLHIV, conducting interviews with a total of 19 people. I enlisted the support of Igat Hope to identify potential interviewees and Igat Hope staff contacted members and constituents they thought might be interested in sharing their stories. Having worked with Igat Hope and PLHIV for 15 years, I have many of my own contacts within the PLHIV community and reached out to these with an invitation to participate. Encouragingly, not a single person I contacted directly (whether PLHIV, MDS or transgender) declined to be interviewed. Overall, around half of all interviews with HIV-positive people were sourced via Igat Hope, with the other half being sourced via personal contacts or word of mouth. Most interviews with PLHIV were conducted at the National AIDS Council, where Igat Hope has its office, although some were conducted in the lobby of my hotel. As was the case with MDS interviewees, word about the research spread throughout the PLHIV community and additional interviewees who had not been contacted by Igat Hope presented themselves for interview. They had heard about the research from friends or colleagues, and often by people who had already been interviewed. In both cases — for PLHIV and for MDS/transgender people — this snowballing presented some challenges in that significant numbers of people turned up for interviews that had not been scheduled by Igat Hope or Kapul Champions, but all were accommodated.

On the third trip I conducted interviews with a further 16 PLHIV, again contacted via Igat Hope. I conducted an additional interview with a transgender person reached via my own networks. Most interviews were conducted at the National AIDS Council, with one being conducted at the interviewee's workplace.

The vast majority of interviewees lived in the National Capital District (NCD), but less than half identified as being *from* NCD. Interviewees came from all over PNG. Around 60 per cent of PLHIV interviewees were female; MDS were all male and transgender interviewees were all trans women who had identified, or been identified, as male at birth. Interviewees ranged in age from late teens to late fifties, with most interviewees being in their twenties and thirties. Few were engaged in formal employment and the majority of those who were employed worked in HIV or health services. Around two-thirds of interviewees claimed some kind of membership of Igat Hope and/or Kapul Champions, although this sometimes meant that they had only been to an organisational event such as a training, workshop or social activity. Most others had some knowledge of the organisation/s, although in some cases this was very recently acquired. Around 20 per cent of interviewees held or had held a governance position with Igat Hope and/or Kapul Champions. Most interviewees indicated throughout the course of their interviews that they identified as Christian, although I did not specifically ask about religion. Interviewees identified as belonging to a broad range of Christian fellowships.

My research involves some study limitations. This cohort would likely be distinguishable from the broader constituency in a number of ways. Interviewees were disproportionately likely to be connected to Igat Hope and/or Kapul Champions, meaning they were more likely to have been exposed to some discussion of human rights and more likely to be connected to HIV or sexual health services. They were more likely to speak and read English. They were more likely to be 'out' about their HIV status, their sexuality and/or their transgender identity.

Interviews were semi-structured. I had prepared a standard set of open questions and always began with one of these, but interviewees were not required to answer all questions or to address them in any particular sequence. I consciously allowed the interviewee to talk about issues of relevance to him/her/them. Where this resulted in the interviewee moving well beyond the scope of enquiry, I gently encouraged the interviewee to return to the research focus. I tried to ensure that interviewees answered at least one question relating to each of my four broad areas of enquiry: understandings of human rights; lived experience of the observance or otherwise of human rights; perceptions of Igat Hope and/or Kapul Champions; and their thoughts about the future. Beyond this requirement, interviewees were free to follow their interests. Not surprisingly, by allowing interviewees to talk about the issues of importance to them, I was exposed to a richness of data that would not have been accessible through a tightly structured interview.

As noted, several interviewees were both HIV-positive and MDS or transgender. They were invited to speak from either or both perspectives and questions were tailored appropriately. When referring to interviewees in this thesis I reference a kind of ‘lead status’, so I might refer to ‘John, PLHIV’ even though John may also be trans or an MDS. I will have done so because I connected with ‘John’ when seeking and conducting interviews with PLHIV and because John will have come to be interviewed because of his HIV-status. I also interviewed a number of stakeholders, selected for their expertise in the issues I was researching. While several of these were also HIV-positive or MDS, stakeholders are denoted as such.

To protect the anonymity of my interviewees, where they are quoted or otherwise referred to in this thesis, they have been assigned pseudonyms (see the list of pseudonyms in the front matter).

Communication processes and challenges of interpretation

Most interviews (85%) were conducted in English. I had been prepared to conduct interviews via interpreters and this willingness had been conveyed to Igat Hope and Kapul Champions. For the most part the organisations sourced participants willing to be interviewed in English, and this has undoubtedly skewed my sample. Some interviewees presented who were not fluent in English, and this was particularly the case where interviewees presented because they had heard about the research other than through direct contact with Igat Hope or Kapul Champions.

The challenges of interpretation and establishing trust were managed in different ways. Both Igat Hope and Kapul Champions had advised against the use of independent interpreters. They advised that their members would not feel comfortable telling their stories in the presence of a stranger (with the stranger being the interpreter rather than me), and that this discomfort could not be managed by my undertaking to engage only qualified interpreters who would be contracted to protect the confidentiality of the shared information. I was not entirely surprised by this. All interviews involved the sharing of very personal information, and fears of unauthorised disclosure (of HIV status, sexuality or transgender identity) are commonly expressed by PLHIV, MDS and transgender people in PNG. These fears are well founded — quite a few interviewees reported breaches of their confidentiality by people professionally bound to respect it. I discussed with my contacts at Igat Hope and Kapul Champions why interviewees might be willing to share information with me (an outsider) yet unwilling to share it with an interpreter (who would be local). I was advised that there were several reasons for this. First, while I was an outsider, I was not a stranger, being well known by organisational staff (who provided a guarantee of sorts) and by many interviewees. Second, my 'otherness' (as a researcher, as an outsider connected with an Australian university) meant that interviewees thought it less likely I would engage in local community gossip and less likely I would accidentally let slip confidential information in social settings. My interests in community gossiping or in divulging confidential information were considered to be comparatively low.

Those interviewees who were not confident in English generally presented with their own interpreters — friends or family members. On several occasions they asked that their interviews be translated by Igat Hope or Kapul Champions staff. Again, this did not surprise me. From my own experience I know that senior personnel in both agencies are highly regarded and trusted by constituents, and it was not surprising that these interviewees felt comfortable speaking via these employees. Where people played the role of interpreter, they were required to sign a confidentiality agreement.

Consent forms and participant information sheets were available only in English. On each occasion where an interviewee struggled to read English, I required that the relevant Igat Hope/Kapul Champions representative translate the information into the relevant language. Sometimes this was done in a group setting.

On some occasions people would seek to be interviewed together (in small groups of two or three and on one occasion in a group of four). Where all group participants were not confident in English, the usual practice was for those people to nominate another participant to translate for them. Where people participated in an interview with others, they were required to sign the consent form relevant to group interviews. On balance I determined that it was appropriate to proceed in circumstances where interpreting was required, even though interpreters were not professionally trained. I formed the strong view that people presenting for an interview wanted to be heard — this was a consistent message across all interviews. Interviewees had stories that they wanted to tell, and I decided that these voices should be facilitated wherever possible and that the denial of voice would have been experienced negatively by those denied. In her research with homosexual men and trans women in Port Moresby, Stewart (2014) found a similar desire for people to share stories.

While I have used translated interviews as important sources of knowledge, I have opted not to use any translated quotes from these interviews. Even though I am confident the lay interpreters competently and faithfully conveyed their peers' sentiments, I suspect their translations may have been less rigorous than those of a professional interpreter. I decided not to ascribe actual words to an interviewee in circumstances where I had not heard them in English or directly from a professional interpreter.

Most interviewees agreed to be audio-recorded. Interviews were transcribed in Australia by a contractor known to me under a contract guaranteeing the protection of data. On one occasion I terminated a recording because I was not confident the interviewee was fully capable of conducting the interview. The partial recording was deleted, and the notes destroyed. On another occasion I deleted a recording, and associated notes, because the records contained highly prejudicial information that may have placed the interviewee in serious danger of prosecution. Despite the security measures I implemented to safeguard data, I was uncomfortable being in possession of this information, even for a short time.

Checking my data with interviewees and communities

Following the first field trip I sent a summary of key patterns and themes emerging from my interviews with MDS and trans women to Kapul Champions. Following the second trip I sent a summary of key patterns and themes emerging from my interviews with PLHIV to Igat Hope (see annexures).

During the second field trip, I conducted a forum for MDS and trans women to report back on my preliminary findings from the first trip. This was conducted at the National AIDS Council with the assistance of Kapul Champions. Twenty-five community members attended, including around half of those who had been interviewed for the research. The report-back involved me presenting key observations in a preliminary form, with participants being invited to critique/comment on my observations. The presentation took the form of key patterns and themes emerging from interviews. Participants took the opportunity to supplement my thinking and, on a couple of occasions, provided important clarifications. The session affirmed my preliminary observations and direction, with participants indicating strong support for the conduct of the research.

On the third trip, I conducted a community report-back session for PLHIV. The session was conducted at the National AIDS Council with the assistance of Igat Hope. Twenty-seven PLHIV attended. Again, I presented the key themes and patterns emerging from my research and invited participants to critique my preliminary observations. As with the forum for MDS and trans women, participants were strongly supportive of the work and my preliminary observations. Participants took the opportunity to supplement their earlier contributions and to engage with some of the preliminary findings, leading to further important clarifications.

With both community reports back I sought to demonstrate respect for the PLHIV, MDS and trans communities by reporting on my work and providing an opportunity to clarify or challenge my understanding. I began by explaining that I was reporting back on what I had heard whether or not I agreed with it or believed it. I explained I had looked for patterns and themes across interviews and that I was seeking to report on interviewee experiences and perspectives. On occasions I offered preliminary interpretations of the data, but my priority was confirming what I had heard, and that I understood what I had heard. My primary questions were: Is this what you said? Did I hear this right? Is this what you meant? Where I had begun to draw conclusions from the data I asked: Does this sound reasonable? Is this a fair conclusion?

I feel strongly that participants in both report-back sessions affirmed my observations and, just as significantly, endorsed the research as generating important data that might potentially be used for the benefit of their communities. The sessions also generated debate and further revelations. For example, some of the richest data regarding the history of homosexuality in PNG came, not from individual interviews, but from the session convened to review the data gathered on my first trip. Session participants were very engaged by the notion that my research might draw some conclusions about this, and that it might attribute these observations to my interviewees. The session generated lively conversation — not just about what individual participants thought likely to be the historical truth, but also about the merits or otherwise of saying these things publicly. There was a concern that my research might be considered to indicate a community perspective, and the subsequent conversation focused on the degree to which the sensibilities of the broader community and the safety of interviewees should factor into the expression of this perspective. This was a community strategising about its place and its aspirations, and I felt privileged to see this in action.

I also conducted interviews with nine people working in relevant organisations: UNAIDS, Poro Sapot, NAPWHA, AFAO, Igat Hope and Kapul Champions. In all cases, these employees held senior positions within their agencies and were very familiar with the work being researched. They were approached for their institutional knowledge and to offer perspectives grounded in their professional role, but in many cases these interviewees were also HIV-positive, gay, and/or Papua New Guinean. They were invited to speak from these perspectives as well. These interviews were often (although not always) more structured than those conducted with community members, and I used a slightly different set of open questions as a starting point for conversations.

Participant observation

I have also relied on participant observation. I have worked with these communities for many years and played a role in the building of both Igat Hope and Kapul Champions. I witnessed many of the events and activities detailed or referenced in this research, particularly those undertaken by the two organisations. I was engaged by NAPWHA over many years to provide technical support to Igat Hope. In the course of my work, I delivered governance training for successive boards and mentoring for secretariat staff. I was part of the organising committee that planned and delivered Igat Hope's first national conference, attending and presenting at the conference. I was part of the team that organised Igat Hope's Inaugural Treatments Advocacy Workshop. I worked closely with the organisation in its transition from a support group for people in the National Capital District to a national peak, that is, an organisation of provincial organisational members, drafting the organisation's new constitution in the process. Over many years I documented the work of Igat Hope on behalf of NAPWHA for use in NAPWHA's reporting to Igat Hope's primary donor — initially AusAID and then, following AusAID's absorption into the Australian Department of Foreign Affairs and Trade (DFAT), to DFAT.

I also played a role in the establishment of Kapul Champions. I was part of a three-year collaboration between Save The Children in PNG and AFAO aimed at supporting the establishment of a national organisation for MDS and transgender people. I was present at the national workshop that resolved to establish a national advocacy organisation, helped draft the organisation's constitution and acted as returning officer for the organisation's inaugural AGM. I was engaged by AFAO to deliver technical support to Kapul Champions over many years, playing a role in the design and delivery of Kapul Champions's human-rights workshops. I provided governance training for the board and support for secretariat staff. I conducted an evaluation of the organisation for AFAO. I documented the organisation's work over many years, often to assist AFAO to report to AusAID or DFAT or to source funds from other donors.

In recalling my past involvement and relying on observation, I attempted to check these against relevant documentation. Documentation of organisational activities (and by extension the experiences of their constituent communities) has been undertaken by DFAT, NAPWHA, AFAO, Igat Hope and Kapul Champions. NAPWHA and AFAO, in particular, have extensive records of the work of Igat Hope and Kapul Champions, developed for reporting purposes and for use in funding applications. I have written some of these documents.

In reflecting on my methodology, as well as my position in my research, I considered work by Lather (1986), who explores ways that research can have validity in circumstances where the researcher is not neutral. Lather rejects traditional (positivist) declarations that research in the human sciences must be objective and neutral and instead she embraces the notion that, since interest-free knowledge is logically impossible, researchers should feel free to substitute explicit interests for implicit ones (64). Lather notes that feminist research, neo-Marxist critical ethnography and Freirean ‘empowering’ research all reject this positivist position. Lather suggests that the challenge that flows from this rejection of neutrality and objectivity is to find approaches to research that advance emancipatory theory building through the development of interactive and action-inspiring research designs. But how can we navigate this new paradigm while still feeling confident that our research has validity, asks Lather, concluding that the best solutions lie in research designs that push researchers towards becoming vigorously self-aware. She offers a reconceptualisation of validity which is appropriate for research that is openly committed to a more just social order. Lather suggests:

> Once we recognize that just as there is no neutral education there is no neutral research, we no longer need apologize for unabashedly ideological research and its open commitment to using research to criticize and change the status quo. The development of data credibility checks to protect our research and theory construction from our enthusiasms, however, is essential in our efforts to create a self-reflexive human science. (1986:67)

To this end, Lather offers some guidelines. First, she recommends ‘triangulation’ that includes multiple data sources, methods and theoretical schemes. Counter patterns must be sought just as convergence of data is sought. Next, Lather recommends attention to *reflexive subjectivity,* the documentation of how the researcher’s assumptions have been affected by the data. This should be accompanied by ‘face validity’, a systemised ‘checking in’ with the subjects of the research, or at least a reasonable sub-sample, to test analyses and emerging theories. Finally, there needs to be ‘catalytic validity’, that is, some documentation that the research process has led to insight and, ideally, activism.

I read Lather’s work as further support for me being comfortable with my role as an advocate and activist in my research. Of course, I need to be aware of how this plays out in my work, but Lather tells me it is reasonable for me to own my interest in the causes I have researched. I consider my work to involve triangulation to the extent that I have used multiple data sources — interviews, documentation review and my own experience as an observer and participant. Throughout this thesis I tease out how my assumptions — many of which I have detailed in this chapter — have been impacted by my research. I consider my cycle of interview and report back to be a solid methodology for establishing face validity. As for catalytic validity, here I see my work as unfinished. The final chapter provides some tools that my research subjects might make use of, and I am already using my research in my own advocacy. My research’s catalytic validity will be determined over time. Here Lather sees a need to consciously channel the impact of the research process so that subjects gain self-understanding and, ideally, self-determination. I cannot speak to the impact, but at the very least I have had regard for the potential for my research to be used by communities of PLHIV, MDS and trans women to enhance understanding of their position in Papua New Guinean life and to support efforts to improve that position.

Having been encouraged by Lather to own my values and assumptions in undertaking this research, I am tempted further towards a degree of ‘reflexivity’ in my work. Linda Finlay (2002) describes this as a process which involves me in engaging in explicit and self-aware analysis of my own role: a ‘thoughtful, conscious self-awareness’ (2002:532). Finlay describes the qualitative researcher as a central figure who influences the collection, selection and interpretation of data. The researcher affects participants’ responses and thereby shapes the direction of the findings. The research that results can be considered a joint-product of participants, the researcher/s and their relationships: it is ‘co-constituted’ (2002:531). The practice of reflexivity, Finlay observes, requires balance, an awareness of self in the research process but an avoidance of navel-gazing. The researcher is present but should not become unduly privileged, drowning out participants’ voices. And so my work will involve an examination of my own beliefs, judgements and practices during the research process, together with reflection on how these may have influenced my research. Having acknowledged that I know quite a lot about the situation I am researching, I will not infrequently reflect on what it is I am doing with this knowledge. In this way I will be acknowledging that I am part of the research. My relationships with the people I am interviewing are key to my work, indeed many of my interviewees became so only because we already had some form of connection. I will be inviting readers to appreciate these relationships and to interpret my work in the context of these connections.

David Mcinnes, Liz Mcdonnell and Gary Dowsett (2010) explore reflexivity in their study of collaborative HIV educational research. The authors acknowledge that complex and expert systems of knowledge about educational practice reside with the practitioners whose work is studied. The researchers set out to extract this knowledge and to make sense of the data with a view to developing a theory and practice of educational work, writing that their research is as much embedded in interpersonal and relational interaction as it is in intellectual endeavour. While taking educators and their work as the research focus, the educators joined the researchers in a consideration of themselves and their work through a set of descriptive and analytical methods. The authors explain that they were open to discussion, description and critique, allowing the researchers and their project, with the aid of their educator collaborators, to be the object of critical engagement.

Mcinnes, Mcdonnell and Dowsett note two axes of reflexivity operating in their work. The first is the reflexivity educators have with their own work and institutional position. The second is the reflexive relationship of all collaborators to the research process and its practices. The authors argue that reflexivity, as a research principle and practice, demanded a continuous, critical dialogue between researchers, participants and ideas. This, they write, occurred within individual moments of research and also, in an accumulating sense, over time. The result, they write, was a deepening understanding of educational logics, problematics and meta-structures. And so, I will be visible to readers of this work. Readers will be encouraged to appreciate my relationships with my interviewees, the context in which our conversations took place, some of my own assumptions that no doubt shaped what I heard during interviews, and what it is I have done as a result. My interviewees will be doing a lot of heavy lifting in this research — I am heavily reliant upon their testimony to tell the story — but I too will be visible in making sense of these stories, and in doing so with reference to my relationships with informants and my own knowledge of what it is I am researching. I would be delighted if interviewees were to feel that we had co-constituted this work.

Finally, a reflection from Christine Stewart (2014), with whom I was lucky enough to work from time to time. Here, Stewart writes of the challenges (and advantages) involved in being immersed in research over long periods:

> My experiences in PNG have served to minimise the distinction between ‘field’ and ‘home’ which persists as a traditional criterion for good fieldwork. Anthropologist friends have gone into the field to meet subjects and emerged having made friends. I was obliged to restructure many friends as subjects, at least temporarily. This positioning has also coloured my perceptions and understanding to the point where I am often unable to distinguish what I have learned from research and reading from what I have absorbed over the years. I can ‘know’ something to be true, without being able to locate an academic reference to support it. I can recall many conversations and events which have subsequently become relevant to my research. Where I refer to such matters in my work, I can only propose them as ‘personal knowledge’. (10)

This really resonates with me. I referred earlier to the number of times my interviewees would invoke shared experiences by using a phrase like, ‘You remember, Tim?’ Turns out, I do.

This chapter has been a lot about me and my quest to understand my positionality in my research. I had to write it in order to work out whether I felt sufficient entitlement to proceed. But enough of me, it is time to hear more from my interviewees. The next chapters are constructed around their stories.

Chapter Three
Understanding of Human Rights

This chapter is dedicated to Don Liriope, a pioneer of the PLHIV and MDS/trans movements in PNG who served on the boards of both Igat Hope and Kapul Champions. He co-authored the HIV Stigma Index for PNG, an important account of HIV-related stigma in the PNG Highlands. He was employed by Igat Hope to conduct this research and to undertake other initiatives to connect PLHIV communities across PNG, which he did with great energy. He was a founding member of Kapul Champions and its inaugural vice-president. He was one of four Papua New Guineans selected to attend the 2006 Anwernekenhe Aboriginal and Torres Strait Islander Conference for PLHIV, gay men and sistergirls in South Australia, establishing a connection between kindred movements in Australia and PNG that endures. He was active in positive and MDS movements across Asia and the Pacific. He died in 2014.

*

> My strength and my rights springs from my family, my roots and my culture. I have a land, I am born to a land, I stand on my land and I have a right. I am someone with a name in my tribe and for me that is the biggest thing … My friends in New Zealand and Australia, they are scared against the prejudice for homosexuality. I am not, I have a home, I have a land and a village and I am recognised in my village. I have a language name and I am known by my language name which is connected to my village, that is where my right springs from and I am not scared of anyone, that is where my strength is. (Thomas, MDS)

Understanding how people perceive their rights is an important foundation for understanding the stories they tell about how they experience their rights. This chapter explores how PLHIV, MDS and trans women think and feel about their human rights. Drawing from interviews with more than 70 PLHIV, MDS and trans women, as well as other stakeholders, understandings of human rights are considered, and patterns and themes are identified. Interviewees were asked what they thought the term ‘human rights’ might mean. They were asked to describe what human rights might mean in the PNG context, and to describe the human rights they thought they might possess. Interviewees were asked their thoughts on the source/s of their rights.

When asked what ‘human rights’ might mean, PLHIV, MDS and trans women interviewees tended to begin by listing the rights they believed they possessed. This was far more common than beginning with an overarching statement about human rights. There were discernible patterns across responses in terms of the rights cited, and interesting differences between the ways PLHIV responded and the ways in which MDS/trans women responded. This chapter separates out PLHIV views from the views of MDS/trans women, and then explores differentiations between MDS views and the perspectives of trans women. The chapter concludes with a section identifying commonalities and differences between the groups.

Each interviewee's perspective is valuable, and I have tried to give voice to as many interviewees as I can in this format. I have also looked closely for patterns and themes, and I have used terms like 'many', 'most', 'commonly', 'occasionally' and 'majority' advisedly. As described in my methodology, I put these patterns and themes to community meetings to evaluate whether I was truly hearing what I was being told, and this chapter incorporates the feedback from these meetings.

PLHIV views on what human rights are

A few interviewees described their rights in some overarching sense.

> People have rights despite their status or disabilities or whatever … We have rights like every other human being. (Serah, PLHIV)

> I know that human rights is just talking about really the basics of life … I mean born into a PNG custom, culture and things like that. (Ruth, PLHIV)

> It means to me, it's like being in the population. I am in the population and living and talking about human rights. Personally, I think it's how I should live on this earth. (Matilda, PLHIV)

> I think human rights is the law that guides people or the service provider with the patients … human rights is the law, the friend that protects people's rights. (Miriam, PLHIV)

More commonly, interviewees described human rights by listing them. By providing examples, they began to build up a picture of their human rights more generally.

> I've got a right to go and take my ART [antiretroviral therapy] freely … to live long, prolong my life. I've got a right to have a child … I've got a right to be employed in any company, organisation or whatever government department. I've got rights to move freely in and around nationally and internationally. (Elsie, PLHIV)

> My right to go to school. My right to medication. My right to go to hospital. My right to go marketing. My right to hop on the bus. My right to come for a meeting. My right to access office, for seeking application for jobs. My right to report my case to the police station. My rights to, you know, put my contribution in public speaking in a leadership role. (Juvelyn, PLHIV)

Some of these interviewees, having listed their rights, went on to conclude with a more global observation. Usually this was around them being treated the same as other Papua New Guineans, invoking the principle of non-discrimination.

Lots of different rights were cited by PLHIV. I added up the number of times each was mentioned, and the most commonly referenced rights were as follows (from most frequently mentioned to least frequently mentioned):

- right to employment/livelihood/engage in marketing or business
- right to movement/freedom from violence
- right to expression/free speech
- right to health care
- right to live free from stigma and discrimination
- right to HIV treatment
- right to have children
- right to marry
- right to education
- right to police protection
- right to participate in a meeting
- right to participate in decision-making regarding HIV programs
- right to access services (generally)
- right to control information about HIV status/confidentiality
- right to seek legal redress
- right to have sex
- right to HIV testing.

Interviewees often talked about their human rights in terms of the violations or abuses of these rights. These violations are considered in detail in Chapter 4, but it is important to note here that the majority of interviewees explained their rights in these terms and this practice emerged as an important theme in my research. Interviewees commonly talked about the ways they were (or had been) treated unfairly, using examples as a way of explaining the human rights they possessed but which were not respected. When describing their rights, and specifically the violation of these rights, interviewees commonly used the phrase ‘stigma and discrimination’. This reflects the language of the HIV response in PNG. The phrase has been extensively used in the Australian HIV response, particularly by the community sector, and even more particularly by PLHIV. The phrase may well have been exported as part of Australia’s aid program, or introduced via HIV activists from overseas, but however it has come to PNG, it has currency. Almost all interviewees used the phrase, although I rarely used it in my questioning. It is part of an international discourse of HIV and human rights.

The *HIV/AIDS Management and Prevention (HAMP) Act* was often mentioned in relation to rights — specifically as a means of protecting the rights of PLHIV. Perhaps not surprisingly, people who cited this statute did not draw a distinction between this kind of legislative protection and international or constitutionally guaranteed human rights. Interviewees' knowledge of the *HAMP Act* was often general rather than detailed. I did not press interviewees on the extent of their knowledge, but I do not think in most cases it would have extended to an understanding of the year of its enactment, any specific provisions, specific cases to have been brought under the Act or the like. The *HAMP Act* is discussed in detail later in this chapter.

Not surprisingly, PLHIV interviewees were more likely than their MDS/trans women counterparts to speak of rights in terms of health care, and particularly access to treatments. The entitlement to access free ART was often cited quite specifically as a human right. The reasons for this are explored in Chapter 4, although it is worth noting at this early point that I see the hand of international PLHIV advocacy at work here. The right to ART was usually linked to the responsibility to take it properly, another theme explored in more detail later.

While there were very different views on what might be constituted by human rights, and while most interviewees struggled to provide overarching descriptions, the ease with which interviewees listed individual rights suggests that 'human rights' has meaning among PLHIV. This was further evidenced by the fact that interviewees seemed, for the most part, very comfortable talking about their rights and seemed to share a clear understanding that they possessed rights that were supposed to be respected. They were easily able to identify multiple cases of their rights being disrespected or abused.

PLHIV views on where rights come from

Despite this degree of comfort in discussing rights, most interviewees struggled to suggest the source or sources of these rights. Where interviewees, having been asked about the source of their human rights, struggled to provide an answer, they were generally offered different prompts — perhaps they saw them as emanating from the PNG Constitution, or from a national law, or an international agreement or something else? Perhaps their rights were grounded in tradition or culture? Interviewees were sometimes asked if they thought their rights were written down anywhere. In fact, very few interviewees had any notion that their rights might be grounded in an international agreement. A few more had a notion that their rights were described in the PNG Constitution, although no interviewees said they had read it. A couple of HIV-positive interviewees thought their human rights were written down in the *HAMP Act.*

Many interviewees seemed a little surprised by my interest in the source of their rights. This seemed not to be much of an issue for them. Anthony, a senior UN officer, thought this unsurprising:

> I wonder if you were asking the same question in Australia or New Zealand, if the majority of people would actually give you a good answer as to where their rights come from. The best hook here … is certainly the Constitution because it is very clear in stating the rights that a Papua New Guinean can expect. Is the average Papua New Guinean aware of what is in the Constitution? No, not likely, but most people in most countries probably aren't either.

My interest in the source of rights is deeply connected to my interest in rights-based advocacy in PNG. Specifically, if human rights in PNG could be said to have multiple sources — and the rights of Papua New Guineans are indeed guaranteed both by international agreements and the Constitution — which source would give these rights the most legitimacy in PNG? Which source would be more likely to win over the hearts and minds of Papua New Guineans? The advocate in me wants to know how to best direct my resources and the resources I can garner from elsewhere. If I am trying to promote human rights in PNG, what is my best hook? Yet this was not a question many interviewees seemed to have asked themselves before, and they tended not to have strong views about it. Most interviewees who expressed a view on the matter thought that the Constitution would be more compelling than an international agreement. Interviewees tended to agree that, regardless of where their rights might be written down, these rights needed to be made real to ordinary Papua New Guineans. For them, a record of their rights was, in and of itself, of limited value, even if that record was the Constitution:

> Ah well, it's in the Constitution but … the Constitution is only in the parliament and it's never brought to the street and talked to the people on the streets. It's only when the NGOs … preach the good and bad about the government — some NGOs come to the street to preach what is good, what is bad, tell the people, that is where people are getting their brains opened — they know what is good, what is bad, when they have these rights and what is happening now. Even a person who is illiterate can tell you that, 'I have the right to live here, I have the right to sell betel nut here, you don't have any right to tell me to stop selling betel nut'. He knows a little bit of his human rights. (Toby, PLHIV)

Toby was one of many interviewees who emphasised the need to make rights meaningful and thought that increasing people's awareness of rights was key to achieving the connection between what is written down and how it is practiced in everyday life.

MDS and trans women views on human rights

MDS/trans women interviewees were also asked about human rights, and specifically what they understood these to mean. There were lots of different descriptions:

> Rights concerning every human being and the freedom of expression, freedom of choice and freedom of movement. (Jasmine, trans woman)
>
> You know when you ask I can’t quickly see it in my head and, you know, for someone who has read so much and been involved in some work in human rights, it is not easy for me to just quickly give you an answer, and I don’t see the answer quickly even after having so many experiences — um, that could be the first answer! If I search through my notes in my head, it would be basic rights for everyone … for people to live and just be free, I guess. (Thomas, MDS)
>
> I think rights is who I am, what I am, what I think of to be or to do … Nobody will say, ‘No it is not good you putting on your makeup, it’s not good you are blow-drying your hair’. No one will say that. What I think and what I do, it is a right for me for my look and for my beautification. It is me and it is part of rights. You can’t deprive my rights as a TG or MDS of doing anything even to the extreme of having sex with a same-sex partner. It is my right. Right comes from within an individual. (Natasha, trans woman)
>
> Well, as a TG, I understand rights as one of the important things that all persons do — rights to movement, rights to education, rights to information and all the universal rights that have been used around the world, yeah, so that’s how I understand human rights and basically rights. (Marta, trans woman)
>
> Human rights is, it’s the feeling that is given to an individual to live a happy, better life … something that is, ah, to be given to them to have a better life free of any harm or persecution from anybody. (Rita, trans woman)

The rights most commonly cited by MDS and trans women were (from most commonly to least commonly cited):

- right to be who I am/self-expression/choice
- right to freedom of movement/freedom from violence
- right to privacy
- right to education
- right to police protection
- right to life
- right to socialise
- right to access basic services.

Many interviewees discussed not only what they knew about rights, but also whether they thought their MDS and trans peers understood rights. Some thought that there was a very reasonable level of understanding within these communities, certainly when compared with the general population. Others thought the level of knowledge to be quite low. Despite these mixed views, there was near consensus that MDS and trans women had a better grasp of human rights than the general population, where the level of awareness was universally considered to be very low. This distinction is highly relevant to understanding interviewee perspectives on advocacy strategies.

While these perspectives are addressed in detail in a later chapter, it is worth making a few important points here. First, most interviewees thought that the effectiveness of rights-based advocacy — meaning advocacy that uses the language of human rights and that asserts the human rights of marginalised groups — would be limited by low levels of understanding of rights nationally. Second, interviewees thought that the fact that MDS/trans women understood human rights perhaps a little better than most other people in PNG meant there was a risk that conversations about human rights might emphasise the divide between MDS/trans women and the general population. This, they thought, was unhelpful when in fact unity was the goal. And third, despite these risks, support for rights-based advocacy remained high among interviewees.

Despite generally agreeing that Papua New Guineans did not understand their human rights, there was reasonable support among interviewees for the proposition that knowledge levels were increasing across the country. Thomas, for example, saw knowledge building across PNG every day. He saw this on TV, in print media, on radio, and in everyday community conversations, particularly among young people. He saw rights being discussed in a variety of contexts — in advocacy around the right to literacy, in programs to prevent and respond to domestic violence, and in efforts to empower women through microfinance and other opportunities. He thought this use of rights language across multiple movements was helping give it real meaning in PNG. He also pointed to rights arguments having been cynically used to access funding from foreign donors. He had seen this in the country’s environmental advocacy movement as well as in HIV programming. He had mixed views about its impact. While using this hook had facilitated support for worthy causes, he said, it also risked undermining the integrity of rights-based advocacy. Over time, this could cause ‘human rights’ to be seen as a term with meaning only for donors and other ‘externals’ and with no real application to PNG.

The evolution of human-rights movements in PNG, was considered by Aletta Biersack (2016) in her research on work by grassroots activists, to reduce gender-based violence in PNG. Biersack observes an ever-greater activism among ordinary citizens, especially among women themselves. In this she affirms observations by Margaret Jolly (2012) that gender violence is increasingly seen as an important problem by many Papua New Guineans and that it is now possible to mobilise large groups of women and men in protest against this violence. Biersack reports on the work of the Highlands Women Human Rights Defenders Movement, a homegrown organisation which, in its work to prevent and respond to gender-based violence, links to the broader goals of the international human-rights movement (2016:290). Biersack sees acknowledgement of this growing social movement in Amnesty International's use of the term 'human-rights defenders' more broadly to signify Papua New Guinean women's rights supporters who, while they may not self-identify as human-rights defenders, are nonetheless on the frontline of the struggle to stop violence against women.

It was common for my interviewees to acknowledge human-rights movements beyond their own. There were occasional references to environmental movements and the struggle to defend Papua New Guinea (PNG) from foreign extractive industries, and some awareness of the plight of refugees imprisoned in the Australian-established and Australian-funded detention centre on Manus Island. But far more common were references to movements to end gender-based violence in PNG. Many interviewees were aware of programs working to reduce gender-based violence and understood these programs to relate to human rights.

Martha Macintyre (2000) adds another perspective on the movement in PNG to promote and protect the human rights of women. She observes that, among the key themes of Papua New Guinean women's political discourse, is a recognition of the United Nations as critical to improving life for Papua New Guinean women and a recognition of the similarities of their experience to those of other colonised people. PNG activists for women's rights pursue their goals with clear reference to universal human rights and global movements for justice, based on shared humanity. At the same time, Macintyre sees that international campaigns have provided a useful arena for the political voice of Pacific women. Macintyre reflects on the initial suspicion of the Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW) on the part of the Government of PNG, specifically that the convention was not consistent with the country's cultural traditions. Macintyre notes that tensions around tradition and difference lie at the heart of the struggle of Pacific women to assert their human rights, referencing work by Jolly (2012), considered further in a later chapter, which demonstrates ways that abuses of Pacific women's human rights are often strategically justified as customary practices.

Clearly, my work is not an analysis of the struggle for women's human rights in PNG. But it is useful to appreciate three things. First, thanks to groups like the Highlands Women Human Rights Defenders Movement, the movement to defend and promote women's human rights is shaping the way people think about human rights in PNG. It can be no accident that my interviewees were more likely to mention this human-rights movement than any other. Second, the barrier of 'culture' as an argument against recognising human rights in PNG is experienced as much by activists for women's rights as by MDS and trans women. And third, this commonality of experience points to a useful alliance between these different movements, perhaps under the banner of shared commitment to an understanding of sexual citizenship that embodies diversity and the principles of human rights through communities of belonging and collective activism (Lepani 2010, 2016). This concept of sexual citizenship recognises the rights and responsibilities of all people to have control over their sexual and reproductive health and to express sexual identity, desire and pleasure in healthy and safe ways, free of fear, harm and force, as an expected part of membership in a shared community. The notion is explored further in chapter 7.

Returning to the question of whether awareness of human rights might be increasing, Lionel, an MDS interviewee, agreed with Thomas that knowledge of rights was building:

> But we have made a lot of progress in the last five years, let me say this. I mean we have really made some breakthroughs and people are beginning to understand their rights and responsibilities, especially in the urban centres and slowly we are penetrating the rural settings in PNG, yeah.

Natasha, a trans woman, agreed that knowledge of rights was increasing. She saw it as being part of a broader community awakening encompassing human rights, an increasing awareness of the Constitution, and a growing understanding of the need for empowerment of women:

> People are beginning to see that, OK, within the Constitution, in our Constitution, we have our right … when it comes to gender especially, especially people talk about gender — gender empowerment in PNG … especially when you look at woman advancing to the male-dominated work industry … and you know, we are looking at, you know, gay men, TG people being in the picture, you know, this and that, and also being employed.

Magda, also a trans woman, agreed:

> I think, um, in the older days Papua New Guineans don't know what is right. What is right you know, but towards this generation where PNG is becoming more westernised, you know, getting informations, accessing new technology coming in, people are now having broader mindset of what is right and I believe that PNG is a signatory to the Human Declaration of Human Rights. I know that, so it's now [that] people are beginning to see that, OK, within the Constitution, in our Constitution, we have our right. It is my right to vote as the man and a woman. It is my right of employment etc., it goes down. So people know that the Constitution is made out of rights, citizens their rights. How to protect themselves, how to uphold themselves in this beautiful country, PNG.

Many interviewees were keen to point out that there was not necessarily a correlation between knowledge of rights and capacity to implement them. Indeed, this turned out to be a major theme. After attending rights training, Jasmine had this to say:

> I build some of my knowledge and some … capacity about HIV and gender equality and gender rights and basic human rights and counselling and the stuffs like that, but I build myself in there and

> knowing some skills … it was very productive but it didn't really enable me to, you know, achieve what I really want. I was still a lack of not being recognised.

This theme was to emerge also when interviewees were asked if their rights were respected. Many returned to the lack of correlation between knowledge of rights and the ability to ensure their implementation.

MDS and trans women views on where rights come from

Interviewees were asked about the source of their human rights. As was the case with PLHIV interviewees, some MDS/trans women interviewees had a view about the source of their rights but most did not. Therese, a trans woman, had this to say: 'Yeah I have heard, I have heard of the Geneva Declaration and rights and human rights comes from Geneva or somewhere.' Many other responses similarly lacked specificity or detail.

Overall, and like their PLHIV counterparts, interviewees did not seem to be overly concerned with the source of their rights, although interviewees were more likely to cite the Constitution than any UN instrument. Interviewees were clearly more interested in the best ways to promote their rights rather than in their source. Often, conversations turned to the question of which of the possible sources of rights would be the easiest to promote in PNG. On balance, and as with PLHIV interviewees, MDS and trans interviewees saw the Constitution as offering the best vehicle for promoting rights. Interviewees who talked about their international human rights mostly saw UN declarations as unpersuasive in the PNG context. They thought Papua New Guineans were unlikely to be won over by reference to things that had been done at the UN level. The Constitution was considered far more meaningful for Papua New Guineans:

> Personally, it [a UN Declaration] would have no meaning. I mean we have signed up for some of the best and most stringent measures for looking after the environment, all the women's rights, conventions we have signed up for, nothing gets enforced here and people are not being held accountable for abuse of human rights … maybe if there was some sort of enforcement and people were held accountable, there was some sort of justice, then people would know that all these conventions or where rights were springing up from are really there, so it is still abstract to us because we don't see the actual thing being implemented, people being punished for abuse of human rights. (Thomas, MDS)

I wondered how others perceived the role of the Constitution in shaping the experience of human rights in PNG. I am no expert in constitutional law, but I am interested in how the PNG Constitution guides or is absorbed into Papua New Guinean life, and the way it interconnects with human rights in PNG. Given that the Constitution, national laws and custom were all being suggested by my interviewees as the sources of their human rights, I wondered about the interconnectedness of them all. In a 2001 collective reflection on 20 years of the Constitution's operation, a series of writers shared their views on the Constitution's origins and the degree to which it has proved fit for purpose. I was particularly interested in the observations of Anthony Regan (2001) who writes of the ways in which the Constitution might be said to be 'homegrown'. He documents that this was indeed a motivation amongst those engaged in the drafting: that the Constitution be both politically and legally homegrown. To be *politically* homegrown it would need to build a framework uniquely suited to PNG and not bound by international precedent. To be *legally* homegrown it would need to derive its legal authority from within PNG, from the people rather than through a transfer of power from the colonial rulers. See also Jonathan Ritchie's (2020) account of the consultative process undertaken by the Constitutional Planning Committee between 1972 and 1975, which gave thousands of Papua New Guineans the opportunity to have input into the development of the Constitution and, incidentally, had a significant impact on Bernard Narokobi's formulation of his 'Melanesian Way'. Ritchie's telling includes reference to the way people who had been consulted felt they had contributed to the Constitution. The retelling of this story would likely foster feelings of ownership of the Constitution, with flow-on benefits for the promotion of the rights enshrined within.

Owen Jessep (2001) describes the interplay in PNG of different legal domains as follows. There are two kinds of law in PNG: statute law (Acts and Regulations passed by parliament) and 'underlying law', being all law other than statute law. This underlying law is formed by the integration of the principles of customary law and English common law (laws inherited from colonial rulers, where these have been identified and articulated by judges rather than colonial parliaments). Jessep explains that where there is inconsistency, common law gives way to customary law. The development and clarification of underlying law then is not straight forward, but rather a complex task involving an understanding of customary law, an understanding of common law, and an understanding of the rules that govern their interplay. (I'm a lawyer by original profession so this makes sense to me, but I appreciate that for non-lawyers trying to work out how they are governed and by what set of laws, it can be a challenge to make sense of these different kinds of laws.) Christine Stewart (2014) also grapples with the interplay of common law and other laws.

The PNG Constitution says customary law cannot become underlying law if it is inconsistent with the Constitution, a statute or repugnant to the general principles of humanity. Jessep explores this notion of repugnancy to the principles of humanity, noting a range of cases through which this notion of repugnancy has been explored and explained. These have involved dispossession of land, cannibalism, payback killings and forced marriage of women. Courts have also begun to explore alternative reasons for rejecting custom, including that the custom results in injustice (in the case of forced marriage), that it is contrary to public interest (regarding the transfer of a child by way of compensation), or that it is contrary to the best interests of a child under 16 (again, the transfer of a child as compensation).

Brian Brunton (2001) writes of the changes to Papua New Guinean society since independence and reflects on the ways these changes have impacted human rights. Brunton acknowledges that the Constitution enshrines structures in PNG to safeguard human rights — a parliamentary system, universal suffrage, government control of the armed forces, elections, and an independent judiciary. And yet, he writes, this deals with formal structures of PNG democracy rather than its real texture. Brunton observes many changes in PNG society that have not, in his view, promoted human rights. He sees dangers in the continued concentration of power in the hands of the few — specifically male politicians, officials and businessmen — while women and youth have no power. Brunton sees this as a shift towards authoritarianism and scapegoating of the masses where the empowered start to describe human rights as a refuge for criminals and misfits and begin calling for the safeguarding of vested interests from the scrutiny of the courts and the regulation of the Constitution (2001:307). Brunton does not lay the blame for this on a weak Constitution, but on factors such as rapid social and economic development, chronic mismanagement, and the inadequacy of statute laws and legal procedures. The problem is not what the Constitution promises, he says, but what is delivered in its name. Brunton notes that while there have been mistakes in the government’s management of the economy, the interventions of multilateral and aid agencies often have not helped. While these agencies might well talk up the importance of human rights, the effect of their interventions has often been the reverse. Brunton reflects on the realisation of various human rights in PNG, noting poor progress in relation to most. He concludes there is a need for judges, magistrates and lawyers to pay more attention to human-rights cases. He advocates for a human-rights commission, supports better rules and procedures for dealing with human-rights cases, and argues for a series of structural changes to the national court system. Overall, Brunton offers a grim account of the status quo:

> While the courts have delivered some notable decisions on the protection of human rights, these positive achievements are overwhelmed by events and pressure of work. To the ordinary Papua New Guinean, the human rights provisions in the Constitution mean little. If you are arrested in Papua New Guinea the chances are you will be assaulted while in custody. The cell you will stay in will most likely be inhuman and degrading. If you are sick, there is no guarantee of a health service. If you are disabled, the chances are you will not be assisted by the state. Children have no right to attend school. School leavers should not expect to find formal employment. If you are a woman, do not

> expect too much at all, except the likelihood of being bashed by your boyfriend or husband. (2001:313)

I find these reflections on the PNG Constitution interesting, while noting they are almost two decades old. I have been interested in the degree to which my interviewees' stories reflect Brunton's grim assessment, or whether they offer a more hopeful perspective. As I have found so often in my work in PNG, the answer is not a simple one.

Thomas, whose words begin this chapter, agreed with the majority of interviewees that the Constitution would have more meaning for Papua New Guineans than international declarations. But, as his quote indicates, he believed the source of his rights to be more indigenous than even the National Constitution. His words struck me as a particularly strong statement about place, land and identity, and it was unusual for that. What was also interesting about this response was that Thomas was almost apologetic for his view. He did not necessarily think the view compatible with the rights-based work being done by Kapul Champions, which sought to ground its advocacy in UN declarations and the National Constitution. His views were internally contradictory, a point he acknowledged. They were also very considered, an example of the complexity often involved in understanding human rights in the PNG context. He thought his human rights to be both real and not real. Having argued that his rights were rooted in his family and culture, he also said he did not know where they came from:

> I am a human being and I have the rights but … I'm homosexual and I grew up knowing that I don't have any rights in this country and even to this day, I have travelled the world, gone to university, read at different levels, I sit at forums on human rights, and I still feel that I don't have any.

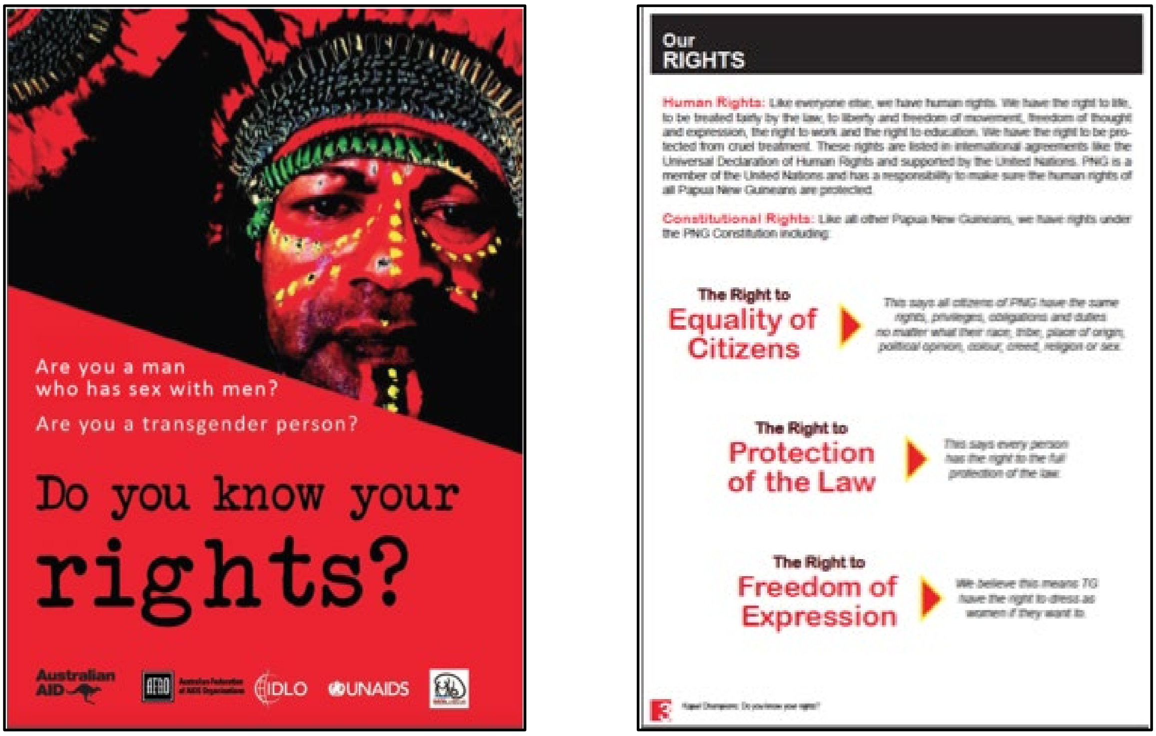
Thomas was asked if the source of his rights ultimately mattered and decided that it did. He thought a clearer sense of the roots of his rights might give him greater confidence in these rights and strengthen his advocacy work. He thought it might have the same effect on other members of marginalised populations.

Work by Kapul Champions to build understanding of rights

Chapter 5 explores the work of Igat Hope and Kapul Champions, but it makes sense to look at some of Kapul Champions's efforts here. Kapul Champions has done some important work in educating its constituency around rights. Its 2013 brochure, *Do you know your rights?,* declares that rights emerge from multiple sources. The brochure begins with a short reference to human rights enshrined in international instruments such as the Universal Declaration:

> Like *everyone* else, we have human rights. We have the right to life, to be treated fairly by the law, to liberty and freedom of movement, freedom of thought and expression, the right to work and the right to education. We have the right to be protected from cruel treatment.

The brochure (Figure 1) gives more prominence to human rights described in the PNG Constitution, specifically referencing the rights to equality of citizens, protection of the law, freedom of expression, freedom of assembly and association, and privacy. The brochure also includes a section on the *HAMP Act.* The brochure illustrates Kapul Champions's approach to building knowledge of rights by bringing together all human rights relevant to MDS and trans women, regardless of their origin. The brochure invites readers to see these rights as a package of connected entitlements; they are all applicable, regardless of where they may be written down.



Our
RIGHTS

Human Rights: Like everyone else, we have human rights. We have the right to life, to be treated fairly by the law, to liberty and freedom of movement, freedom of thought and expression, the right to work and the right to education. We have the right to be protected from cruel treatment. These rights are listed in international agreements like the Universal Declaration of Human Rights and supported by the United Nations. PNG is a member of the United Nations and has a responsibility to make sure the human rights of all Papua New Guineans are protected.

Constitutional Rights: Like all other Papua New Guineans, we have rights under the PNG Constitution including:

The Right to
Equality of Citizens
This says all citizens of PNG have the same rights, privileges, obligations and duties no matter what their race, tribe, place of origin, political opinion, colour, creed, religion or sex.

The Right to
Protection of the Law
This says every person has the right to the full protection of the law.

The Right to
Freedom of Expression
We believe this means TG have the right to dress as women if they want to.

Figure 1. Brochure: Kapul Champions, *Do you know your rights?*
Source. Screen shots taken by author of resource in his possession, 15 Sept. 2020.

The brochure had its roots in the 2012 Kapul Champions's workshop on rights and law, for which I was one of the facilitators, and I was able to observe the ways participants grappled with human-rights issues. The event signalled strong support for Kapul Champions continuing its human-rights advocacy. It also encouraged Kapul Champions to emphasise the Constitution as the most effective vehicle for rights promotion. Kapul Champions held a follow-up workshop on rights and laws in Lae in 2014. At this workshop, where I was again lucky to be a facilitator, participants explored the synchronicity between international human-rights instruments and the PNG Constitution.

The interrelationship of rights and responsibilities for PLHIV, MDS and trans women

> [W]e have our own customs that protects us and there are things we should do, there are things we should not do, it's right to do this, it's wrong to do that, so those sort of guide us and with the, what will I say, with the laws that are now into the human rights thing. (Ruth, PLHIV)

It was very common in my interviews for me to enquire about rights and have interviewees talk to me about responsibilities. Most interviewees made the observation that rights are linked with responsibilities. No interview questions were posed that suggested these links — instead, interviewees made the links for themselves. These linkages were complex and fascinating, and I wondered about their genesis. One influence may be the PNG Constitution, which lists both human rights and basic social responsibilities, although interviewees had limited familiarity with constitutional provisions. Another, more likely factor seems to be the *HAMP Act.* The *HAMP Act* is the best source of legal rights for PLHIV, MDS and trans women in PNG (apart from the Constitution) and it is likely that most interviewees would be familiar with the *HAMP Act.* Almost all HIV awareness or HIV training programs for marginalised groups in PNG include a component on the *HAMP Act.* It is featured in Kapul Champions's resources on rights. A feature of *HAMP* is its dual focus on rights and responsibilities. The Act enshrines the rights of people to HIV testing and the rights of people with HIV to live free from discrimination, and at the same time includes penalties for wilful or negligent transmission of the virus. It may be, then, that this legislative linking of rights and responsibilities has shaped the views of PLHIV, MDS and trans women. Matilda, a woman living with HIV, observed of *HAMP:*

> It's there to protect all PLHIVs, people affected with HIV and AIDS. It's like, I mean it helps us because it is written document that tells us that this is right, this is wrong, and who we can go to. Yeah, like if someone verbally calls me names in a public place, then I can take it to court and I know where to go to.

But while the *HAMP Act* may have *contributed* to the linking of rights and responsibilities for PLHIV, MDS and trans women, interviewees seemed to be pointing to a more fundamental link. It seemed to me that they were referring to a very basic interconnection in PNG society between the exercise of rights and the fulfilment of responsibilities. Interviewees talked about these connections in different contexts.

Responsibility to practise safe sex

Rachel, a woman living with HIV, took up the balance between rights and responsibilities in the context of sexual behaviour. She talked about discordant couples (where one partner has HIV, and one does not) and the need for prevention to be seen in that context as a shared responsibility. Neither partner should leave responsibility for preventing transmission entirely to the other. Other PLHIV agreed that prevention was a shared responsibility and that it was unfair to put the entire burden upon PLHIV. But this commitment to share responsibility did not mean that PLHIV could be flippant around prevention — many interviewees with HIV talked passionately about their role in prevention. While willingly undertaken, this role was generally described as a responsibility.

> A sex worker has the rights to maybe sell sex — maybe that's what she believes in but it's also the partner's responsibility to use condom. The same as discordant couple. If I am a woman who has a diagnosis negative, it's not only my responsibility to talk about condom, it's my responsibility that I have to think about my partner's responsibility to also have condom … there is a law that if now you are here getting HIV status, and getting HIV status you are now responsible, that you are not supposed to pass HIV virus to another person and if you do so, then this law will get you. (Rachel, PLHIV)

Holly Wardlow's (2006, 2018) work with HIV-positive women from the Huli community illustrates just how seriously these women take this responsibility. Her research shows incredible diligence in this domain. She also notes (2018) that women with HIV are, in a sense, relieved of any expectation that they should marry or that their husband must stay with them, and that this can be experienced by women as a kind of freedom to which they ascribe considerable value. While this may be a contributing factor to their willingness to divulge that they are HIV-positive, Wardlow sees this openness about status with suitors and potential sexual partners as part of an exaggerated demonstration of ethical behaviour. Her research participants were demonstrating individual agency by acting with others in mind.

The responsibility to take your treatments and live well

> I am seeing many PLHIVs who are on medication and they are still dying and when one PLHIV dies it really makes the rest of us be scared because is the medicine really helping us? … Yes … I know the medicine is helping us but it's our behaviours that is not helping us. The medicine is there but I think it's the behaviours that is causing us to die. (Serah, PLHIV)

> Some doesn't understand the importance of treatment. Like ART, it's a treatment, it's a medicine and we have to just take it for as long as we live … Some, they do like alcohol, they forget to go and get their medicine … That is the big challenge. (Elsie, PLHIV)

Many interviewees with HIV talked about the responsibility of PLHIV to take their treatment properly and live healthy lives. In her comments above, Serah was offering a variation on a common theme. Serah was referencing the responsibility that PLHIV are said by many to have, that is to contribute to national confidence in ART. According to this thinking, not only is it important for PLHIV to have hope (and ART has indeed given them this), but confidence in ART is also critical to shaping general community attitudes towards PLHIV. While this is dealt with in some detail in Chapter 4, it is worth noting here that the advent of ART has reshaped national thinking around HIV so that it is now seen as a manageable illness rather than a death sentence. Interviewees agree that this shift had been the single biggest contributor to reducing stigma and discrimination against PLHIV. By extension, PLHIV are expected to act appropriately so as to maintain national confidence in ART, thereby securing the gains that reduced stigma and discrimination have brought about.

Wardlow (2018) also picks up on this phenomenon, observing how clinicians emphasise the responsibility to take treatments properly. She documents that this responsibility is an important factor in the clinical treatment of women with HIV in Tari, contextualising this by reference to extensive anthropological literature emphasising the governmental and disciplinary effects of ART adherence counselling. For example, Wardlow refers to work by Vinh-Kim Nguyen (2013), which analyses HIV counselling as a confessional technology that seeks to produce a particular kind of patient subject, one that is empowered to live a more ‘morally responsible’ life. Critical to this empowerment, writes Nguyen, is the confessional disclosure of the kind of personal behaviour that has exposed the confessor and others to the risks associated with HIV. Wardlow also references work by Dominic Mattes (2011), which observes that medical authorities seek to radically change the way patients think and behave towards a more ‘appropriate’ and ‘healthy’ perspective in order to produce an obedient and responsible patient (160). Wardlow continues with this theme by considering work by Anita Hardon (2012) on the treatment of PLHIV in sub-Saharan Africa, particularly Hardon’s observations that patients’ lifestyles were morally reframed through this treatment with the goal of producing compliant, docile subjects who would submit to biomedical, and ultimately state, authority (78). Wardlow helpfully demonstrates that the pressures being placed by clinicians on PLHIV in PNG around treatment compliance are not novel, but the continuation of a practice seen elsewhere in the international HIV response.

The issue of discrimination in health care is considered in the following chapter, but it is useful to note here that there is a connection between this and the perceived responsibility to take treatments properly. Miriam, a woman living with HIV, described clinic staff as follows: ‘Yeah, they are not open, they are not friendly, they are a bit aggressive.’ There is a temptation to simply log this as an example of health-sector discrimination, but Miriam went on to explain this behaviour as follows:

> Okay, in this situation I would say most of the times like, patient itself, they don't turn up on their appointment, this is some of the reasons that I saw. They miss their appointment several times. Continuously, they [clinicians] are telling them the importance of their appointment and coming there and adhering to their treatments and that is part of it but, yeah, they are not adhering to them … I think they [the clinicians] are doing all the best that they could do trying to bring everyone in but the problem I see is with the clients itself … not coming for follow up and they don't even come in for the treatment, support or not disclosing their status to anyone.

This was not the only time I heard this kind of clinician behaviour justified because of the PLHIV's 'failure' to take ART properly. Several interviewees mentioned that they or other PLHIV had been lectured about 'lifestyle'. It should be noted that there was some pushback by interviewees against this moralising. For example, Matilda, an HIV-positive woman, had this to say:

> Doctors, counsellors … should be trained not to give their point of view. I mean that's myself, that's how I see it. They should be giving options to them [PLHIV] to take choices. Some of the counsellors tell us to leave whatever activity we are doing and get on with Christianity … get on with life like them. They are not there to tell us what to do but they are supposed to be on a whole supposed to be telling us options only so we can choose the way we want to live.

These different accounts point to a tension in clinical efforts to support adherence. For good reasons, health-care workers want people to take their treatment. But these same workers are not always managing to respect patient autonomy. PLHIV understand the expectations of other PLHIV and the community more generally when it comes to taking treatment. If this is being resisted, then there are probably sound reasons why. These tensions emerged not only through interviewees' accounts. A treatments forum in 2010, which brought together PLHIV and HIV practitioners to discuss access to ART and adherence supports (Leach and Rule 2013), also heard of these competing interests. The forum is revisited in Chapter 5 where it is discussed as an example of Igat Hope's achievements in treatment advocacy, but it makes sense to cite it here also as an example of the tension around perceived 'failure' to take treatment. The forum is considered in Tim Leach and John Rule (2103) and the forum's important Waigani Statement on HIV Treatment Action can be viewed on Igat Hope's website.

The responsibility to moderate behaviour

Some of the conversations around responsibilities left me wondering whether these ‘responsibilities’ might include an obligation to not act *too* gay or transgender. Many MDS and trans women interviewees talked about their behaviour as relevant to the exercise of their human rights:

> [Changing the law] will start back to us as an individual. How can we fix our lives? It falls back [to] TG. How can they be successful in their life? One: They must be educated so that they can think broadly and differently [and] Two: We try to be public figure of what we know and how much we can educate and give the people … we can’t just consider our rights without, you know, we [must] be equipped with what we know without all relevant information — it’s sexuality not just sex, sex, sex, at the end of the day. That’s just immature and inhuman. (Jasmine, trans woman)
>
> Why am I disrespected, why haven’t I achieved that far, why am I not being employed? Is my approach and my attitude towards the community good? How may I change my attitude so that they may accept me for who I am? OK in terms of employment, why am I not getting this job? Is it because of my identity or is it because I am more feminine? How will I attract this employer to employ me? Maybe next time I can go for a haircut, groom myself, dress as a man, go and sit at the interview and when at the interview let him figure my sexuality, not me expressing him telling him that this is me and this and that … You know sometimes people need to be desensitised about us being different, not us telling them that we are different. We now start looking at this — how we can change ourself when it comes to attitude? How will we behave ourselves so that we get less discriminated and less stigmatised? How can we express ourself or how can we help the community to, you know, like us for who we are? (MaryAnne, trans woman)
>
> Our approach should be more empathetical. We should sort of blend in with the community. It is not about forcing the issue like ‘this is what we feel’ and ‘this is what we deserve’. (Lionel, MDS)

As on many matters, Thomas had a fascinating and considered position. He concurred with many other interviewees that the rights of MDS and trans women had to be respectfully exercised. He was critical of many of his peers for exercising their rights in ways that were disrespectful — being too overt, too sexual:

> The difference I see with fellow members of my MDS community is that there is generally a lack of responsibility and respect for people. We push too much our agenda. We don’t have to be entirely 100 per cent entirely gay and scream and shout, ‘We are women’, and all of that. We can be effeminate in our villages, in our home, but, you know, just tone it down and be respectful. And our sexual exploits also doesn’t help. We do it without discretion, it doesn’t help, it just gives people the wrong idea … We have the rights but we have to have responsibility and respect to the community because the community have all, you know, conformity, the rules, the norms, and if we step out of those norms then we get hassled.

Thomas shared stories of trans women living happily in villages, presenting in effeminate ways but still being accepted in their communities because they were otherwise respectful, toiling in community gardens and conforming to other community norms. He also had stories of MDS who were ‘out’ but still living happily and accepted within their communities provided they did not flaunt their homosexuality. This tolerance did not apply where alcohol was involved, however. Thomas was one of several interviewees who noted the impact of alcohol on acceptance:

> Everyone knows [about my sexuality], everyone in my village knows, they know but they don’t come up to me punching me and swearing at me. Of course you’ll get drunks doing it, but they are drunks. All drunks say all kinds of nasty things to anyone.

Alcohol aside, interviewees also suggested that MDS and trans women might need to ‘tone it down’ if they wanted their rights respected. This is a complex area and I found it a little challenging. It seemed to me that this view might reflect the reality of communal interdependence in PNG society. The system is built on mutual support within families and *wantoks* where strength is often calculated in terms of what is shared (including the sharing of religious and cultural perspectives). Behaviour that is too aberrant might undermine the strength of the community and is likely to have both individual and community consequences.

Collectively, interviewees’ responses seemed to me to reflect an acceptance on their part that, through their sexuality and transgender status, they had breached community norms to some extent. Their mitigation was to moderate their behaviour and this mitigation lessened the opprobrium to which they were subjected. Alternatively, it can be seen as a kind of transaction — in return for permission to depart from societal norms, the individual undertakes not to depart too far. Alternatively, the individual exercises agency to live their sexual or gender identity while also choosing to uphold social obligations. There is a balancing of benefits — individual identity and social belonging. This moderation was taking place on the part of many interviewees. Most MDS were hiding their homosexuality at least to some extent (although here, of course, self-interest may have been just as compelling a motivation as desire to placate community and ensure continued belonging), and trans women often reflected on their efforts to do the same. Alternatively, this might be seen less as a transaction and more as a form of reciprocity, with everyone upholding their social obligation as best they can; MDS and trans women moderating behaviour and community affording a place of belonging.

I wondered whether this willingness to modify behaviours represented an acceptance by PLHIV, MDS and trans women of the stigmatisation of status and, at the same time, an acknowledgement that they are to be tolerated by agreement. I wondered whether this approach just accepted that certain statuses warrant stigma, and that opportunities to challenge this stigma head on might be lost as a consequence. It was interesting for me that these observations were made so frequently by people prominent within the two organisations, who had been disproportionately exposed to rights-based advocacy.

Institutionally, Igat Hope and Kapul Champions have both wrestled with this challenge. Consider this objective from the Kapul Champions Constitution: ‘To educate for and promote adoption of personal behaviours which positively impact the health and wellbeing among transgenders and men with diverse sexualities in PNG.’ This is partly a reference to the need for Kapul Champions’s constituents to protect themselves from HIV and other health risks, but it is also about the need to model good behaviour. The need to model good behaviour has been a common theme at Kapul Champions’s meetings and workshops, where discussion of good behaviour often affirms commitments to the following: sobriety, honesty, compassion and respectful behaviour. The term ‘respectful behaviour’ is often used, explicitly or implicitly, to mean modest conduct or controlled expression of sexuality or gender identity.

The Kapul Champions’ objective regarding personal behaviour sits alongside three other objectives:

> To empower individual transgenders and men with diverse sexualities (MDS), and strengthen local transgender and MDS communities in PNG; To oppose discrimination against transgenders and men with diverse sexualities and to raise awareness on HIV, human rights and the law in PNG; To promote the health and wellbeing of transgenders and men with diverse sexualities in PNG.

Clearly then, the organisation sees the importance of pursuing rights alongside the need to encourage constituents to behave in ways that uphold their responsibilities as members of families, communities and as citizens.

There is a chicken and egg question here. Has Kapul Champions’s packaging together of rights and respectful behaviour shaped the views of constituents, or vice versa? To me it seems to be a case of the latter. Interviewees routinely saw rights and responsibilities as fundamentally and inextricably linked. These views appeared to be grounded in lived experience and not to reflect institutional advice. Indeed, interviewees tended to speak quite passionately about the inter-relationship.

The Igat Hope Constitution also addresses this link. The Constitution includes this objective: ‘To promote a positive image of people living with HIV and affected by HIV, with the aim of eliminating prejudice, isolation, stigmatisation and discrimination arising from HIV/AIDS in PNG.’ This objective provides another clue to understanding the conceptual link between rights and responsibilities. The objective suggests that by promoting a positive image — by working extra hard to demonstrate contribution to community, including by managing behaviours — a marginalised community might break down the barriers and eliminate the stigma. The result over time, presumably, is that the need to 'manage' the behaviour reduces. This notion that, by behaving appropriately and demonstrating contribution to community, PLHIV, MDS and trans women might demonstrate their worth and earn respect for their human rights deserves further exploration, because it is not as simple as just committing to a set of admirable behaviours.

The problems with requiring 'good behaviour'

The list of failings of which interviewees or their peers were being accused was lengthy: not practising safe sex, not taking treatments properly, not looking after their health, being overtly sexual, being too flamboyant, drinking too much. But it is easy to see how my interviewees' 'aberrant behaviour' might also be linked to the marginalisation they experience and their nonsensical criminalisation. For example, if HIV were not viewed so negatively, more PLHIV would be open about their status, fewer would feel the need to hide it from partners and potential partners for fear of rejection or worse, more would feel safer to be open about their status, more would carry condoms and safe sex would more often be practised.

Claims that interviewees are too sexual must surely be rooted, to some extent at least, in the belief that they should not be sexual at all. Here I draw from my experience in other HIV epidemics where PLHIV sexuality has been deemed problematic; the quick (illogical and highly discriminatory) fix has been seen to prevent PLHIV from having any sex at all and thereby, in theory at least, eliminating risk. This has led to a counter movement asserting sex positivity, with an emphasis on eliminating risk rather than eliminating sex. Lawrence Hammar (2008) writes eloquently about illogical, discriminatory responses to controlling sexual behaviour, concluding 'Papa New Guineans will figure out how to avoid HIV when they figure out how to make sex consensual and enjoyable—that is, how to have it, not how not to have it' (79). But beyond this flawed notion that all PLHIV sex carries risk, there is also a fear (similarly illogical and similarly highly discriminatory) of a risk of 'wilful' or 'negligent' HIV transmission. It is worth noting that while stories of these incidents abound in PNG, there are very few substantiated cases. This follows an international trend where such stories (actual or imagined) garner massive amounts of media attention but are in fact very few. In all my work in PNG I never once heard of a successful local prosecution. There have been relatively few internationally (Cameron and Rule 2009). And when it comes to allegations that MDS and trans women, in particular, may have been too promiscuous, by what measure? Having multiple sex partners is not something unique to PNG MDS and trans women.

The issue of PLHIV 'failing' to look after themselves is complex. So many people with HIV, living and dead, are held to have failed. During my decades of working in the HIV response I have seen countless examples of PLHIV being blamed. I have seen this in many countries, including in PNG. Interviewees talked about how people who die of HIV infection are held to have failed in their responsibility to remain alive (to contribute to community, to care for family, to ensure confidence in ART is maintained), or to have failed in having caused cost or shame to the family. PLHIV who do not take treatments or for whom treatments do not work are said to have failed in their responsibility to protect public health, because PLHIV for whom treatments have failed have a higher viral load than people being effectively treated and are consequently more infectious, with this being interpreted as representing a greater threat to society. (Although, of course, even the most infectious of PLHIV can have sex without risk by using a condom.) And yet, there is more to taking ART than being handed pills. Adherence can be challenging when medications are not explained, when drug stock outs are common, when side-effects, poverty and other illnesses complicate compliance and where fear of stigma and discrimination mean PLHIV have to take treatments secretly and without family and community support.

On the issue of public drunkenness, again the issue is more complex than it may at first appear. A lifetime of acute stigma and discrimination might well cause people to seek the release that comes with drinking, and exclusion from hotels, clubs and bars might well mean that consumption of alcohol is more public. No doubt this issue is related to sex in that alcohol very often shapes sexual behaviour, and of course the flirtatiousness of drunk MDS and trans women is offensive to many not because it is driven by intoxication, but because it is directed at men. And in any event, interviewees recounted so many experiences of the appalling treatment of PLHIV, MDS and trans women that it is no wonder that members of these communities might seek escape or relief by engagement in the very behaviours associated with escape and release. I could make a point here about the celebration of hedonism within gay and PLHIV communities in Australia. I have always understood it, indeed experienced it, as linked with the experience of marginalisation and the trauma of the HIV epidemic. There is reason to celebrate survival; it is liberating to forget the struggle for a short time and exhilarating to thumb your nose at wielders of mainstream power by owning (by engaging in) the very acts for which you are stigmatised.

All of these ‘responsibilities’ associated with the enjoyment of rights clearly are more complicated than they seem. It is not a simple case of *choosing* to meet these responsibilities, as interviewees have often limited control over the factors that determine whether or not these responsibilities can be met. Given this, I was struck by the frequency with which interviewees linked rights and responsibilities and by the frequency with which interviewees reported cases of their peers not behaving ‘appropriately’. Here I wondered about the role of lateral violence, the phenomenon by which highly marginalised people sometimes react to their powerlessness by expressing frustration at each other rather than those with power. This issue was identified by Australian development workers over a decade ago as being highly relevant to PNG MDS and trans women. I had conversations with at least three workers over a decade ago who separately identified lateral violence as a problem within MDS and trans communities. Indeed, lateral violence within PNG MDS and trans women communities was observed by an AFAO-commissioned researcher in 2012 (Muwadda 2012), and some steps were subsequently taken by AFAO to address this challenge. It may be that this willingness of interviewees to be harsh on each other reflects this phenomenon, at least to some extent.

Esther, a Papua New Guinean community worker highly regarded within MDS and trans women communities, had an interesting story to tell about rights and responsibilities. She acknowledged that Kapul Champions had promoted the linkage between rights and responsibilities in its own advocacy. In this regard she felt the organisation was reflecting the views of many members, but also using the advocacy strategy most likely to work. She described the argument as follows: Yes, MDS and trans women possessed human rights to choose their sexual partners and to express their true identities, but the *automatic* recognition of these rights by society had to be *earned.* This could only be done, according to Esther, by contributing to community and demonstrating utility to, and respect for, community. This hard work needed to be done so that, in future, MDS and trans women would enjoy automatic recognition of their rights. In short, recognition had to be earned by this generation so that future ones could enjoy it automatically. Esther thought it was wrong to see it as a clash between the collective culture and individual rights — each was impacting on the other in a country undergoing rapid cultural change. Over time, she thought there would be a rebalancing of traditional culture and the human rights of marginalised groups. Esther imagined that this rebalancing would involve finding ways to limit the extent to which assertion of one person’s rights might negate the rights of others. Trans women were entitled to express their identity, and people were entitled to not be offended: ‘Yes, it’s very common … but I must admit I don't know where to put that balance, I must admit.’

As my writing progressed, I reflected on my problems with what I perceived to be a requirement that interviewees ‘behave’. I wondered about my initial analysis of interviewees as feeling pressured to behave and whether I was robbing them of some of the power they in fact possessed. There is a different analysis which also makes sense. In behaving in certain ways, particularly in modifying behaviour, interviewees were in fact choosing to fulfil certain family and community responsibilities, comfortable in the knowledge that they would continue to have a place within these structures. They were demonstrating agency in choosing to protect the thing they valued most, their belonging and place, while living their identities in ways they thought their communities might tolerate. This is consistent with the reciprocity so central to Papua New Guinean life, and very different to a transaction on harsh terms. It seems to me that this analysis is, on balance, the better one.

The responsibility to contribute to community (and to be seen to be contributing)

Trans women talked about the importance of demonstrating contribution to the community. This was also a theme across PLHIV interviews, but it had a slightly different feel when discussed by trans women. Trans women felt strongly that they needed to remind Papua New Guineans that they were contributing members of community. Ideally their fellow citizens would acknowledge the historical presence and role of trans women in PNG life, but at the very least trans women wanted to be recognised as valuable contributors to contemporary community life.

> But it took some time for us to get that respect and get accepted in our own families and in our own communities … I had to tell all my fellow TGs back in my village, you know, that for us to gain respect we have to engage ourselves in community activities, the church activities, so that is what happened. It took a while for us to gain that respect back from the community, we get pushed away and we kept going in and getting ourselves involved and, like now, the reaction and behaviour of the community has changed totally [so] that they really accept us well as to who we are. (Therese, trans woman)

This story is consistent with the commonly stated belief that trans women must ‘comply’ with societal norms and not behave in ways that offend or affront. But it also reflects a commitment to visibility (assuming trans women have a choice). Therese’s story was echoed by other trans women, and together they make clear that ‘to comply’ is not to be invisible. In fact, the objective is the opposite. These trans women seek to be noticed for their efforts; they want their contributions to communal life to be acknowledged and appreciated. But one of these women, Therese, cautioned against expecting too much return on community contribution. She thought it resulted in only fleeting acceptance, and that trans women would sooner or later (probably sooner) be exploited again:

> The more we give of ourself in socialising and contributing, they still have this, you know, mentality that, ‘OK, it’s just for today. Tomorrow is another day’ … Tomorrow when I come to say ‘Hello, hello’ he does not want to talk to me because I am different. It’s just because of yesterday, because of the gathering, because I am doing the cooking, I am serving to the guest and so they accept me. Because tomorrow comes they don’t even know me. You know these are some of the things, you know, that people see in us. They don’t like to socialise with us because of our identity.

These stories of labour called to mind work by Katherine Lepani (2015) who explores the way labour is used to make statements about ‘relational personhood’. Lepani begins with Marilyn

Strathern's (1988) work on the notion of the 'partible person', the relationship between the individual and society in different cultural worlds, and the relational dimension of gendered personhood in Melanesian social life. Lepani considers subsequent exploration of these ideas by Irène Théry (2009), in particular Théry's question:

> What then of the agency of the individual and their ability to act for themselves and, in particular, are we obliged to think that an individual does not have this ability in traditional societies where the higher value is that of relationships? (11)

Lepani is uncomfortable with the way the question presents binaries of tradition and modernity, but nonetheless appreciates the way the question undercuts the assumption that the dividual person does not have autonomous will. Lepani shares the stories of two women living in the Trobriand Islands as a way of exploring 'the locus of individual autonomy in Melanesian sociality, where relational personhood shapes identity and modes of exchange in the moral economy' (2015:51). Lepani observes that, 'agency resides in externalised action that creates, realigns, or discharges relations. In important ways, the effect of agency is the displacement … of autonomous acts, which tend to be viewed as the consequence of the persuasive power of others' (55). She argues that, while assertions and transformations of relational personhood are made known to others in different ways, they are done so most visibly through acts of labour. Lepani discusses how people's labours are directed towards activating and making visible valued social relationships. Lepani reflects on how Strathern's work presents an image of social life as transactional — ongoing exchanges between persons that demonstrate individual autonomy and relational connections. Lepani's two stories reveal how agency is both capable of mutation and transformative and inextricably linked to the gendered social relations that influence the capacity to act: 'The mind is made visible through relational effects. Autonomy and relationality cohere; individual assertions and acts are expressions of the collective integrity that ultimately defines Trobriand sociality' (61). I was struck by the ways my trans interviewees were also using labour as a means of making a point about themselves as individuals, while also using it to position themselves firmly within their community. In Chapter 4, I explore in greater detail this notion of trans women and their labour, including the claim that, in bringing considerable physical strength to the work done by women, trans women exhibit their special value.

Responsibilisation

In the course of my writing, it was suggested to me that I might like to think about the responsibilities being raised by my interviewees in the context of Nikolas Rose's theory of responsibilisation. Rose (2000) writes about the developing ways governments exercise control over people who, in advanced liberal democracies (as he described them), have an expectation of freedom. He acknowledges the work by Michel Foucault (1991), particularly Foucault's observations on how governments are motivated to act through a whole range of other authorities and through complex technologies in order to exercise control over personal behaviours in a broad range of environments — the street, the schoolroom, the home, the workplace. He observes that contemporary strategies for the control of behaviour do not so much seek to crush personal capacity but rather to shape it so that people *choose* to act in ways that are broadly compatible with efforts to

> regenerate and reactivate the ethical values that are now believed to regulate individual conduct and that help maintain order and obedience to law by binding individuals into shared moral norms and values: governing through the self-steering forces of honour and shame, of propriety, obligation, trust, fidelity, and commitment to others. (Rose 2000:324)

Rose's focus is on advanced liberal democracies, and his theory in part involves the problematisation of behaviours because they undermine the 'self-advancement through legitimate consumption upon which government regimes … depend' (321). At first glance this focus suggests the theory may have limited application to PNG, but Rose is also interested in the problematisation of behaviours because they threaten moral consciousness and self-control. Rose sees that people are included or excluded based on behaviours, and this is intended to push a set of ethical values that are believed to regulate individual conduct and promote law and order by binding individuals into shared moral norms and values. This then becomes governing through the self-steering forces of honour and shame.

This notion resonated with me as it reflected what many interviewees had been saying about responsibilities. Many spoke about the shame involved in behaving or not behaving in certain ways, about the epidemic of self-stigma, and about disappointing their families or letting their community down. While PNG might not be described as an advanced liberal democracy, and the focus of my work is not government control, it is useful to think about how interviewees feel (or have been made to feel) that their behaviour is problematic. It is interesting to think about the way their behaviours are perceived and talked about through a risk lens. MDS and trans Papua New Guineans are often described as a 'risk group'. The longer version is to say that they are disproportionately likely to contract or be impacted by HIV, but the short hand, used everywhere from government bureaucrats to development workers to media, is to say they are 'high risk'. This drives a problematisation of their behaviours, already considered subversive. The risk lens is applied with arguably even greater gusto to PLHIV. *Every* sexual encounter of PLHIV can be considered in a risk framework. Indeed, the *HAMP Act* imposes a legal obligation on PLHIV each time they engage in sex, and the whole conversation about taking ART properly is based on theories of risk: to the individual, as well as to the efficacy of ART in PNG and therefore to public health.

I acknowledge how much of my own work has asked communities to think about their behaviours through a risk lens. I, too, have problematised unsafe sex and not taking ART properly. I wondered about the impact of this problematisation on staff and volunteers with Igat Hope and Kapul Champions. What effect had our complicity in the problematisation of their behaviours had on their work and ours? In engaging them in the monitoring of compliance and conversations about risk, we had perhaps functioned as middle-men and -women, helping to transfer the state's public-health responsibilities to individuals — and marginalised ones at that. Clearly, problematisation is not just an issue for government, but for development workers as well.

Wardlow (2017) deftly walks readers through many of these issues, particularly this idea of needing to demonstrate a positive contribution to community in recognition of some degree of 'culpability'. Wardlow was focused on the experience of positive women in Tari but her work has application to my own. The interconnectedness in the minds of many people between HIV and morality emerged often in my interviews. My interviewees reported this connection being routinely made by those around them. Wardlow notes that anthropologists have long examined this intersection in different respects. First, the connection has been explored through the experience of HIV-related stigma and the way PLHIV become morally discredited as a result of their infection, leaving them vulnerable to avoidance, exclusion, abandonment and violence.

Wardlow also observes how Foucauldian analytical frameworks have been used to consider the way biomedical and public-health directives become morally compelling governmental regimes. Wardlow acknowledges work by Nguyen (2013) in analysing HIV counselling as a 'confessional technology' that makes the morality of the self a part of the picture of HIV care. Of her research subjects in Tari, she writes:

> The women I interviewed were well aware that HIV ushered the positively diagnosed into a new moral status — not necessarily morally bad, but morally suspect — that required them to ensure that others could see the work they put into being morally upright. Despite their stated wishes to be apprehended as 'normal' — that is, not to stand out as exceptional or different — it was incumbent upon them to be perpetually interpellated and to interpellate themselves as HIV-positive, to reflect self-consciously on the implications of this essentialized difference, and to show others that they acknowledged and acted ethically in accord with this. As a consequence, many spoke of trying to achieve a less morally suspect status through engaging in an excessive or exaggerated version of ordinary female morality — what I came to think of as (extra)ordinary ethics. (Wardlow 2017:107)

After observing some of the ways the HIV-positive women of her study were pressured around the 'rules of ART' (2016:59), Wardlow also observed 'the small, commonplace, sometimes tentative ways in which they had forged new relations of intimacy and care with clinic staff, family members and even strangers' (2018:59). The example Wardlow used was this one: in between lecturing women with HIV about the importance of not smoking or chewing betel nut, the clinicians could often be found during their breaks relaxing, smoking and chewing with these same women in a friendly and relaxed atmosphere. In this moment, writes Wardlow, 'the neoliberal "clinical gaze" which seeks to "responsibilise" patients is disrupted by a shared flouting of the "rules of ART," and through this shared disobedience the personhood (rather than the patient-hood) of the patient is recognised' (2018:62). Importantly, Wardlow is not saying that this responsibilisation does not occur; in fact, her research references the reality of this practice in multiple settings around the world. But Wardlow asks readers to see the shades of grey, the multiplicities of people's lives.

What to make of this complex interrelationship of rights and responsibilities? I have considered the interrelationship as taking three alternative forms. One might be considered a kind of compatibility: if not symbiotic then at least comfortably interconnected, with rights and responsibilities giving each shape and meaning in an environment of reciprocity. A second relationship might be conceived of as involving a degree of conditionality — you get the rights only if you deliver on the responsibilities. This dynamic can easily take on an unhealthy dimension where people's rights are made subject to the exercise of responsibilities that they cannot possibly meet, precisely because their rights are not respected. And then there is a third kind of relationship, where the individual is shaped through a process of 'responsibilising'. In this dynamic the 'victim' is turned into the responsibilising agent, with responsibility to monitor self and peers and where monitoring becomes a governing strategy. Here, people see their rights and entitlements as entirely conditional upon social norms, and as they are the ones doing the monitoring and censuring, tensions between rights and responsibilities are managed.

It seems likely that all three forms of interrelationship operate simultaneously in PNG, with interviewees moving in and out of these dynamics depending on the circumstances. But all have in common an appreciation that human rights may be inalienable, but they cannot be understood in a vacuum. They are understood, enacted and respected within family and community life.

Stakeholder views about rights

I wondered whether stakeholder interviewees had thought about rights within these different dynamics. As I demonstrate in the next chapter, PLHIV, MDS and trans women expend significant effort just managing the impacts of rights violations. Had stakeholders, less impacted by day-to-day stigma and discrimination, had more energy to invest in thinking about these dynamics?

Anthony, a senior UN official, said that most Papua New Guineans could say something about what they perceived to be their rights — to land ownership, rights around language and other cultural matters, rights of men over women — even though they might not know the source of these rights. But the most distinguishing characteristic of this knowledge, he thought, was the absence of any expectation that the government would observe these rights:

> I think that people are so beaten down by the system and so lacking in expectation that the state is going to provide them with anything and so used to just getting on with their lives in the vacuum … that that also kind of 'dumbs down' the expectations because, you know, who is going to provide these rights to you other than state actors and if the state doesn't provide you with anything from an aspirin through to your basic rights then, hey.

This official was adamant that the most valuable tool in promoting rights was the PNG Constitution because, 'it's theirs, they own it — they can't deny it'. Anthony thought that PLHIV, MDS and trans women were really leading the charge on building rights awareness in PNG. He saw this all around him: PLHIV 'coming out' about their status and demanding to be treated fairly as HIV-positive people; trans women demanding their rights; sex workers expressing their right to earn a living. He challenged the notion that human rights cannot be an effective tool in a communal, collective country like PNG. To begin with, he challenged the notion that PNG even *was* a collective society anymore. Instead, he thought it an environment in which people valued themselves first, followed by family, and then perhaps clan or village. He believed the *wantok* system was collapsing across PNG. People confronting modernity were increasingly aware of what they might attain as individuals, of what they required in order to live in an increasingly expensive environment, and increasingly frustrated by the social need to share the fruits of their labours with less productive *wantoks*. These factors, Anthony thought, were straining the bonds of the *wantok* system. The rapid increase in the size of the youth population across the country, enthusiastically absorbing technology and subsequently being exposed to alternative ways of doing things, was adding to the strains on traditional systems. Anthony saw social media as likely to break down existing social controls. He also saw the control of the Christian churches in PNG as slowly diminishing, as the grip of mainstream churches was splintered by evangelical churches and more people, particularly young people, rejected organised religion altogether. Overall, Anthony thought Papua New Guineans' understanding of human rights was not so different to the understanding in other countries, including in the west. By this he meant that Papua New Guineans have a general understanding of rights while having little knowledge of, or interest in, their origin. This was the same the world over, he thought, and this point was important to acknowledge in assessing the work Igat Hope and Kapul Champions had done to promote an awareness of human rights. Just because rights' violations might be greater in PNG did not necessarily mean that it was easier to promote the understanding of human rights in the country. But what *wa*s different in PNG, he thought, was the level of expectation that the state would protect these rights. He thought this level to be extremely low.

Esther, drawing on her work with MDS and trans women communities in PNG cautioned against any expectations of a single community perspective on rights. You would get lots of different perspectives, she thought, depending on the people you asked. A well-educated person might talk about human rights or the Constitution, while someone from the village might talk about their right to land ownership, or the right to be head of the household, or the right to participate in decision-making for the clan. Despite these variations in expression, there was, she thought, a shared attachment to and respect for the Mama Law (Constitution). Esther thought that most Papua New Guineans had a basic understanding of the Mama Law and a belief that it afforded them some protections. There was also a sense of ownership of the Constitution. By contrast, few people were aware that PNG had signed up to international agreements. And for those who *were* aware, they were *also* aware that PNG routinely flouted its international responsibilities — whether these be in relation to gender equality, environmental protection or other commitments. Esther thought the national attachment to the Constitution was the best way of addressing concerns that human rights were ‘western’ concepts. While she had heard this argument often in her conversations, there seemed to her to be some acceptance that these western notions had been sufficiently indigenised through their inclusion in the Constitution. The human rights in the Constitution were legitimate in a way that those of international instruments were not (even though they might say much the same things).

Returning to the theme of diversity of perspectives, Esther thought that utilising human-rights arguments might be a useful strategy for some rights, but not for others. Esther saw Papua New Guineans as generally comfortable with the notion that PLHIV have human rights and that these rights should be protected despite their health status. This was compatible with what she saw as the Papua New Guinean values of compassion and care. But human-rights arguments were likely to be less effective for MDS and trans women because their behaviours were seen as somewhat anti-social. Esther noted the irony that some traditional Papua New Guinean societies had accommodated both homosexual behaviour and gender fluidity, yet these behaviours were now being resisted on the basis they were anti-Papua New Guinean. Esther concluded that PNG society was comfortable talking of human rights in relation to PLHIV, because this was a health issue that involves the need for compassionate care, but homosexuality and transgenderism were considered western practices with human-rights arguments being imported to justify them.

Dante, a highly regarded community worker with extensive experience with PLHIV, MDS and trans women communities, thought human rights to have limited meaning in PNG:

> I would say in general that people have no concept of what rights are — aside from the very general one where people say, 'I have a right to do something,' like 'I have a right to wear a shirt,' or whatever it might be, but actual rights that are based on law or based on international conventions — this is something that is really foreign to these people, including people in positions of government such as the police, that should know about that.

Dante thought that understanding of the Constitution across PNG was very low, and that few people would see much distinction between this as a source of rights and other sources of these rights. He observed that learning about human rights can be a mixed blessing for marginalised communities:

> I think it's often very personal about what an individual is able to do and what access they have to education, to work, and I also think there is often a kind of tension with it because people, as soon as they are aware of the concept of human rights, they are very conscious that those are rights that they don't have. The right to education, the right to work, the right to a life free from violence, the right to live free from discrimination, the right to equal access to government services, these are things that people do not have and certainly the women and men that we have worked with and transgendered and gay/lesbian communities in PNG and, of course, people with HIV, they don't have access to their rights … it is always a double (edged) sword and it becomes conceptual. People say, 'Oh we are supposed to have that, but we don't have that in PNG, so what's the point?'

Despite this, Dante concluded that knowledge of human rights was still important. Even though PLHIV, MDS and trans women knew these rights were not respected, they at least valued the knowledge that these rights were possessed. Possession of these rights was a source of hope and promotion of these rights was something to work towards.

Damien offered a perspective informed by engagement in HIV and human-rights work in more than a dozen developing countries. In most of these countries he had worked with community movements of PLHIV, gay men, trans women, sex workers and people who use drugs. On the issue of rights awareness in PNG he said:

> I think they get very confused … the people I've dealt with in the community start attributing all kinds of things to [human rights], start assigning, start saying that they have a right to a whole bunch of things, but they are never really sure whether they are 'Human Rights' or not, but, you know, and they use the term 'Human Rights' quite loosely in their advocacy … So in the workshops I've done, people would say everything, just about everything was a 'human right'.…
>
> … I think there is a real silence in our presence of any discussion of what their real obligations are and rights … not in human-rights terms but in terms of being a member of the clan or having a community or having an extended family. I think they don't talk about that very much in front of white people at

> all, and I don't know whether they talk about that amongst themselves or whether that isn't articulated in language, but I think they have a whole banter that they trot out for us.

I have also often wondered how the presence of white people (donors, development workers) shapes discussions in PNG about rights. I have no doubt that some of the Papua New Guineans I worked with in PNG had a 'banter' about human rights that was tailored especially for me. I no doubt continued these conversations even while understanding what was going on, with all parties complicit in the echoing of a scripted narrative. I was struck also by Damien's observation that discussion of rights can at times be terribly imprecise — where all sorts of things get described as human rights. When I lectured law students in Australia on human rights and development, I would start each semester by asking students to list their rights under the Universal Declaration and was always amused by some of the rights students seemed to think they possessed.

Knowledge of rights is only part of the picture

Many interviewees were keen to emphasise that knowledge of rights might be important, but alone it would not improve life for PLHIV, MDS and trans women. MDS Lionel offered one of the most detailed analyses of this challenge, arguing that knowledge of rights was important but that better knowledge was not a complete solution. He said that what was needed was a four-part response. First, rights had to be enshrined in local law. He thought the *HAMP Act* was important in this regard, but that there was room for a more comprehensive legislative effort. Second, Papua New Guineans needed to understand the law. They needed knowledge of its existence and of the mechanisms for enforcement. This involved an element of confidence in there being capacity to enforce the law, which connected to the third element, the need for police support. Lionel considered protective laws pointless unless police were prepared to enforce them.

Finally, Lionel talked about a fourth element to rights protection: individuals needed to not only understand their rights, but they needed a preparedness to enforce them even where to do so would mean acting against custom/traditional practices. PLHIV, MDS and trans women would not use the *HAMP Act,* he said, unless they truly believed that respect for their rights warranted change to usual practices. This would involve a degree of comfort in being critical of custom, and peer support for those individuals brave enough to take up the fight. While he did not spell it out, it is clear that this fourth element requires that members of marginalised groups overcome the self-stigma that might otherwise prevent them from taking remedial action.

Overall observations on rights awareness

The concept of human rights has currency among PLHIV, MDS and trans women interviewees. This is despite several factors that, it might have been anticipated, would render them of little value. Despite the fact that interviewees thought national awareness of human rights to be very low, and despite the fact that they saw some potential for human-rights debates to divide rather than unify, and despite the fact that very few people understood where their human rights came from, interviewees thought human rights to be important. They thought human-rights advocacy to be an important strategy. (Significantly, this did not mean they necessarily thought it to be the *most* important strategy. Some did, some didn't.)

Interviewees generally understood themselves to possess human rights and understood further that these rights were very important possessions. They believed that, at some fundamental level, there was an entitlement to have these human rights respected by the Government of PNG and the PNG community, and that this was a worthy goal. This was a particularly interesting observation for me. Despite low expectations that these rights would be respected, there was a shared understanding that this should not be so. There was a strong sense of entitlement denied.

I have reflected on whether this is a good thing, or not, and in part this reflection has been driven by my role in rights promotion. If all I have done is help make people aware of a set of their rights that are not respected, of yet *another* way they are treated unfairly, what has been the point of that? In the HIV movement it has often been said that 'knowledge is power', but I wondered about the value of knowing you have rights if they are not observed and you feel powerless to enforce them. Where's the power in that? Yet interviewees generally saw value in possessing knowledge of human rights. They mostly considered human rights as potentially unifying for PLHIV, MDS and trans women communities, and that it was likely they could all agree to work towards promoting their rights. As such, human rights were a sound foundation for shared advocacy efforts. And while there was agreement that human rights were not a complete solution, and that the state of PNG was not a great respecter of their human rights, interviewees could generally conceive of a world where their human rights were acknowledged and respected.

PLHIV, MDS and trans women can list some of their human rights. They cite different individual rights and list them in different orders of priority. But they understand that their rights are many and varied, and that they are linked. There are not huge differences in the rights listed by PLHIV, MDS and trans women, and those differences that are apparent also seem logical. PLHIV are, not surprisingly, more likely to reference health-care-related rights, such as the right to non-discriminatory health-care services and treatments access. Trans women are more likely to speak about the right to safety, given the very high rates of violence to which they are subjected, from often an early age (see Chapter 4). They are also more likely to mention the right to education, as many are excluded from schools, again at an early age. PLHIV and MDS are more likely to reference privacy and confidentiality rights than trans women, who seem not to expect such rights. This likely has something to do with the fact that many PLHIV and MDS are hiding their status or sexuality, whereas many trans women consider this not to be an option.

The fact that interviewees think their rights come from multiple sources, or that they do not know where they come from, or that they do not care, is not a significant problem. Whether they come from an international instrument, the Constitution, a national law, from custom or culture, the idea of human rights can easily encompass all these potential sources. Indeed, it is a strength that the notion of human rights in PNG can so easily accommodate entitlements flowing from these different sources. Interviewees talk about human rights as encompassing all these entitlements, which they see as broadly compatible. There is strong support for the notion that the PNG Constitution is the best hook for rights-based work in PNG. Papua New Guineans feel ownership of the Constitution and its statement of human rights is trusted, if not exactly familiar. Inclusion of human rights in the Constitution has effectively indigenised these rights, helping them to be seen as more Papua New Guinean and less alien.

The interrelationship of rights and responsibilities is keenly understood. Interviewees share the view that, for PLHIV, MDS and trans women, having their rights respected involves meeting community responsibilities. There is a shared view among interviewees that, over time, this continued fulfilment of responsibilities will likely persuade Papua New Guineans that the rights of PLHIV, MDS and trans women are deserving of greater respect. There is also a sense that something is being negotiated and agreed, and that change is already occurring at some level. It is no accident, and should come as no surprise, that the interconnection of rights and responsibilities is reflected in the Constitutions of both Igat Hope and Kapul Champions, just as they are linked in the Constitution of PNG.

There are elements of this intimate partnering of rights and responsibilities that are challenging. Where it is framed in a transactional context, suggesting that respect for human rights needs to be purchased in exchange for something else, the whole relationship feels very problematic. But there is another way of looking at these transactions; as a system of exchange and reciprocity with PLHIV, MDS and trans women choosing to engage in certain behaviours in return for continued inclusion within family and community. This conceptualisation would be consistent with exchange being a core value in PNG. But, however the exchange is understood, some of what interviewees were giving was the modification of behaviours that are in fact core to the stigmatised status. For example, trans women are expected to ‘tone it down’ but the right to express themselves is one of the human rights they most value. Despite these challenging elements, it seems that PLHIV, MDS and trans women are broadly comfortable with an analysis of rights that sees these rights as being inextricably linked to responsibilities, and they are generally happy to move ahead on that basis.

This chapter asserts a sound understanding of human rights on the part of PLHIV, MDS and trans women, even where they may not have a clear or agreed sense of the source of these rights. These communities understand their human rights as individual entitlements, but also in relation to their responsibilities to family and community. Interviewees indicated that their social relations and obligations are strong features of individual identity, personhood and sense of belonging. The exercise of individual agency and rights is reflective of people's social connectedness and the responsibilities that these relations entail. Interviewees are aware that they are engaged in a navigation of these rights in the context of their family and community responsibilities, and that their context is complicated by notions of the 'risk' they purportedly pose to others. This understanding of human rights gives shape and meaning to the stories that are to follow in the next chapter, where interviewees talk about how their rights are or are not respected.

Chapter Four
Experience of Human Rights

This chapter is for Manu Peni, a human rights champion from Sepik who has inspired so many people in PNG and around the world with his leadership roles in several social justice movements. Manu was the inaugural president of Kapul Champions and is its president today. He has been one of the most visible faces of the MDS and transgender movement in PNG. He is also a leader in the fight to protect communities' environmental rights from foreign extractive industries. Manu is known locally and internationally as a great advocate for his communities. He is a published author of fiction and a strong supporter of the arts.

*

Building on analysis of how rights are *understood* by PLHIV, MDS and trans women, this chapter explores how these rights are *observed* in Papua New Guinea (PNG). The chapter draws heavily on the stories of interviewees who were asked if and how they thought their human rights were respected or not respected. Interviewees were encouraged to share stories of their experiences. Where they thought their rights were not respected, they were asked why they thought this might be the case.

When talking about how their rights were not respected, or were abused or violated, interviewees often used the phrase 'stigma and discrimination', the origins of which were discussed in the previous chapter. Interviewees talked about *kinds* of stigma and discrimination, and *settings* for stigma and discrimination. The kinds of stigma and discrimination reported included self-stigma, rejection by family, community exclusion and demonisation and rejection by the general population. The manifestations of these different kinds of stigma and discrimination were often quite extreme, and violence was a common component. Stigma and discrimination were being experienced in health-care settings as well as in education, employment and in access to government services.

This chapter has three parts. The first details the experiences of PLHIV. The second details the experiences of MDS and trans women. The third looks for similarities and differences between the experiences of the three groups.

Part One. The Experiences of PLHIV

The view that things have improved for PLHIV

There was a common view among interviewees that the past (10 or 20 years ago) had been much harder for PLHIV than is presently the case. However, before exploring how attitudes have changed and how life has improved for PLHIV, it is important to begin with some of the stories that interviewees told about times past. There have been many stories told in PNG about PLHIV having been killed or tortured, or tortured and then killed, for being HIV-positive or suspected of being so. These stories have been run in the PNG press from time to time, and I have heard them often in my years of work in PNG, but I was surprised to hear them so often in interviews. Here is an example from Alani, a woman living with HIV:

> Well in the earlier years, 90s, there were burning of people alive, people were buried alive, people were burnt alive, people were drowned alive, babies born to positive women were killed or even left to die, so this kind of things happened and, you know, as time came by, people attempt to verbal stigma and, you know, how will I say, talking about people at the back of people, making life hard for people in the communities. So it … has improved a bit but stigma is still there.

Other interviewees had similar accounts. Obi, an MDS, told of people with HIV being thrown off cliffs. Caleb, a man living with HIV, spoke of people with HIV being burned alive or thrown into rivers. The numbers of PLHIV (or suspected PLHIV) murdered because of their status will never be known, but it is important to understand that PLHIV know these stories to be true — interviewees talked about these occurrences as historical facts, not as dark rumours, and this is the backdrop against which they reflect upon their current experience. Despite the past, or perhaps because of it, many interviewees talked about positive developments.

> When I was first diagnosed, that was like, how many years ago, more than 10 years ago, it has changed a lot, maybe because I am open about my status now and everybody has accepted that I am a person living with HIV. Back then HIV was new in the country so stigma and discrimination was very high, but now it's like just another ordinary or common illness or, it's no one seems to point fingers as much as they do back 10 years ago. I'm just one ordinary woman just walking up and down the streets trying to make ends meet. No one sees me as a woman living with HIV anymore. (Ruth, woman with HIV)

> I am very proud of Igat Hope too and also the slowing down of stigma and discrimination in the city and in the country as well … Now anybody can sit down and talk about HIV in the family homes, community, but it was not like this before in the 80s. (Elsie, woman with HIV)

Interviewees generally agreed that there were two main reasons for this improvement in urban areas. First and foremost, people said that HIV treatments had contributed to changed attitudes among the general population. The health of PLHIV on ART had *visibly* improved, so communities no longer feared HIV as a killer disease and instead had begun to see HIV as a manageable illness. PLHIV were no longer seen as posing the same level of risk to the lives of others and fear of PLHIV had subsequently reduced. The second reason for reduced stigma and discrimination, according to interviewees, was increased understanding around transmission. As people have come to understand that HIV cannot be spread by casual contact, fear of contact with PLHIV has reduced, as have related efforts to exclude PLHIV from families and communities.

> Back then we didn't have much information, especially our families, they didn't know how to take care of us when we were sick and down. They were all scared because they thought that HIV — you could get it just sitting next to a person, just eating or whatever, they just didn't have that information, and why they were all scared and they didn't want to. So most times, like when I was stigma and discriminated, like I was thrown out of the house, put under the house. (Ruth, PLHIV)

Interviewees saw a clear distinction between urban areas like Port Moresby and the rest of PNG. Said Rachel, a woman with HIV:

> For what I know ... stigma and discrimination here in PNG has dropped a little bit, I'm saying in the urban area where information is being given and more awareness on HIV. The awareness starts from the community level and the school, it's inbuilt in the school curriculum that students are taught about HIV so less stigma and discrimination in around the urban area, but in the rural area there is stigma and discrimination because of lack of knowledge. People are not aware of what is HIV and how they can care for people living with HIV, so yeah, there's a higher percentage of stigma and discrimination.

In an interview with Miriam and Moia, Highlands women with HIV, both observed the differences between the experience of PLHIV in Port Moresby and (possibly) major centres and the experience of PLHIV outside these centres. Miriam said:

> In Moresby I would say a lot of awareness has been going on, a lot of stakeholders, NGOs partnering with health facilities and generally they are just doing a lot ... every week, information is just passing from one person to another which is okay, but within the Highlands itself … those ones within the main centre of the Highlands like Mt Hagen, the centre itself or Mendi … could be easy, but within the districts, it's really hard still and stigma and discrimination is very high ... they don't have the correct information. People with HIV and AIDS [there] are still thinking that this is a killer disease and that's what they understand. Lack of information, that's why stigma and discrimination is still high out there.

Miriam then translated her friend's story as follows:

> She is telling me that she is not so confident. She was diagnosed in 2004 and all of 15, she was being put on ART in 2016 and had no family and she is also feeling fear to go about and she is one of them too, hiding (from) services … So she is telling me it is very hard [in the Highlands] and we are not coming together like this, we are just hiding away and just being individuals. Here in Port Moresby, mostly we have a lot of ART sites and people get treatment here and there and it's OK, but out there, there is only two sites in Mt Hagen … and they have been coming and accessing services and it's very

> hard for them to come out and expose themselves. But it takes time and this is what I am saying, it takes time, and like when we get confident from others then it might be helping me to come out freely.

Despite the fact that most people consider life to have improved for PLHIV in urban areas, many interviewees had recent or current horror stories of gross rights violations. PLHIV told gripping stories of the ways in which their rights were abused. In sharing these stories, many interviewees seemed to be describing a life that was hardly, at least in my view, 'much improved'. For me, this seemed a little contradictory and raised the possibility that, in assessing current levels of stigma and discrimination by reference to past levels, an overly positive contemporary picture might be being presented.

Interviewees reflected on the reasons for improvements in the understanding of transmission and disease progression. By and large they agreed these improvements had resulted from the combined efforts of non-government organisations (NGOs) and civil society organisations (CSOs), including Igat Hope and Kapul Champions, active in Port Moresby and other urban areas. Interviewees thought that advocacy by PLHIV, particularly in being public about their condition and showing the human face of the virus, had been enormously helpful.

> That [improvement] results from people living with HIV having engaged and being involved in public speaking and coming out and running trainings, just speaking publicly on media on what HIV is and what they live with it and living a positive life — that is with treatment. (Rachel, PLHIV)

Caleb, a man living with HIV, suggested that once fear was addressed it became possible for the caring nature of Papua New Guineans to come to the fore:

> I think once you take away the fear factor, once you have people educated enough to know that they are not going to get it from shaking hands or a drinking glass or a mosquito, that the caring side of PNG and other places kicks in. And as brutal and violent as PNG can be, and as uncaring as people can be to each other here, there is an unbelievable pool of care and support and, you know, if you play the right game with people here the affection and love and support you'll get back is unlike anywhere and I think that side of PNG is kicking in now because the fear factor has been taken away for most people.

In talking about the reduction of HIV-related stigma and discrimination, interviewees commonly qualified their positive reflections in three ways. First, although things had improved, PLHIV continue to experience stigma and discrimination. Second, outside of Port Moresby, stigma and discrimination levels remain very high — possibly as high as at any time in the past. And third, many interviewees warned that gains could be lost with some indicating losses were already occurring.

Stigma and discrimination are still realities

Interviewees described having experienced many, many different kinds of discrimination, but these experiences might be grouped as follows: self-stigma, family rejection, village/community discrimination and general-population discrimination.

Most interviewees reported some experience of 'self-stigma', a term specifically used by many interviewees. This term, like 'stigma and discrimination', has been a feature of the international HIV response and has, I suspect, been similarly imported to PNG via this route. For example, self-stigma is analysed in helpful detail by John Rule and Don Liriope (2016). It might be, and was, otherwise described as shame. Very few did not report some experience of self-stigma, and even interviewees who did not say they experienced it said they had observed it in their peers. Interviewees tended to describe self-stigma in much the same way: as a phenomenon by which people with HIV, often lacking knowledge of the virus, its transmission and treatments options, cut themselves off from family and community to avoid the shaming and rejection they (very reasonably) anticipate. They often feel shame in having contracted the virus and blame themselves for the impact it will inevitably have on their family and community. Once in this place of self-isolation, it is hard for PLHIV to anticipate anything other than blame and rejection.

> I'm just going to give an example. If a PLHIV person, he or she knows that he or she has the virus and they are kind of like feeling unsafe to go and they actually lock themselves in a compound place because they don't want people to see them. They are actually self-stigmatising themselves, thinking that they might go out and people will talk about them and stuff, so they actually are not helping themselves and they are hiding themselves and killing themselves. (Serah, woman with HIV)

Self-stigma was said to have disastrous results for PLHIV as it caused them to deny themselves access to the life-saving treatments and other support that they require to survive. It was said to contribute to loneliness, despair and suicidal thoughts. Many PLHV were said to have died as a result of self-stigma.

> I think basically at the community level, in terms of observation, I think it [stigma and discrimination] has been minimised quite a lot and the community is coming very close to us and this is one of the breakthroughs … but in terms of self-stigma, it is very high, where a person for himself or herself is not able to really express [themselves] and involve effectively on what is right to share and express. This is coming from self-stigma, which people are not able to come out very openly … And there was a … sense that came to me: *I can suicide myself too because I don't want to live.* I thought there was a person of mindset that came to knock me off and I am trying to push my mindset, you know, *no one will love you and so why do you want to live?* But I said 'no'. (Juvelyn, PLHIV)

> Each individual is different, and it is up to that person how he or she carries herself and it's sometimes to do with, mostly it's to do with self. Then the stigma and discrimination comes but I think it's self-stigma first. We are not confident. I am not confident and then I show somebody else that I am not confident, that's when the discrimination comes. (Matilda, PLHIV)

To me, Matilda's particular analysis of self-stigma seemed to include an element of culpability for the way she was subsequently treated. Self-stigma was being acknowledged as its own unique form of negative experience but was also being seen as the genesis of other forms. By self-stigmatising, PLHIV were encouraging other people to discriminate against them, or at least facilitating this discrimination. Matilda was not the only interviewee to describe self-stigma in this way, as a kind of vulnerability that invites others to treat them in a negative way. This was consistent with a much broader theme for PLHIV (and indeed MDS and trans women), that they share responsibility for the ways they are perceived and treated by others.

Many PLHIV described having experienced rejection by family. This was said to have resulted from fear of infection and the shame family members felt at being linked with HIV. Interviewees described the fear as being grounded in misunderstanding of transmission risks and a lack of awareness that HIV need no longer be a death sentence. They thought the shame was linked with the sexual nature of transmission, with sex being an uncomfortable topic for public conversation, and transmission being associated with promiscuity, adultery and sex work, often groundlessly. It was apparent from interviews that female PLHIV in particular were likely to be pejoratively described as sex workers, whether or not this was actually the case, and here we see one of the less desirable effects of public-health practitioners categorising people according to actual or perceived risk. People are tossed into 'communities' based on a practice and the risks associated with that practice and stigmatised as a consequence. The heightened risk of infection to which women are exposed was mentioned by interviewees again and again, especially the inability of women to exercise control over sex generally and condom use specifically. Where women's husbands were engaging in sex with others, this powerlessness placed them in great danger. Interviewees talked about cases where monogamous women had become infected by their husbands or partners only to be subsequently blamed for the infection and maligned as sex workers. This vulnerability has been noted by many researchers including Lawrence Hammar (2008) and Holly Wardlow (2019).

Family rejection involved refusal by family members to share food, plates or beds with PLHIV. In many cases it involved being ejected from the family home, often with disastrous outcomes for people with no other accommodation or support options.

> Oh, it's happening in the house as well. In their own communities, in the places they live around with people. Name-calling, you know, disowning that person, you know, pushing away from the family, not housing them, thrown out of the house. (Matilda, PLHIV)

Community discrimination was often described as 'gossiping', and many interviewees reported this kind of experience.

> Even though you tell people that you are HIV-positive they say, in front of you they say they are going to try to help you, make you feel better, but at the back of you when you leave there is always things coming out from people's mouths, and then at the end of the day you just realise that the whole community knows who you are. (Serah, PLHIV)

The term 'gossiping' seemed to encompass a fair degree of name-calling and prejudice expressed towards PLHIV and their families. Refusal to share food, cutting off contact, name-calling of PLHIV and their families and talking about PLHIV (notably enthusiastically spreading information about their status) were commonly reported.

> In churches that you know women try to assist in — you know, we have Melanesian culture, so if there is a big gathering there is food and ladies stand on the table and prepare food and I've seen and noticed and experienced — *Oh it's alright, you don't touch that food …* It's another form of stigma. (Rachel, PLHIV)

Other interviewees had similar examples. Alani talked about having ordered room service in a hotel and subsequently been sent food in a plastic bag on a broken plate that was not collected — every indication was that her hosts wanted no physical contact with the interviewee. These same people had refused to share lime for chewing betel nut with Alani. Alani told a story of a woman living in a nearby settlement who had been expelled from the family home and was living in a chicken coop. These were not stories of times long past, but accounts of recent experiences.

Angela, a community worker with extensive experience working with PLHIV, told a particularly harrowing story of discrimination dating from 2014. A woman had received a positive diagnosis from a Port Moresby clinic. She had returned to her family, but they had rejected her because of her diagnosis. She had then returned to the clinic seeking any support that might be available, at which point the clinic had referred her to Igat Hope. Igat Hope had tried to get her into a charity-run refuge but, upon learning the woman had HIV, the refuge had refused her accommodation. Igat Hope had taken the woman back to her village and sought to mediate with her family. When they arrived at the village all the woman's clothes had been thrown out and she was not permitted to return to the family home for fear that she might infect the children. A neighbour had finally agreed to take her in. The woman offering refuge was subsequently threatened by her own sons for taking the woman in and thereby allegedly exposing her sons and their children to the risk of infection. Igat Hope had intervened again, trying to explain to the family that the woman posed no risk of HIV infection. Yes, the woman was sick and was coughing, but that was likely to be TB. And while the risk of TB infection was real, the risk of HIV infection was not. The woman with HIV died not long afterwards.

> Lately I heard that she passed away, because there is stigma and discrimination. It's nothing to do with ART. I can honestly say that ART is working perfectly for the PLHIV community, but it's just the love, care and support from family [that is missing]. There is something missing within the family and the community and the society. (Angela, stakeholder)

This story illustrates the enduring challenges for PLHIV, including so many of the elements that contribute to ongoing stigma and discrimination. It is a reminder that ignorance and fear of HIV outside of Port Moresby remain at very high levels. This so often leads to family rejection and subsequent, avoidable death, robbing communities of what might otherwise be opportunities to learn that HIV is not a death sentence, and of the assets that these villagers represent. The story also serves as a reminder that women with HIV are particularly vulnerable, and that without a shift in community understanding, not only will PLHIV continue to be at great risk, but so too will those who provide them with refuge and support.

One of the commonly reported manifestations of self-stigma is the way in which PLHIV self-select themselves out of opportunities in anticipation of discrimination and rejection. In inviting interviewees to talk about their experiences of discrimination, I often heard stories of rejection anticipated, with this anticipation leading interviewees to take steps to avoid this rejection. While understandable as protective measures, these steps often robbed interviewees of possibilities. This phenomenon is considered in most sections below, but this story from Elsie (PHLIV) is a good example:

> I was on treatment and after six months on treatment I just totally changed, my weight and everything and I looked much nicer than before, than I used to be, and then when my partner saw me, he thought that I was a normal lady, so we be going around dating and that's all. Then when our relationship wanted to go further and too deep, I just told him straight — after eight months, I told him: *Look, I am a person with HIV, so I am sorry, you have to go and find a new life.*

I wondered how many other PLHIV had terminated relationships for fear of rejection. Elsie, however, reported that there had been a happy outcome: 'And he said, you should have told me a long time ago, now it's eight months. I said, yeah, well it's eight months, you can go. Then he made up his mind to be with me and we stayed since nine years.'

Some interviewees reported stigma and discrimination directed by communities towards their children. Rachel said her children had been subjected to name-calling on the basis of her status and that this had necessitated them being transferred to another school. She had done this quickly and while they were very young, so her children did not yet know her status. This was particularly a risk for ‘out’ PLHIV activists, she said. Rachel reflected more generally on the challenge for PLHIV in telling their children about their status. In her own case her status had generated multiple issues for her children, including the hurried changing of schools and the ‘protection’ of her children from the impacts of any of their mother’s advocacy. She was worried about how to explain her status to her children, when they were old enough for this discussion, in view of the many negative messages about PLHIV to which her children were otherwise exposed. Rachel observed that with the advent of ART, it was now an option for mothers such as her to *not* tell their children. With ART these women might well remain healthy, whereas positive women a decade before would have had to prepare their children for the loss of their mother. It was interesting that Rachel thought many women would consider this option, even in these times when stigma and discrimination were, by all accounts, much reduced.

Rachel wanted to share her HIV-positive status with her children but recognised that this carried with it a risk of rejection. She would need to manage the telling with great care and felt ill equipped to undertake the task. Where is the advice or support to help parents with HIV take this step, she wondered? Rachel was also worried about what would happen to her children if she died. She thought this was probably the greatest fear that PLHIV experienced — what would happen to their children if the treatments failed and they died? Several interviewees raised this issue and did not feel confident that the community would deliver the family or communal care required for their orphaned children. For a number of interviewees, their HIV status had already strained their family bonds, and they worried that their families would not step in to look after their children in the event of their deaths. For these interviewees, this fear remained real, despite advances in treatment.

Angela, an NGO employee working with many PLHIV, observed that HIV-negative partners of PLHIV also experience stigma and discrimination. This was not reported to me by other interviewees, but it would certainly be consistent with trends experienced in Australia and other countries (Rispel, Cloete and Metcalf 2015).

Discrimination in health-care settings

Interviewees reported many cases of discrimination in health-care settings. Interviewees reported that discrimination in health care took different forms, including delaying or rushing appointments with PLHIV and judgemental attitudes on the part of clinic staff. Interviewees also reported that PLHIV experience hostile looks and criticism from other patients, creating yet another barrier to health care.

Rachel, highly experienced in navigating clinical services, told frightening stories of discrimination in health-care settings. She began with a personal account of having given birth several years before. She experienced discrimination early on in her pregnancy, being told by health-care staff and counsellors that, as a woman with HIV, she should not have conceived at all. She was admonished for having placed her unborn baby at great risk. When she went to Port Moresby General Hospital to give birth, she was abandoned in the ward by nursing staff in fear of infection. ‘The midwives in there couldn’t help me with the delivery so I kind of delivered my own child and that was a disaster for me that there was so much, much, much, way discrimination.’

She thought that, by comparison, staff at Heduru Clinic (Port Moresby General Hospital’s specialist HIV clinic) were much better informed and far more capable of delivering stigma-free services. Yet she shared a recent story of staff there taking a very heavy-handed approach to non-compliance with ART regimens. Like many interviewees, Rachel observed that a significant number of PLHIV were struggling to adhere to the requirements of ART, specifically the need to take it regularly and not miss doses. Given that non-adherence, perhaps more commonly described as non-compliance (although PLHIV prefer the former, less judgemental term) undermines the efficacy of treatment and can lead to drug-resistant HIV, missing doses is most certainly an issue, and Rachel said that she had seen staff withhold ART as a punishment for non-compliance. This was a violation of human rights, she thought. More generally she thought Heduru staff to be quite committed but overworked. The consequence of being overworked was that PLHIV received rather cursory treatment services — basically just the distribution of pills rather than any of the counselling that might support adherence. Any care that was not about ART was generally not provided, she said.

Rachel was touching on an issue of great complexity that was raised by many interviewees. That is, PLHIV have strong views around compliance and the responsibility of PLHIV to adhere to their treatments. As detailed in Chapter 3, the fulfilment of these responsibilities is seen as inextricably linked to the entitlement to human rights protections. Put bluntly, there is a view expressed or reported by quite a few interviewees that PLHIV who fail to adhere to treatment regimens forfeit their human right to non-discriminatory health care. This view holds that there should be some form of punishment for such failure. Others see it as more nuanced, with health-care workers being entitled to use whatever strategies they consider effective in order to increase compliance, even if these might appear a little heavy-handed. But not everyone sees this as a legitimate strategy, with some outraged by the idea that PLHIV should be patronised or punished for exercising their right to decide if and when to take medications.[1] What does seem clear from

---

[1] Heduru is the model HIV treatment and training clinic in PNG. It is very possible that the deliberate withholding of treatment is a reflection of individual nurses or clinicians and not the clinical service on the

interviews, however, is that some health-care workers *are* being ‘heavy-handed’ with PLHIV and are straying beyond issues of strict treatment compliance into matters that might otherwise be described as ‘lifestyle’. Matilda touched on this issue in her own story, talking of how proper adherence was seen by health-care workers to involve lifestyle factors like sobriety and leading a ‘good’ life:

> I’m involved in the clinics and I think when the peers come in to be treated or to get treatment, the facial reaction, they are not counselled well [by] doctors, counsellors … Counsellors, most counsellors should be trained not to give their point of view. I mean that’s myself, that’s how I see it. They should be giving options to them (PLHIV) to take choices. Some of the counsellors tell us to leave whatever activity we are doing and get on with … life like them. They are not there to tell us what to do but they are supposed to … be telling us options only, so we can choose the way we want to live.

Matilda continued to explain that the ‘options’ being somewhat forcibly promoted included living soberly, along with the avoidance of partying and anything else that might be described as a little ‘wild’. Several other interviewees mentioned the negative treatment PLHIV receive from clinical staff in response to non-compliance or behaviours that might, in the view of these staff members, lead to non-compliance. Alani (PLHIV) talked of the role his clinician had played in shaping his behaviour: ‘I came back and then I started getting medicines. I had to quit some things where the doctor told me to … and then I started like, I behaved. I had to quit some of my bad attitudes and then I stay with my kids.’

Miriam acknowledged that non-compliant patients would be subjected to negative treatment by clinic staff. But like many other interviewees, Miriam thought this was different to the kind of stigma and discrimination that PLHIV experienced elsewhere in their lives. This treatment was more acceptable, said Miriam, because it had a worthy objective: ‘I think they are doing all the best that they could do trying to bring everyone in but the problem I see is with the clients itself.’

---

whole. A major issue has to do with the reliable supply of ART to meet the need. Not everyone who tests positive is immediately enrolled in therapy, instead there is a hierarchy of provision, partly based on disease progression, and individual treatment regimens. When stocks are low or there are ‘stock-outs’ (supplies temporarily unavailable), clinicians (and PLHIV too in their advocacy with peers) are known to implore patients about the importance of adherence on the grounds that they should respect valuable resources or else make room for another HIV-positive person who could enrol in treatment and enjoy the benefits. The increasing incidence of multidrug resistance in PNG compounds the problem. These issues were discussed at the 2010 Waigani Treatments Forum in Port Moresby, which I attended. At the forum there was some discomfort with the notion of a right to decide if and when to take treatments. Yes, a person has a right to decide whether or not to begin treatment, but once enrolled, and in a context of under-supply or unreliable supply nationally, this right must surely start to evolve into a responsibility. ART care in PNG is variable but it is better at Heduru than anywhere else and Heduru patients do receive information on the importance of adherence. Arguably the ‘rights’ issue is not if and when to take pills once enrolled in a treatment plan, but the question of securing regular supply of drugs. This is a government management issue — budgeting, procuring, distributing, and PLHIV activists are very vocal about how the government continually fails them in this way.

Not all interviewees were so comfortable with this notion, critiquing health-care workers for failing to acknowledge the many factors that impact on adherence such as poverty and lack of family/community support. There were other observations on poor clinical care, especially the failure to explain how treatments must be taken:

> They are not seeing the importance of the medication. Because it has not been stressed. All they do at the clinic is just giving them the medication, they don't stress that you have to come back, and you have to take it on time, on time, and stay in a good manner or a good way, not being hushed and rushed and you rush things up. (Matilda, PLHIV)

Sifting through these stories, it is useful to try and understand to what degree PLHIV's complaints about health care were actually grounded in HIV-related stigma and discrimination. The PNG health-care system is woefully under resourced relative to need, so many Papua New Guineans receive poor care. While Rachel's story of giving birth is a clear case of discrimination, stories regarding treatments and compliance are more complex. The inadequacy of clinical advice around adherence might well relate to failings in training of health-care workers and the relative 'newness' of HIV medicine, but some of the clinical 'care' relating to directives on lifestyle and behaviour most definitely is experienced by PLHIV as discriminatory.

While around a third of interviewees with PLHIV reported discrimination in health-care settings, I had anticipated this proportion might be greater. Some interviewees were asked to reflect on the overall numbers of such complaints. Dante (stakeholder) thought the reports needed to be considered in context. He said that it was likely that many interviewees were actually accessing health-care services from a very small number of clinics that were highly sensitised to the needs of PLHIV. This analysis was consistent with so many interviewees being connected to Igat Hope. It is also reasonable to assume that, given the cohort's connection to Igat Hope, they would be disproportionately likely to be aware of their rights and more capable advocates than average PLHIV in Port Moresby. Perhaps this means they were less easy targets for discrimination. It is also true that significant donor funding in PNG has been directed towards capacity building in clinical services, including in relation to non-discriminatory health care, so this clinician training may well be impacting on PLHIV experience.

A huge proportion of health-care services in PNG is delivered by religious institutions, and the Catholic Church in particular. An understanding of HIV care in PNG does require consideration of the way Christianity might be shaping service delivery. Wardlow's research (2008) suggests that Christian perspectives in PNG tend to see HIV, somewhat perversely, as an ally in affording a means of punishing 'sinners' (fornicators, adulterers, homosexuals, sex workers), and in a handily immediate way. Not having to wait until doomsday for the point to be made, instead these sinners are punished in the prime of their lives by disease and early death, serving as a stark and powerful warning to others. In this sense, HIV reinforces Church teachings on sex and is capable of driving sinners back to a more pious life:

> Arguments about HIV prevention policy seemed to have galvanized a kind of postcolonial Christian nationalist discourse with some health officials asserting that, as a 'Christian nation', the Papua New Guinea state should not be in the business of encouraging extramarital sex and prostitution through condom promotion. (188)

Of her work in Tari around 2004, Wardlow says:

> Almost everyone I spoke with associated AIDS with sin: AIDS was either God's 'punishment' for people's failure to live Chistian lives, or it was a test from God to see if people were capable of obeying his guidelines for a moral life. (2008:191)

Wardlow's informants bemoaned the erosion of traditional gender and generational taboos and social restrictions that saw people in a kind of moral free fall. Christianity was seen as a set of restrictions that might keep people restrained in the absence of other social controls, at least to some degree.

In dissecting public-health approaches to HIV in PNG, and HIV education campaigns in particular, Hammar (2008) has this to say: 'In Papua New Guinea, just beneath the progressive movements regarding AIDS, lurks the bogeyman who insists, via Christian and public-health discourse, that sex is bad, bad, wrong and bad' (64). Drawing on the work of Volker Hauck, Angela Mandie-Filer and Joe Bolger (2005), he continues:

> The expressly Christian staffing and running of health services are problematic. To be sure, without the churches, health care in Papua New Guinea would be in a far worse situation. Christian churches deliver more than half of all health services and train thousands of health personnel. (Hammar 2008:67)

Hammar notes observations by Vicki Luker (2004) that, compared with government health services, church services generally have better reputations, efficiency and morale. That said, Hammar notes that Catholic missions, which administer half of all church-run facilities, continue to discourage condom use, despite this being a central plank of national public-health responses to HIV. Some Baptist missions, he argues, can be even more extreme, refusing all supplies from health services that promote condoms. Local Christian radio, a critical source of HIV education, refuses to run health messages that reference condoms. Hammar observed in his own work, health-care staff who were conducting their HIV education and HIV servicing through the lens of church teachings, and not those that exemplify the Christian principles of compassion and forgiveness: 'The judgemental attitudes that we and others have found in STI clinics contribute to stigmatization, to poor sexual history taking and to unlikely return and follow up' (2008:68).

I know from my own experience that the role in the PNG HIV response of the churches, and the Catholic Church in particular, defies easy summary. It has been multidimensional. Despite its (at one level) hierarchical, singular structure, in practice it operates through multiple structures that take often very different approaches to the interpretation and application of Church doctrine. I have seen firsthand the damage done to HIV prevention efforts by Catholic obstruction of condom distribution. I've also seen this position completely ignored by Catholic services and by devout individuals (including members of religious orders). Catholic responses to people with HIV in PNG have been amongst the nation's most compassionate. My work is not a story of Catholic responses in PNG, but where that story is told it will need to reflect the complexity of and variation within the Catholic response. Angela Kelly's (2009) work is a fine example of the writings that consider this complexity.

Discrimination in employment/workplace

Three HIV-positive interviewees told stories of discrimination in employment.

Alani told a story of a peer who had very recently been denied employment when the employer had insisted on a health test and the applicant's HIV+ status had been subsequently revealed. Alani said this was not uncommon amongst larger employers and the discrimination did not stop at the recruitment stage. Employees subsequently discovered to be HIV-positive were encouraged to leave or replaced. Toby told a story of being demoted within the police service, and said his story was not unique: 'Well I have a good job but, as I have told you, we have some workplace discrimination, like I was a Sergeant, but I was demoted … we have workplace discrimination for some other policemen that are also infected.' Bosai (PLHIV) had this to say:

> So working environments they are not really understanding of HIV. Maybe people with HIV, they are working with them; maybe they can gossip about them, or maybe some bosses who don't know the HIV information they still remove them from their job. In our country HIV information is lacking so they might still sack them from their job. That's why discrimination comes in. It happens commonly but it depends on information not really reaching us.

Matilda (PHLIV) thought the incidence of HIV-related discrimination in employment was probably higher than reported: 'I think it's happening but it's being kept quiet and mostly it's like information. The person who is involved does not know where to go or who to talk to, that's why it's been kept quiet.'

There are reasons to think Matilda may well be right. It is worth acknowledging that few interviewees were formally employed. As a result, few would have been exposed to workplace discrimination. It is likely that many PLHIV in PNG decline to seek employment in anticipation of rejection, particularly where they fear workplace testing for HIV. Christine Stewart (2010) observes with frustration the continuing interest in instituting mandatory workplace testing for HIV. She considers it settled that repressive measures to combat HIV simply drive those affected underground and fuel the epidemic (UNHCR/UNAIDS 1996). After 20 years working in HIV, I, too, consider the matter settled. Despite this, Stewart writes, 'It has proved incredibly difficult to persuade the general Papua New Guinean community of this simple message: that repressive measures do not stop the epidemic, they actually assist its spread' (2010:276).

The high incidence of self-stigma is similarly consistent with the proposition that PLHIV do not seek employment even where this might be possible. Many PLHIV reported feeling at different times a very reduced capacity to contribute to the community and an expectation of rejection, and presumably this held many back from offering their services as employees. It is also probably the case that many interviewees do not identify this behaviour — self-selection out of employment — as being discrimination, and do not complain about it. And more importantly, the overwhelming majority of PLHIV do not disclose their status in the workplace and work hard to prevent anyone from knowing about it. The risk of HIV-related discrimination is managed by keeping an HIV diagnosis confidential. It is also worth acknowledging that, of those interviewees who were in formal employment, a significant proportion work in the HIV sector where HIV-related discrimination would presumably be limited. For these reasons, the low number of employment-related complaints by HIV-positive interviewees is as likely to be evidence of a problem as it is to be evidence that no problem exists.

Discrimination in education

PLHIV shared relatively few stories of discrimination in education. This is not entirely surprising: most (although not all) of my interviewees would have likely contracted HIV as young adults. Even if they had contracted HIV while a student, given the low rates of testing nationally, they may not have learned of their serostatus until some time after infection (and after they had left school). One interviewee commented that HIV was now being covered in the school curriculum and that this had helped reduce stigma and discrimination. In fact, HIV has been included in the school curriculum since 2000, and the Education Department's website includes a range of HIV resources. The only reported cases of discrimination in education involved the bullying at school of children of PLHIV.

Discrimination on multiple grounds, and the particular vulnerability of women

Several interviewees noted that HIV-positive members of particularly vulnerable populations, including women, MDS and trans women, often experienced discrimination on multiple grounds. I have seen this elsewhere described as 'double discrimination', and indeed a couple of my interviewees used this phrase (again, no doubt, having become aware of it via the global HIV discourse), although the grounds can sometimes number more than two. This experience was not, but could have been, described as intersectionality (Crenshaw 2008), a relatively new framework for understanding how different aspects of a person combine to create different modes of discrimination and privilege.

> Firstly, I think for general population, like if a married man and a heterosexual, not quite discrimination has been given to them but for our key populations like sex workers and MSM there is double discrimination — there is the thing with who they are and their status. Like … the example I gave earlier on — she is a young sex worker and she has got HIV, like there was a kind of a blame given to her — like it's your fault, you were out there partying and bringing in different men so that's what you face. I think it's a level of a different category we come under. If I am a heterosexual and I am HIV-positive the discrimination level will be different while an MSM and trans women and female sex worker will face a different level of discrimination (Rachel, PLHIV).

Kutan (PLHIV) spoke of his attitudes towards sex workers before he became infected: 'I hated them, because the only mentality I have is "bunch of prostitutes"'. His earlier attitude was commonplace, he said:

> Like back in the village if you are infected they will just simply say, look, we don't want the disease … in our custom, prostitution is not allowed so if you are about, do it but make sure, take extra care and nobody sees what you are doing, and if they see you … they take you to court, or they kill you or they belt you up.

While double discrimination was acknowledged as an experience for MDS and trans women with HIV, interviewees more commonly reported double discrimination in terms of HIV-status and sex. Being a woman intensified and exacerbated the impact of being HIV-positive. The particular vulnerabilities of women with HIV have been widely documented. Katherine Lepani (2016) notes the global recognition of gender violence and HIV as 'twin epidemics', which are connected via the structures that perpetuate gender and sexual inequalities (164). Lepani draws on her earlier work (2008) and the work of others to reflect on the ways this interconnection between gender violence and HIV has reinforced fear and stigma in PNG, especially for women who are disproportionately blamed for HIV transmission. Naomi McPherson (2012) considers how violence 'may very well be a cultural trait, learned, practised, and integral to concepts of gender' (48). McPherson acknowledges decades of anthropological research in PNG documenting male socialisation and cultural concepts of masculinity as critical to the ‘rituals of manhood’ in many PNG societies, and work by Gilbert Herdt (2003, 2009, 2011) is discussed later in this chapter. McPherson sees that, through these rites of initiation, boys are taught cultural concepts of male superiority. The rites often involve acts of violence inflicted on boys by men ‘to eliminate female essences from their bodies in order to re-create (rebirth) those boys as strong men and members of their kin groups’ (2012:48). McPherson writes that violence is often connected to sexual jealousy and this has emerged as a theme in blaming women with HIV for their infection. But also, violence is often perpetrated on women because of a failure to bear children and to labour to generate men’s wealth. For women living with HIV, these expectations may be more difficult to fulfill. McPherson also notes the frequency with which women who are sexually attacked are blamed for provoking the rapist’s sexual desire, rather than recognising the perpetration of sexual violence as a criminal act.

In her study of Huli women with HIV, Wardlow (2017) observes how their management of their status is shaped by the fragility of their position within their households. While most of the women in her study were living within their family homes, they had all gone through periods of dire vulnerability before securing this degree of familial protection and most knew other positive women who had been ejected from their homes. The women continued to experience vulnerability and their behaviour within their family units (notably doing as much labour as their health allowed) was driven by this vulnerability. Wardlow observes that where a man is thought to have become infected through his rape of a woman with HIV, whether or not this is true and leaving aside questions as to how it could ever be proven, his infection can inspire as much sympathy for him as being raped does for her. She concludes:

> The social construction of women as morally unreliable, [means that] high levels of violence … and the morally exceptional nature of AIDS all intersect to produce an environment in which HIV-positive women must consider whether their behaviours (and others’ interpretation of their behaviours) put them or their families at risk for retaliatory violence or compensation demands. (114)

Rachel agreed that women with HIV like her were vulnerable to double discrimination. Women who contracted HIV were at risk of being blamed for their infection, even in circumstances where it was far more likely that the virus was contracted from their husband or sexual partner. Rachel thought there was some growing acceptance that, where married or partnered women became infected, the source of the infection was likely to be the husband. And, in these circumstances, there might be some sympathy for the woman, but this was not likely to continue beyond the husband’s death. Rachel said that at this point the husband’s family would likely claim anything of value, leaving the woman with nothing. And Rachel did not see this growing acceptance of male culpability as extending to women who were single or sex workers — they likely would be fully blamed (as would MDS and trans women).

Caleb (PLHIV) warned that, to get a full appreciation of HIV-related stigma and discrimination and its impact on women, it was important to recognise where it occurred under a different guise. It was common for links to be made between HIV and sorcery: 'There are certainly cases around the country where it is tied up with sorcery and used against people.' Caleb thought it possible that violence being perpetrated in the name of combating witchcraft might in fact just be violence against PLHIV, positive women in particular. Research on the phenomenon of sorcery accusation related violence (SARV) in PNG has found that women are more frequently the targets of accusations than men, and that sorcery accusation is commonly considered to be part of a wider problem of pervasive violence across PNG, including domestic violence and sexual violence (Forsyth and Eves 2015).

The link between an apparent increase in witchcraft accusations over the last two decades and PNG's HIV epidemic has been noted in the media and various research studies (Gerawa and Rheeney 2004; Haley 2010). In many reported cases of witch-killings — including the incineration of a young Mt Hagen woman in early 2009 — AIDS has been explicitly implicated. Drawing on research in the Southern Highlands, Nicole Haley notes:

> It is typically women, especially those who are seen by men to have rejected their customary obligations or to have failed to conform to local gender and sexual stereotypes, who are accused….
>
> … At Kopiago … the HIV epidemic has contributed to the rise of witch-hunts and trials by torture. This has come about because of the culturally specific cosmological understandings Duna have of illness and disease; because AIDS produces the very kinds of deaths that attract witchcraft accusations; and because the illness and death associated with HIV add to a generalised anxiety about witchcraft. (2010:231)

While Haley was writing of a particular Southern Highlands community, the Duna in Kopiago, she notes that associations people make between witches, promiscuity and the transgression of social and moral boundaries are likely to be common across PNG. These associations can have serious consequences for women with HIV, who are often associated (usually with little or no foundation) with promiscuity and sex work. Trans women are similarly associated with promiscuity and sex work, as well as transgression of social and moral boundaries. MDS too are associated with promiscuity and transgression of boundaries and, while most victims of violence perpetrated against those accused of sorcery are women, men can also be victims.

Interviewees mostly talked about the combination of HIV-status and gender, and the demonising of women with HIV as witches or sex workers was commonly acknowledged by interviewees. But there was also acknowledgement that HIV status can intersect with sexuality and sexual behaviour to intensify vulnerability.

The issue of class is relevant to the experience of discrimination

> I see that people have understood more about HIV and AIDS and STDs and more people are practising the safe sex by using condoms [but] I think people from the lower class are still yet to be educated on the issue of HIV and AIDS because most of them are affected … They have less information about the HIV and AIDS virus, that's how when one of them is contracted the virus they have little information and that's how most of them have been affected by it and, um, for the people who have a little information on HIV and AIDS they are OK. They, like I actually have many friends who are PLHIVs and when asking them about um, that those are not HIV-positive too, when I ask them about HIV most of them have come back with positive feedbacks as to how they are protecting themselves when having sex, that's through prevention by using a condom but um, yeah, that's the way I see it here in PNG now. But that's here in Moresby but I am not sure in the other provinces. (Bosai, PLHIV)

> I think people from the lower class are still yet to be educated on the issue of HIV and AIDS … I'd say half of the population they know about HIV and half of them don't know because, like, in settlements most people are not coming out trying to find out about the HIV information because they think that [if] they ... come out [to find information] people will say that they are [HIV-positive], maybe they want to find out the information because they are infected [but] they don't want to go to clinics and ask … that's how the mentality of people [is] ... They have less information is because most of them are actually from the villages coming into the city and they are illiterate … most of them don't read and write too, that's if you go into settlements and shanty places you will realise that most of the people are illiterate so if you ask them about HIV, they are not really sure but they only know that it's a killer disease, that's what they will tell you. But about information on how to protect themselves and how to take care of themselves when they are infected, they are not really sure about there. (Serah, PLHIV)

I was surprised to hear interviewees raising the issue of class so regularly, as it had not come up so often in my previous work in PNG. They talked about class in different ways, but illiteracy, having had little education, being without employment of any kind, and/or living in a shanty, settlement or village were all associated with being 'lower class', although the actual term was used only very rarely, such as by Serah above.

There has been some study of class in PNG. Deborah Gewertz and Frederick Errington (1998) observed the emergence of class inequalities in PNG in the 1990s. They describe a clearly established indigenous urban elite that was able to perpetuate itself. The key, they write, is access to highly restricted western-style education, and argue that this process of class formation has led to the development of new forms of inequality understood in terms of relative capacity to make lifestyle choices, the capacity to consume and to display consumption. The authors note a link in public discourse on class between poverty and crime, specifically a recognition that poverty can drive people to engage in criminal activity. While the authors suggest these linkages can be understood in sympathetic terms — that poor people may engage in crime to demonstrate their frustration with the failure of the state to provide them with the necessities of life — the association of Igat Hope and Kapul Champions with people of the 'lower class', whatever that might actually mean, probably does not help combat the stigma and discrimination experienced by PLHIV, MDS and trans women. Here the work of Sinclair Dinnen (2000) sheds some light, in exploring the issues of law and order in the context of PNG's rapid modernisation. Dinnen sees economic change centrally implicated in recent escalations in lawlessness, including in relation to the acquisitive crimes of *raskols* (Tok Pisin for thief/criminal), conflicts arising from resource exploitation, and in the concentration of problems in the most developed areas. Class also gets a mention in this work, with Dinnen noting the criminal targeting of economically marginalised groups and the emergence of class as a major source of division (46).

As early as 2005, Stewart was observing class as a factor in Papua New Guinean sex work. Referencing work done by Carol Jenkins for the PNG Institute of Medical Research (1994), Stewart notes different categories of sex workers including escorts maintained in high-class houses and 'the increase in class ranking in the *disko meri* category which sees the emergence of those at the lower end of the scale who are more likely to frequent guesthouses during the daytime' (2005:4–5). Stewart (2010) also observes, in her work on the police raid of the Three-Mile Guesthouse, how different drinking and accommodation venues cater to different classes of Papau New Guineans, exposing patrons to different kinds of police surveillance. Stewart (2014) sees also that, while there are exceptions to the general rule, most drag performers are lower class and poor. She also observes MDS seeking sexual partners for money in higher-class establishments.

People of lower class were said by interviewees to have less understanding of HIV and to be more likely to discriminate against PLHIV. This is consistent with a view common among interviewees that knowledge of transmission and treatments is key to reducing discrimination, and a view that illiteracy and poverty are barriers to this knowledge. A contrary view was also expressed, that people living in settlements were *less* likely to gossip about PLHIV or discriminate against them, as they were too busy just trying to survive. Gossiping and discriminating were luxuries that could be better afforded by those with employment, it was suggested. While an interesting perspective, this was definitely a minority view, and ultimately unpersuasive: it takes no time at all to gossip or discriminate.

Interviewees most commonly raised the issue of class when talking about perpetrators of discrimination, with lower-class members of the community being more likely to discriminate. But class was also raised in relation to the membership of Igat Hope. Many interviewees observed that Igat Hope members are disproportionately poor and without formal employment when compared with the general population. In explaining the reasons for this, interviewees said that connection with Igat Hope exposed people to a greater risk of being publicly known as HIV-positive, but that 'lower-class' people were more prepared to take this risk. Such people were said to have less to lose by their status being known. For example, they do not have jobs to lose or positions of authority that might be jeopardised. They were also said to be more in need of support and assistance so more likely to seek these out from Igat Hope, even if this exposed them as being HIV-positive. In fact, such assistance was generally *not* provided as Igat Hope sought to establish itself as an advocacy organisation rather than a community service agency. This ongoing tension between Igat Hope as advocacy organisation and Igat Hope as service provider is considered in a later chapter, where it is discussed as an institutional tension that impacted on the success of the organisation. Suffice to say here, however, that this institutional tension is grounded in class and the needs of people impacted on by poverty.

Class plays out in other ways as well. If, as seems to be the case, Igat Hope members are disproportionately poor, unemployed and illiterate, they represent that part of the community least able to protect itself from the impact of infection and the most exposed to HIV-related stigma and discrimination. They are, then, the most vulnerable of the vulnerable, and their insights into stigma and discrimination will be particularly important. Their connection to Igat Hope has also arguably meant this cohort has greater awareness of their human rights than other PLHIV in PNG. This underscores the importance of their observations in developing an understanding of rights violations in PNG.

Not everyone is comfortable with the idea that class is emerging as a significant factor in PNG. While the issue of class was raised by interviewees, I have also heard in my work the view that class distinctions are overrated, at least in so far as they are suggested as emerging as alternative structures to kinship bonds. John Cox (2014) calls for more research into class issues. He writes that the commonly referenced 'grassroots' versus 'elites' is an over-simplification. Cox argues that 'elites' can often include anyone in formal employment, or indeed anyone who has completed secondary education, and disguises the working class, many of whom could be described as working poor and who are emerging as a group important to social and economic planning, as well as to public discourse on the future of the country. He sees the growth of this middle class as being quickened by urbanisation, and encourages recognition of the 'predatory elite', those who really control money, resources and economic direction in PNG. In this category he includes powerful parliamentarians, senior public servants and millionaire landowners. For all these distinctions, Cox sees the barriers as porous, noting that many working-class people still aim to return to the village upon retirement, and work to maintain relations with their rural kin. Cox's call for further research makes sense to me, as he notes this is a (yet another) dynamic space in PNG. But whatever researchers may discover, interviewees see class as a factor shaping the experience of being HIV-positive, sexually diverse or trans.

So how much has life really improved for PLHIV?

The *HIV Stigma Index Report* (Rule and Liriope 2016) is a study on the experience of HIV-related stigma and discrimination in the provinces of Western Highlands and Chimbu. Interviews with 80 PLHIV showed that 70 per cent had been assaulted in the past 12 months because of their HIV-status. More than half had not attended social gatherings during the same period because of their status. This was because they anticipated being gossiped about or otherwise made to feel uncomfortable. Almost all interviewees had been subjected to community gossip. A third had felt excluded from community religious activities. Most of the PLHIV surveyed for the report had felt isolated from family and friends at some point over the previous 12 months and nearly half had felt suicidal during this period. Almost a quarter of participants had declined to access health services, and many had refrained from seeking work or had withdrawn from training or educational opportunities. The study offers a bleak account of life for PLHIV in the Highlands.

While the vast majority of PLHIV interviewees agreed that life had improved for PLHIV, they all had stories of ongoing stigma and discrimination, and it seemed clear that the present was being made to look much better by its comparison with the earlier days of the HIV epidemic. I wondered how the contemporary experience of PLHIV might be described, other than 'improved' and determined that these 'improvements' needed to be deconstructed and interrogated further. All interviewees who commented on how much life had improved for PLHIV acknowledged that stigma and discrimination still existed. On occasions, as conversations with interviewees continued, it seemed that there was a conflation of two separate factors. While life for many interviewees had improved, this was sometimes more about their personal circumstances and their own triumph over adversity than it was about a wholesale change in community attitudes towards PLHIV.

Ruth, whose quote above is used to illustrate how much life has improved for PLHIV, also acknowledged challenges for those newly diagnosed:

> Those who are young it just depends on the parents, on the family having the information to support the young ones. Because I can imagine you are told that you are HIV-positive it can be so scary and you would even think of committing suicide.

Ruth also spoke about putting her desire to be a public advocate for HIV on hold because her family opposed the idea (both her parents and children wanted her to remain silent). This did not seem entirely compatible with her original observation that HIV was now just a manageable condition generating little public interest.

Although stigma and discrimination were said by all to have reduced, many interviewees said they still carefully controlled information about their status — it is shared with some people and not others (including others within the family). A positive diagnosis was still seen as something about which people would be likely to gossip. Again, this is consistent with a continuing prejudice against PLHIV.

In talking about stigma and discrimination, two other points were repeatedly made. First, although things have improved, stigma and discrimination remain realities for PLHIV. And second, outside of Port Moresby (POM), stigma and discrimination levels remain very high — possibly as high as at any time in the past. Finally, it is worth noting that while the vast majority of interviewees said that stigma and discrimination had reduced, several disputed this proposition. One thought it to be on the rise again, as a result of a combination of factors including reduced funding for a national response to HIV, declining national media coverage, reduced outputs from Igat Hope and a general failure on the part of the National AIDS Council and its secretariat. Concerns such as these seem to underscore the fragility of gains for PLHIV. In the absence of a properly funded and supported HIV response in PNG, what might happen for PLHIV? Several interviewees expressed a note of caution that improvements in community attitudes should not be taken for granted; progress could be reversed.

It’s all about the treatments

The experience of stigma and discrimination cannot be disconnected from ART. Interviewees agreed that ART has been one of the two greatest factors in reducing stigma and discrimination (the other being enhanced knowledge of transmission dynamics). ART changed HIV from a death sentence to a manageable illness and this reduced community fear of HIV. This in turn reduced the stigma and discrimination directed at PLHIV.

Several interviewees also talked about the negative treatment by health-care workers they had experienced (or witnessed) because of a failure to ‘comply’ with drug therapy regimens. Most interviewees spoke of the challenges involved in encouraging adherence to HIV-treatment regimens in PNG. Many reasons were proffered to explain the lack of compliance and many of these related to stigma and discrimination. Self-stigma, family and community rejection were all cited as key reasons that PLHIV do not take their treatments as required. Serah’s story of the death of a young positive woman (summarised above) concluded with the observation that it had been stigma and discrimination that killed her rather than a failure of ART. Others made similar observations.

> So you have people on ART who drop it and you have people who die in other ways and I think if we had a record of the number of friends of ours, whether they are men of diverse sexuality or transgenders, who have died from either not taking their drugs or stopping drugs or some other direct form of suicide, then I think … that number would be higher than the number of people we have actually known over the years. (Dante, stakeholder)

Other factors, such as being unemployed and poor, were also recognised as undermining adherence. Interviewees noted that adherence is facilitated by good nutrition, getting enough sleep, and living a healthy lifestyle. PLHIV who were without any income could not live healthy lifestyles. Several interviewees observed that financial insecurity brings its own set of stigmas and discrimination, further undermining adherence efforts.

> We have free supplement of ART and this is a well-done job by the government, but we have not been subsidised in terms of employment and that is one of the need areas that I always like to address in a public debate with the government … If I am given my chance, I will put my hands up to say, ‘Create some job opportunities for the PLHIV so that this job opportunity [will boost] their income to help support them to take medication on time with food and they will be happy, living happy, living positively in happy lifestyle [and this] will sustain and expand the lifespan of PLHIV in this country.’ (Juvelyn, PLHIV)

Geography, and its impact on medication in relation to stigma and discrimination, was also a factor in people’s experience of stigma and discrimination.

> Yes, for people living in Port Moresby treatment is very easy to get. Unlike people from other provinces there is still stigma and discrimination which is making and affecting them not bringing them to where they are supposed to get their medicines. (Serah, PLHIV)

> Being in Port Moresby it’s like a privilege because they have the medication around in Moresby itself. If it’s in other provinces there’s expenses involved to travel in and out of the districts. Being in Moresby is a privilege and we have many people working with different organisations that we can go to and ask for advice. (Matilda, PLHIV)

> Ah, yes. It is more easy here in Moresby. Like before two years, that I followed that I was infected for that two years I was up in [location X]. I was working up there and when I came back to the village to see my mama there are lots of people infected there. But it is hard to get the ART there and save the

> lives there, so most of them just die. Like back in the village if you are infected they will just simply say, look, we don't want the disease — they all believe this — this disease occurs from prostitutes or prostitution. (Ruth, PLHIV)

In these accounts we see the complex relationship between geography, lack of money, adherence and discrimination. There is broad agreement that the improvements experienced by PLHIV are related to community understanding that HIV is not a death sentence, because this understanding reduces discrimination. It is also clear that positive community perception depends on PLHIV looking healthy and staying healthy, and that this depends on adherence. Yet many PLHIV report barriers to adherence such as geography and financial insecurity, and the resulting inability to comply with treatment regimens undermines evolving community acceptance of HIV as a chronic but manageable condition. The links then between adherence and reducing discrimination are clear, and the fragility of the gains for PLHIV is similarly revealed. Many people in PNG will, for the foreseeable future, continue to struggle financially, and geography will continue to present challenges while transport remains prohibitively expensive and while travel brings with it security concerns. To reduce infections, some conditions will need to be established. People who may have contracted HIV will need to feel safe that in seeking testing they will not be exposed to discrimination. PLHIV will need to feel safe, able and supported to take ART. This in turn requires that ART is seen to be effective, and that factors like lack of financial means and geography do not undermine this effectiveness. The interconnectedness of all these factors is apparent.

Miriam offered a neat summary of the challenges with adherence, listing them off one by one. First, some PLHIV could not afford the bus fares to get to clinics. Second, some PLHIV, particularly in rural areas, were unable to access clinics because of the distances involved. Third, some PLHIV experienced stigma and discrimination in accessing clinic services, more commonly at the hands of fellow patients rather than doctors or nursing staff, but the impact was much the same regardless of the source. Fourth, some PLHIV feared seeing family or friends at the clinic or otherwise being outed as having HIV. A fifth common challenge to adherence was that some PLHIV had moved away from their place of diagnosis for various reasons and had not sourced a new ART provider. Finally, some PLHIV simply lacked information on how to take treatments properly. And this from Bosai (PLHIV):

> The biggest challenge — first one is people understanding about HIV and how to live with it. People's understanding of HIV and how to live with it. The next thing is people's understanding of the antiviral treatment and how to adhere to it and how to live with it. Those are the big challenges. Adherence understanding is very poor. I work at Heduru [Port Moresby's primary ART clinic] and I experience it — adherence level of people in PNG is very poor. In PNG there are plenty of issues. Accessibility of treatment is another issue — where people are staying far away. Maybe bus fare or to and fro to the

> clinic or on the way they stop and some things like that. Distance of going to and from. In PNG there are lots of other reasons. Maybe private issue of that person, personal issues of that person … or family issues, maybe, not maybe, plenty of families they don't know the importance of ART. Families not supportive. Sustainability of their livelihood, that is the big challenge where I don't know other places but Moresby, but that is the big challenge, but it contributes to not adhering to ART because in the city, most of those people who are accessing treatment they are not working and unemployed so that cause treatment default and other issues.

As this quote shows, Bosai has quite a comprehensive analysis of the factors impacting on adherence. Bosai is one of a dozen or so PLHIV employed within HIV clinics as expert patient trainers under a program operated by Igat Hope. The program locates people like Bosai in paid roles within clinical settings, bringing their intimate knowledge of treatment and adherence issues into these environments to facilitate better connection between health-care workers and patients, and better clinical outcomes for PLHIV.

A final point must be made about treatments. While there is general consensus that ART has been a 'game changer' in PNG and has converted the virus, in the public's mind, from death sentence to manageable illness, to many PLHIV the gains seem fragile. Many expressed concern that the gains may turn out to be temporary.

> Yeah, okay it's like — for me it's like every day when I get up in the morning, I used to feel a bit emotional. I used to be happy that I am still alive, that's it, to see my child, to see my family, and I used to ask, 'Why have all my friends gone and I am still alive — what is so special about me?' I believe in God and I want to take this time to thank the Heavenly Father for me to be dead long live that long. I've seen all my peers have been going down this finish, finish, finish, even though they have been on treatment … We started treatment together, all of them are gone. There is only the ones that came after me that are still on treatments. I am happy to be alive. (Elsie, PLHIV)

> I don't know. I keep thinking — I may be wrong, I don't know, it's just that I think that the virus gets smarter. We've been on ART for such a long time and I'm thinking that — I sometimes think that because we are on ART for such a long time our immune system is not as strong as it used to be. It's amazing how I see other expatriates, especially PLHIVs, they can leave and they still around and our friends still get to die and I don't know, I'm thinking that it's our ARV. I know that we are eating healthy. I'm eating healthy. Is it the food, is it the air I breathe? I also confused. I have no idea. It's just that I see myself, I am going skinnier and skinnier and I'm thinking is it the ARV is decaying my body, I don't know. It's yeah, I think it's the medication is too strong for us. Every time I walk into the [Igat Hope] office and I see [other PLHIV] I am thinking, oh my goodness, my friends are dead, like I mean you can tell just by looking at them they don't look so well and I'm thinking that maybe it's because we are on ART for such a long time, I don't know. (Ruth, PLHIV)

Wardlow (2017) found similar concerns among the HIV-positive women of her study, who had experienced stock-outs and were understandably concerned that the drug supply might be continuously interrupted. But more generally, they also worried that the drugs might just stop working, and almost all of them claimed to know of people who had been taking ART and died anyway. And I have seen this too. I know at least a dozen PLHIV who have been, at least at some stage, taking ART and who have still died. Significantly, all these people were publicly/openly taking ART, all were connected to Igat Hope and hence better linked in with HIV care services than most Papua New Guineans. All died as young adults, and all are thought/said to have died of HIV/AIDS. Whatever this means for the efficacy of treatments in PNG, it must surely shake public confidence in treatment as life preserving.

The truth is that it is complex, and complexity does not always lend itself to easy public-health messaging like, 'Take your treatment' or 'ART works'. Some of the complexity relates to the challenges all people face in sticking to treatment regimens, and some relates to the reality of treatment supply in PNG, with irregular supply and stock-outs.

Seeking redress for discrimination and other rights violations

The *HIV-Related Stigma and Discrimination and Human Rights in Papua New Guinea: A Report on the Application of the HIV Stigma Index in the Western Highlands and Chimbu Provinces* (Rule and Liriope 2016) noted that although all subjects had experienced stigma and discrimination — and often very extreme incidents — only a quarter had sought help in resolving these issues. My interviewees were asked to talk about steps they had taken, or contemplated taking, to seek redress for the many rights violations they reported. Interviewees agreed that knowing about their rights generally, or the *HAMP Act* in particular, might be one thing, but it was quite another to seek redress. 'No, they are not just confident to take it up because taking it up … would mean having to take it eventually to court and they are scared to do that.' (Matilda, PLHIV)

While there was knowledge of the *HAMP Act* in very general terms, there was a very low level of knowledge among interviewees of the details of the Act or its implementation. This was raised many times by interviewees as a real problem. The *HAMP Act* was of little use on its own because it was only one piece of the puzzle, albeit a significant one. The other missing pieces were an actual understanding of the Act and a commitment, capacity and preparedness to implement it. Several interviewees observed that despite the guarantees of protection under the *HAMP Act,* PLHIV continued to experience high levels of stigma and discrimination. Several interviewees observed that people continued to die as a result of the stigma and discrimination they experienced, despite supposedly having legislative protections.

> So having seen … the early advocacy around the need to have laws in place and all that, you know, the discrimination and stigma, some people faced daily [that led to] launching the HAMP Act which also has a section on addressing stigma and discrimination to people living with HIV, and that was a good thing because it was passed as an Act, but [we needed] to do a lot of advocacy around that and that is one of the challenges that Igat Hope is faced with, having to really push for that law to make people to use it, to understand it … I don't know where it is placed within the whole law system, whether it's hanging outside or it's within the Acts … it's a challenge to really understand that but then another challenge is really implementing it. (Alani, PLHIV)

The need for legal literacy regarding the *HAMP Act* is clear. DFAT's development of *HAMP Act* guides in accessible language (in English and Tok Pisin) was a good start, but more is needed.

Alani thought the final piece of the puzzle was around justice outcomes. PLHIV would not be prepared to take legal action unless they were confident the outcomes would properly compensate for the original offence as well as the associated trauma of taking legal action. And by 'compensation' she did not mean that the victim's family was paid, but that the victim felt in some way restored or satisfied with the outcome.

The public-health impact of being treated poorly

The role of PLHIV in HIV prevention is a huge study in itself and cannot be properly considered here. However, some basic observations seem appropriate. PLHIV are critical to preventing the spread of HIV — you can't have transmission without an HIV-positive person — and prevention efforts are weakened where they ignore PLHIV. But similarly, PLHIV are not responsible for preventing transmission. Risk of transmission often occurs in contexts where people are engaging in sexual activities by mutual consent. Obviously, this is a generalisation that does not apply to circumstances where parties do not freely and willingly consent, but the point is that in most cases HIV-negative people also have an opportunity and responsibility to prevent transmission. And yet the history of the HIV pandemic shows internationally a willingness to place the burden of responsibility to prevent transmission on PLHIV. This fits neatly with Rose's theory of responsibilisation. It is convenient to make one group of disenfranchised individuals responsible for an entire population's management of risk. For one thing, it is cheaper than having to educate and monitor an entire population, and there is an easily available censure for failure to prevent infection, that is, further exclusion from those who are 'inside'. Criminal penalties imposed on PLHIV for not managing risk (in the *HAMP Act* and internationally) can be considered in this context (see NAPWHA's 2009 monograph *Criminalisation of HIV transmission in Australia: Legality, Morality and Reality*).

Against this backdrop, Jara told a story of how trans women such as herself were impacted by all this treatment. She talked about the common experience for trans women of being refused access to services, including health and education services, and of being denied police support: ‘I mean, if I don’t get help from government services then I am nobody.’ But she went on to say:

> If they are doing that to me, fine, what have I decided to do? If I am a positive trans woman once they see that then okay, and then I go and infect my other general population. Because if you treat me in a way that is supposed to be then I would be good, but if you treat TG like that then she has other thoughts.

I do not consider this to be a confession or threat of wilful transmission. Jara was talking in more general terms, but the comment offers a useful insight into the challenge of engaging marginalised groups in public-health responses and ties back in with this oft-mentioned PNG value of reciprocity, a useful framework for understanding the rights/responsibilities nexus. Alani also shared a story in which a man with HIV had recklessly infected his partner, who had subsequently had sex with members of his family as payback. In this case the woman had not been treated poorly by the state as such — leaving aside the state’s general responsibility to afford her the means of protecting herself — but the state would still experience the impacts of her poor treatment.

The incidence of wilful or negligent transmission of HIV has been well documented in Australia and elsewhere. NAPWHA’s 2009 monograph (Cameron and Rule, eds) is a comprehensive picture of the complex phenomenon, and clearly illustrates some key points. First, the incidence of wilful transmission is extremely low, and far lower than media reports might suggest. Second, the overwhelming majority of PLHIV are committed to not passing on the virus. Alani’s story is not uncommon as a story, but it is uncommon as a fact. Third, negligent transmission cases are often very complex, and often involve questions of capacity (influence of alcohol or other drugs, mental health issues) and issues of trauma and consent. But marginalisation *is* relevant to risk. It is unreasonable for a government or polity to systematically persecute a community while expecting that same community to contribute to public-health efforts that benefit all. And that ask is even greater when the individual being persecuted has already contracted the disease, which public-health measures are seeking to prevent, but has no reasonable expectation of being able to access treatment or care services.

PLHIV interviewees were overwhelmingly committed to combatting the spread of HIV, and this has been identified through other PNG research. Wardlow (2017) found in her study of positive women in Tari that they were extraordinarily candid about their status, particularly with men who propositioned them for sex. But Jara’s story reminds us of just how significant this commitment is as a contribution to prevention. In the face of such adversity, confronting stigma and discrimination at so many turns, PLHIV continue to lead prevention efforts and to facilitate the efforts of the very governments that fail to protect them from persecution.

Alani's story is a useful window into public-health challenges. Alani went on to say that her story demonstrated the need for more and better prevention education, and for greater access to the means of prevention. In all the cases of transmission in her story, the expectation had always been that the PLHIV bore responsibility for advising of his or her status. In none of these sexual encounters, according to Alani, had either partner sought to use protection (noting again, however, that women in PNG often have limited capacity to shape sexual experience, including the use of condoms). The *HAMP Act* placed the burden of prevention squarely on PLHIV, but what was needed, said Alani, was a shared approach to prevention, with PLHIV and non-PLHIV working together to prevent transmission. This was particularly critical in an environment in which PLHIV have so much to lose by disclosing their status.

> How do positive people know their rights as well as their partners know their rights, so that they do things which is balance? You have the right to protect yourself. I have the right to protect my confidentiality so, you know, it's everyone's right to protect themselves. (Alani, PLHIV)

Alani was really making the point that it is unfair to place the prevention burden fully on PLHIV. It is both a right and a responsibility to prevent transmission. For Alani and other interviewees, disclosure carried clear risk of rights violations (including violence) and needed to be balanced with other factors. While Alani recognised the shared nature of the responsibility to prevent transmission, she was not confident all her peers recognised this. She saw many cases of people with HIV just not caring enough about prevention. Despite the legal prohibitions on negligent transmission, people were not taking prevention seriously enough and she was seeing new infections every month as a consequence.

Part Two. Experiences of MDS and Trans Women

This section explores the lived experiences of MDS and trans women. Having been asked about their understanding of human rights, interviewees were then asked if they thought their rights were respected in PNG. If they thought their rights were not respected, they were asked to share stories of these experiences. Interviewees were asked why it was that they thought their rights were not respected.

As with HIV-positive interviewees, MDS and trans-women interviewees often spoke in terms of stigma and discrimination. Sometimes interviewees talked specifically about their human rights being violated, or just talked about treatment they considered unfair.

Are the human rights of MDS and trans women respected?

> The general perspective in PNG, some people are so bloody mean about this, I mean they are so mean about MDS and trans women in PNG because of the way they perceive these people to be, without really understanding them. (Lionel, MDS)

When asked whether they felt their rights were respected in PNG, the vast majority of MDS/trans-women interviewees said that their rights were routinely violated. They often went on to explain the frequency of these violations, or the breadth and depth of community discrimination, giving an overall picture of widespread and frequent abuse of their rights. Therese, a trans woman, said she thought her rights were respected by perhaps 3 or 4 per cent of the population, and that she was subjected to name calling (or worse) every day: ‘Oh no, no, it’s every day in life. Yes, it’s an everyday life thing. It’s not on a weekly basis, it’s not on a monthly basis. It happens every day and I bet you all the TG are going through the same thing.’

Very occasionally an interviewee might answer something like, ‘yes and no’, but upon further discussion it became clear that these interviewees had experienced extensive discrimination. No interviewee thought that his or her rights were mostly respected, and every interviewee had a story (and most had many stories) of the ways in which their rights were not respected.

The right to ‘be yourself’ and what this means for trans women

Many trans-women interviewees talked about their right to ‘be themselves’, a kind of identity right. By this they meant being able to dress as they wanted, to present themselves freely as women without fear or inhibition. Many of the trans women I interviewed spoke of the burden they experienced in having to constrain their true identities and to live a lie on a daily basis.

> OK, as a transgender person in my own point of view is I want to be just me, an ordinary normal person, just like any other person, and to be treated equally amongst the rest of the people that are around me, especially in my community, and in the country as a whole. I just want me to be treated fairly and equally as who I am regardless of my identity, and I am proud to be a transgender person. (Therese, trans woman)

> We look for a safer, more conducive environment where we come together, where we feel free to express ourselves … Every time it is like putting on an act. We are always putting on an act to show that we are straight but in reality it is very hard to put on an act for the rest of your life. It’s so hard in PNG. (MaryAnne, trans woman)

These kinds of observations were very common among trans interviewees, who emphasised that the right to be themselves, to act naturally, involved being able to do so without fear of violence. As such this right to ‘be yourself’ was intimately connected to questions of safety, which in turn shaped all decisions about where trans women could and could not move freely in public or travel.

Most MDS talked about hiding their identity, as did many trans women. Some trans women hid or modified their identity as best they could. ‘When I am out in the public area, especially in the city, I have to be very, very cautious about my appearance to the general population. I have to carry out myself well to gain respect’ (Therese, trans woman). But many trans women were unable to hide their identity — they could not act sufficiently ‘masculine’ to pass as straight men, even if they had wanted to (and some did). Trans women and MDS understood that this made them different and agreed that this was why their community movement was disproportionately comprised of, and led by, trans women rather than MDS. Trans women could not, as a general rule, hide their identity, so disclosure of their transgender status (and oftentimes by default their sexuality) was less of a choice. By contrast, those MDS who could pass themselves off as heterosexual would in many cases choose to do so. Many trans-women interviewees spoke of their pride in being trans women, whereas MDS tended not to speak of being proud of their sexuality.

The ‘special nature’ of trans women was often discussed as a factor that might ultimately contribute to acceptance, in a way that being an MDS or a PLHIV would not. Interviewees had different takes on this, but Lionel was typical of most MDS (and some trans women) when he said that because trans women were ‘kind of like women’, and because there was a place for women in traditional PNG society, there was a kind of place for trans women (although he acknowledged that trans women would be considered as less than a ‘normal’ woman). By contrast, Lionel said, there was no place for a homosexual man. He drew a distinction between homosexual practice, which he believed had always been a part of PNG culture, and homosexual identity. Being gay challenged male culture in a way that placed such men in a very dangerous position, he said. Lionel thought there had been historically no place for such men in PNG society, and building a space for them in contemporary society was an enormous challenge. The special nature of trans women is picked up again later in this section, but it is important to note here that while Lionel’s view reflected the views of other MDS, most trans women had a different take. They described the special nature of trans women not so much in terms of being ‘like women’, but more as being uniquely trans women.

In the introduction to the edited volume, *Gender on the Edge*, Kalissa Alexeyeff and Niko Besnier (2014:2) explore the nature of non-heteronormativity in the Pacific Islands by beginning with some overarching observations on sexuality and gender.

> Non-normative Pacific Islanders are at once part and parcel of their societies and subversive of the social order. They are deeply enmeshed with what many think of as ‘tradition,’ but they are also the heralds of the new, the experimental, and the exogenous. Suspended between the visible and the invisible, the local and the global, the past and the future, and what is acceptable and what is not,

> they call for a rethinking of morality, what 'acceptance' (or 'tolerance') means, and the very relationship between agents and structures. They bring new ways of being in and thinking about the world, to the delight of some and the indignation of others. Their very existence embodies the contradictions of the contemporary social order.

Working with Igat Hope and Kapul Champions over the years, I have wondered at the ways in which seemingly incompatible views might be reconciled for trans women and their communities. Many trans women spoke of their historical place in Papua New Guinean community life, yet I have heard many people bemoan transgenderism in PNG as a symptom of western cultural influence. Trans women argued for, indeed were causing, social change, yet wanted keenly to be part of the communities seemingly intent on resisting that change. Like Besnier and Alexeyeff, I wonder how these contradictions might be reconciled across the Pacific, noting that Pacific Islanders express deep hostility toward non-mainstream sexualities, yet non-heteronormative people are so visible and established in many Pacific Island societies. Like me, Alexeyeff and Besnier wonder how rejection and acceptance can seemingly co-exist? Alexeyeff and Besnier question any notion that these contradictions might simply be explained away as the result of a rigid Christianity imposed upon 'traditionally' permissive societies, observing that, across the Pacific, Christianity is often so intricately intertwined with the social and cultural structure of community life that it *is* tradition. I found this a helpful analysis as I, too, have often wondered about the use of the word 'traditional' in my work and have been confounded by people both speaking of practices before Christianity as 'traditional', while speaking of 'traditional values' as almost always incorporating Christian beliefs.

Alexeyeff and Besnier draw a distinction between the way contemporary western ideologies seem to view sexual identity as being a property of persons, while Pacific cultures see them shaped by families and communities.

> Sexuality [in western cultures] is an issue of 'being' and only incidentally an issue of relatedness to others. One *is* male or female, and consequently one *is* a man or a woman and performs these identities socially. Gender performance is thus merely an index of one's essence. Yet, as anthropologists have amply demonstrated, this theory of sexuality is far from universal … In many other societies, sex and gender are much more squarely matters of interpersonal relationships, of dispositions that enable and restrict social action … persons whose subjectivity is at odds with their sexual status emerge as a sociological puzzle rather than a psychological problem, and the mismatch tends to be managed by reassigning the person to a different social category. (2014:5)

On the way that families shape sexuality and gender, Alexeyeff and Besnier make an interesting observation about several of the chapters in their volume: 'Thus it is not surprising that many chapters in this book … foreground the importance of family relations (including fictive families), friendships, and other forms of relatedness to understanding nonheteronormative identifications in Pacific Island societies' (2014:5). This reference to fictive families emerged often in my research — the idea that constructed families are legitimate families — and I will return to it in the section below on finding a new community following expulsion from an old one.

Safety and freedom of movement — 'a prisoner in my own country'

All MDS and trans-women interviewees talked about safety. Many said that they felt safe within their own community, but that outside of this community they were at serious risk of abuse and violence. All interviewees base decisions about where they go and how they travel with reference to these risks — marketplaces, bus stops and public buses (PMVs) were considered high risk. Trans interviewees named freedom of movement as the most commonly violated right. It is interesting that this is described in terms of the right to freedom of movement rather than, say, a right to feel safe or to be free from violence.

> The other thing is freedom of movement. In PNG TG people, we don't have freedom of movement, not in public places, even in schools … or on buses even in anywhere we go there is stigma and discrimination there. People look at us and laugh at us, call names. There is no law there to protect us, you know. So, you know, this is like, I feel like I am a prisoner in my own country. (Kiteni, trans woman).
>
> My community accepts me for who I am and if I happen to come into the city and the general population, the attitudes [of] the general population is so different where they don't really accept people like us. Some do, but the majority don't, so like in terms of my rights being respected in the general population in PNG, my rights are not respected. I am not respected at all. (Therese, trans woman)
>
> OK, for my opinion I would like to say TG are mostly treated in a bad way … They will do all sorts of violence to you, even they going to take out a knife and, you know, threaten you, that's how. They never treat TG properly. But as for me in community, they do understand who we are in the community but if we are to go out into the public they really [treat] us badly. (MaryAnne, trans woman)
>
> We face a lot of violence and that means including gender-based violence, family violence, community violence. It's all to do with our identity, our femininity. (Natasha, trans woman)

All interviewees talked about having experienced verbal abuse, threats and violence connected with their sexuality or transgender status. Many talked of this experience as commonplace. Many reported sexual violence, and many had been raped.

> It's like when they look at me like a TG person just appearing in front of them they are just looking at a monster … and I am just like an object when it's kind of like … I am kind of like a problem to them. It's like a TG person is kind of like taking the peace away from them, so they quickly react by saying names, they are already tagging me, labelling me. (Therese, trans woman)

> A lot of us in this country really have a lot of stigma because of shame, lots of violence against the TGs. Many of my good friends have been raped and been the victims of HIV and have passed away. (Marta, trans woman)

Jonah, a trans woman, told a story of multiple assaults and robberies. She felt that trans women were considered 'fair game', unlikely to be able to fight back or protect themselves. She talked about having been threatened with a knife multiple times. She had been bashed. She had been robbed at least twice, knifed at a market and raped. She had never been to the police; her fear of police being greater than her expectation of police assistance. Jonah's story positioned her experience of violence within 'normal' community life. The assaults listed in the preceding paragraph were all connected with her status as a trans woman, but she also reported a life of family violence disconnected from her status. Her father had beaten her mother, her family had been mistreated by relatives and others in the community, and she had experienced much ill-treatment based on factors other than her trans status, notably gender and power imbalances. She went on to note that many perpetrators of violence against her were members of her own community, mostly youth — whom she described as 'good boys' — who became aggressive when under the influence of alcohol. At different times Jonah was both the victim of these boys and their sexual-health counsellor. She regularly distributed condoms to these same boys, talking to them about the risks of HIV infection.

Another MDS interviewee echoed this culture of violence in his own story. As a policeman, Justin had routinely beaten-up sex workers, he said. He had since come to understand that sex workers are just like everybody else and is now an advocate for their rights. Now, he said, when he hears people speak poorly of sex workers he 'bashes up' those people rather than the sex workers. This is an unhelpful response to the problem Justin now recognises as another example of the police brutality of which so many interviewees complained, and of the acceptability of violence as a means of punishment.

Interviewees felt keenly the limitations on their movement. They could not use some bus stops because they were too dangerous. Chris, a trans woman, said she routinely caught buses in the wrong direction because they would take her to a safer bus stop from whence she could get another PMV (albeit a less direct one) towards home. Chris talked about a literal comfort zone:

> In my community I feel, you know, it is just normal, I can go anywhere I want, I can do anything I want, but, you know, then when I am out of that community — when I am in cities there are some

> choices I have to make. Whether to go to that particular market or to that particular bus stop or shopping mall or even [if] there are risks involved. And I hear about them. Some of my peers get basically abused or bodily abused so those are some of the places like it's high risk for me to go so I don't go in them. So this is some of the things so when I step out of the comfort zone I make choices, you know, because of the risks involved you know, yeah.

Stories about the places and situations where MDS and trans women feel unsafe sometimes led to stories about the safe places that they had found, and in some cases built. Safe places might be geographically distinct, like a home or a village, or a social unit such as a family or other group.

Exclusion from community, but finding community elsewhere

As many of the preceding quotes indicate, trans interviewees often drew distinctions between feeling safe 'in community' and unsafe as soon as they stepped outside these communities. All trans-women interviewees talked about the risks they faced as soon as they moved outside their safety zone, whatever that zone might look like. Many said that their family had come to accept them over time, but others talked about having built a family or community with other trans women. Jasmine, for example, described her community as a group of unrelated trans women with whom she now lived:

> I am part of them because I face these types of issues concerning my life and I face discrimination, neglected by my family and I have nowhere to stay, so I've been accommodated right there, given benefits, freedom to express my life, and I feel accommodated and I wash and get up and move like a human being at the end of the day.

Several other interviewees had also formed their own communities with their friends and peers, and most interviewees had observed this being done by other trans women. These immediate communities might comprise *wantoks,* family members, sexual partners or close friends. These communities were critical to the emotional security of members and provided physical security as well.

Dante, a community worker with vast experience with MDS and trans women in PNG, suggested that trans women who grew up within a family that enjoyed a level of status within the community might enjoy a level of acceptance within that community, but this would depend on the family supporting him/her first. Most interviewees agreed that community acceptance of trans women could never be assumed and, in fact, community rejection was the norm. Instead, trans women had to reconceptualise community, using immediate family (where possible) and other trans women as the building blocks for a different kind of community. This community formed a protective barrier against the rejection and violence beyond.

Police violence

The police force was the state service most complained of by interviewees. Interviewees overwhelmingly did not trust the police to protect them. Many had been harassed, assaulted or sexually assaulted by police in connection with their sexuality/transgender status. There was no confidence among interviewees that the police would apply the law to protect them. Some interviewees had stories of having tried to get the police to assist them but to no avail. Many said that they would not bother going to the police for assistance.

> Yeah, well, in fact we all know that there is law there, there is police there, but again if I go to the police, the police won't really take my case seriously, they will intend to try to, you know, take me to a room and interview me, but not really, you get my statements very seriously but then they will try to, you know, abuse me in the room. So that's one thing that I get afraid of when I go to the police. I don't go to the police to report my case when I have been punched by someone else in the street. (Marta, trans woman)
>
> Ohhhh so many times, even though the both of us you are interviewing here now, we are victims of abuse by police … It is always common for TGs and MDS as well — brutality by police, security guards, any uniform person. (Natasha, trans woman)
>
> If we do crime and they took us to the police station and they held one of us they don't treat us properly. Sometimes they rape us, they don't treat us properly. It's my experience, I have been raped by the policeman at [X] police station. (Dau, trans woman)

Marta told a story of her two interactions with police. On both occasions she had been assaulted. On the first occasion she had been on her way home from performing at a local club's regular drag night, where she had been feted by the largely heterosexual audience. Despite possessing some 'status' locally as a well-known performer, or perhaps because of it, she was stopped and brutalised by police. On the second occasion she had been forced to provide oral sex for three officers.

In his extensive experience as a community development worker, Dante had worked often with police and argued that the police force included good and bad elements. Dante noted that significant work had been done with the force and that the force now boasted some outspoken champions of MDS and trans women.[2] Despite these occasional champions, Dante thought police

---

[2] The Poro Sapot Project of Save the Children in PNG conducted an innovative education program with officers from the Boroko Police Station, seeking to build greater understanding among officers of Poro Sapot's MDS and transgender clients. The work had been operating for several years by the time I conducted my interviews. Anecdotally, this project is considered to have achieved some important successes in building understanding and changing the attitudes of at least some station personnel. The initiative was discussed favourably at the MDS/trans women report-back in April 2016 (detailed in Chapter 2's Methodology section). This work was

culture was still sufficiently accommodating of homophobia and transphobia to enable individuals with negative views of MDS or trans women to use their authority to persecute members of these communities. Dante reported that this persecution had included repeated instances of sexual assault.

Dau had had a positive experience with local police. Upon being arrested Dau was full of (reasonably held) fear at the idea of being held, as a trans woman, in the men's cells. Instead she had been permitted by the local police to stay in the women's cells. While this was a welcome development, Dau also believed she had been arrested for no real purpose and she had previously had very negative experiences with police. On balance, her view of the police remained negative. Veronica held a similarly negative view of police and said it was commonplace for police to request sexual services before providing assistance to trans women.

At the April 2016 community report-back, there was some spirited discussion of police attitudes towards MDS and trans women. Some participants were very keen to point out that there has been some progress with the police force. The work that Save the Children has done with police was acknowledged, as was the role of some police in championing the rights of MDS and trans women. But there was also agreement that much more work needs to be done and there was no suggestion that the stories of police brutality, which formed part of my report-back, were exaggerated.

Angela Kelly-Hanku and others (2015) explore the treatment of Papua New Guineans in custodial settings and endorse observations by other researchers and writers (Luker and Dinnen 2010) that PNG has two entwined epidemics — serious law and order issues and widespread HIV. Kelly-Hanku and others (2015) document the experiences of Papua New Guineans in correctional settings, including police holding cells, and write:

> It was widely reported that police cells are both social and geographical spaces that place women (more than men) at risk of non-consensual sex by police personnel, the frequency of which is not possible to estimate as cases are rarely, if ever, reported. A senior officer suggested that in the case of juvenile boys being raped or sexually assaulted, it would be unlikely for them to report the crime, especially as many are repeat offenders thus returning frequently to the holding cells. The rape of female detainees has been reported in a number of locations but everyone agreed that most go unreported as the risk to women who report can be severe and usually they are treated poorly and not afforded a fair hearing. One woman disclosed that while in police custody she had been repeatedly raped. (992)

---

conducted as part of Save the Children's national work with police and gatekeepers. See Save the Children (2017).

Stewart (2014) details at length police mistreatment and abuse of sex workers and homosexual men in her volume on the criminalisation of sex work in PNG. In her 2010 report of the infamous police raid on the Three-Mile Guest House, which involved mass arrests and abuse of women (some of whom were sex workers), Stewart considers what remedies may have been available at law for these women and concludes that, given the history of the persecution of sex workers by the police in recent years, it is unlikely that such action would have serious repercussions for those involved. Stewart writes that while complaints of police mistreatment of prostitutes (her language) have on occasion been successful in the past, the chances that a group of alleged prostitutes might bring a successful complaint against the police are poor (2010:279).

While the police service was the most criticised government service, it was not the only setting in which MDS and trans interviewees had experienced discrimination.

Barriers to education

Interviewees commonly spoke of their right to education and told stories of how their educational opportunities had been curtailed. Mostly this was because they had been harassed, assaulted and, in some cases, sexually assaulted at school by both students and teachers. Some said their parents or families had withdrawn them from school when their sexuality or transgender status became apparent or a problem (which was usually the same time). Most trans women interviewed said they had experienced discrimination in relation to their education, and many recognised that this had negatively impacted on most other aspects of their lives.

> We don’t get better treatment when being seen as trans women and MDS, we don’t. Sometimes it will really affect our education even though we are very bright and we know that it is our goal to be a teacher, we want to be a doctor, we want to be a lawyer, but because of, you know, not accepted within the community, being rejected from the family and loved ones, these are some of the factors that make us, you know, we don’t have free access to those things and sometimes a lot of my friends, you know, get scared and being bullied at school at a younger age. That is how most of my friends dropped out from school, it’s because of this. (MaryAnne, trans woman)

> Most of them are still nothing in the families and they have never been of any, you know … more priority to the real men to get an education than compared to TGs. You will see they tend to do sex work and then eventually get infected with HIV and then most of them die and all this. (Kiteni, trans woman)

In making this observation, Kiteni touched on a complex issue that was raised frequently. Many trans-women interviewees had engaged in sex work, and many of these drew a connection between this and their reduced opportunities in education and employment. Having been denied educational opportunities by virtue of their transgender status, their employment options were subsequently much reduced. This meant that, for many trans interviewees, sex work was the only means of survival. Most trans interviewees were keen not to be disrespectful towards sex workers or to denigrate the practice of sex work, but they tended not to speak of sex work as a desirable profession. It was invariably described as an industry into which interviewees were forced by lack of alternatives. The lack of alternatives was very often blamed on discrimination in education.

Health care generally and HIV treatments in particular

Interviewees also complained of discrimination in health care, although these were less common than complaints about education. Health care-related complaints included discriminatory attitudes being expressed by nursing staff, discriminatory treatment by other patients that in some cases forced MDS and trans women to give up seeking treatment, and at least one count of being given the wrong medications allegedly because the patient was a trans woman. ‘Especially the hospital, sometimes the nurses or the sisters, like they don't want to treat us in a good way … they usually tell somebody to come in and serve us rather than them’ (Natasha, trans woman).

Jara, a trans woman living with HIV spoke at length of her own experience in accessing ART. She said that when she attended the (government) clinic she was treated poorly, and she had no doubt that this treatment was based on her being transgender. She had been made to wait longer than other patients and had then been given the wrong treatments. She knew this, she said, because the treatments given to her had different names to the ones listed in her treatments book. Jara believed this treatment was typical of the way trans women were treated. Jara complained that she had been berated by clinic staff for failing to take ART as required (arriving a few days late to pick up her next supply of treatments), and thus touched on the complex issue of compliance.

Several interviewees complained of judgemental attitudes on the part of health-care workers, and some did so in relation to judgements around compliance with ART regimens. This is, of course, a multi-layered matter and was considered in some detail in the preceding section on the rights and responsibilities of PLHIV. Threading interviewees’ stories together it seems that some trans women are struggling with their treatments because of a lack of information about how these treatments should be taken. Specifically, some trans women do not understand the need to take ART every day without fail. Responsibility for this lack of understanding lies with health-care providers who have failed in many cases to adequately explain the importance of adherence. Some interviewees said that these failings on the part of health-care workers were grounded in discriminatory attitudes towards trans women. But trans women also talked about the failings of some of their peers in relation to ‘lifestyle’, whereby partying (notably alcohol consumption) had reduced compliance with ART regimens. In these cases, clinical staff may have felt an understandable degree of frustration with patients, and their failure to properly manage this frustration might be similarly understandable. Yet not all negative attitudes on the part of clinicians could be attributed to frustration with the poor health decisions of their patients. Some were likely to be the result of discriminatory attitudes towards MDS and trans women, including attitudes in relation to their actual or inferred 'lifestyles', thought to involve alcohol and partying, multiple sexual partners, engagement in sex work or sex for favours.

In a group interview of three trans women, Dau, Veronica and Elizabeth agreed that while trans women were subjected to discrimination in clinical settings, this was far more likely to be caused by fellow patients rather than doctors and nurses.

> One thing about doctor and nurse — we don't face discrimination from them; it's only the client … Some of these TG passed away because of the stigma and discrimination in hospital — not the doctors and nurses but the clients when we are trying to access the services. (Dau)

The number of health-care complaints would no doubt have been much greater had it not been for the fact that many interviewees were actually accessing health-care services from a very small number of clinics that were sensitised to the needs of MDS and trans women. Dante, a stakeholder whom I consulted towards the end of my research and who has an excellent understanding of my interviewee profile, thought it likely that most interviewees would be receiving care via Save the Children's Poro Sapot clinic, and thus were being cared for by the most sensitised clinic in PNG. Indeed, of the MDS and trans women who talked about their health-service providers, most were in fact using the Poro Sapot clinic or a similarly sensitised service. But Dante also said it was likely that when accessing other health services interviewees were not disclosing their sexuality or transgender status wherever it could be avoided. Indeed, Dante said, they were very likely to be trying very hard to hide it. This then did not mean that services were not homophobic — by and large they were, he thought — just that clients were doing a good job of hiding their identities. The pressure to do this was itself a form of discrimination, Dante thought, although he suggested interviewees might not recognise it as such. If indeed interviewees did not recognise it, I wondered if this might be an example of self-stigma. But ultimately, while I appreciate Dante's point, I suspect many interviewees did recognise this as a kind of discrimination, particularly given their preparedness to describe 'being themselves' as a human-rights issue.

Formal employment

> At work too sometimes, those of my friends, they get bullied at work, and even they get sexually harassed at work sometimes. (MaryAnne, trans woman)

Few trans women interviewed were engaged in formal employment. As with their PLHIV counterparts it is likely that many trans-women interviewees declined to seek work in circumstances where rejection was anticipated. Several trans interviewees worked in the HIV sector. As such they enjoyed a more respectful attitude towards trans women than could be expected in most PNG workplaces. MDS interviewees did not report specific instances of workplace discrimination.

Why are rights respected or not respected?

Interviewees spoke at length about the reasons they thought their rights were not respected. Whereas PLHIV were likely to attribute their unfair treatment to fear of transmission, misunderstanding of the virus and/or the shame associated with sexually transmitted infections, MDS and trans women spoke of a different set of factors. Most commonly, interviewees said their rights were not respected because they were seen as undermining or disrespecting ‘culture’, but within this general observation interviewees canvassed a number of distinct factors. The following section deals with three issues that were raised in relation to culture: the existence (or not) of homosexuality and transgender identity in pre-colonial Papua New Guinean community life; the role of Christianity in shaping views of MDS and trans women; and regional cultural differences.

History and culture

Interviewees had a range of views on why they were so badly treated by their fellow citizens. A common theme was that the general population did not understand them. They were considered suspicious and shunned, so there were limited opportunities to build friendships and understanding between trans women and others. Interviewees said that the general population saw them as ‘going against culture’, indeed this specific phrase was used by several different interviewees. Natasha, a trans woman, framed it as follows:

> I think one thing that is being aparting us is because of the culture and tradition and the response from the general public about our identity … the belief of the tradition and culture is being valued more, you know, seeing people like this [transgender], it’s against the tradition and the customs in our culture in the Melanesian culture … so I think the main thing that the general public are looking at is, they are standing on two main things, the culture and the tradition.

Natasha saw the contravention of culture as involving a challenge to the biological definitions of male and female:

> We came out in the picture of male, you know, and then we are trapped in the women’s whatever and then, like, why some of the men usually get mad with us, we are spoiling the image of a man. That’s what I’m thinking of, you know, that some of them initially think — sometimes I heard from men calling to me, spoiling this image is not good, you know.

However, some interviewees rejected this notion that being a trans woman was to go against culture. Quite a few saw PNG culture and history as inclusive of MDS and trans women:

> MDS and trans women have always existed in PNG. They have always been included in every aspect of our society. I don't care how many other anthropologists or historians [have] come and done research, I believe we have always existed … people in our villages all over PNG they have always known that there are homosexuals, and they take them on, and they just leave them just like that. (Thomas, MDS)

This issue of the degree to which MDS and trans women had been a part of PNG society before colonisation engaged many interviewees. Herdt (2003, 2009, 2011) has written extensively over decades about the practices of the Sambia men of PNG. His research reveals that traditional initiation rites involved homosocial elements, including oral insemination of maturing boys by older men, over multiple stages as boys matured into men. These ritualised practices were considered necessary to prepare boys for warfare, marriage and reproduction. I have, over the years, seen and heard this referred to as evidence of a traditional practice of homosexuality, but Herdt is careful to describe it in great detail and with extensive context. He documents the secrecy surrounding the practices and observes how the practice bonds men together through an affirmation of masculinity and simultaneous rejection of the maternal bond. Herdt describes this as a kind of ritual secrecy: 'a high form of utopian male culture that produced sexual hierarchy and exaggerated gender differences … they created a language of desire and transgression hidden from the public' (2011:260). This implementation of ritual secrecy created a sexual objectification of the male body. Herdt observes that this male objectification took the form of ritual homosexuality or boy insemination for the Sambia and their Anga neighbours, but that elsewhere in Melanesia it resulted in other forms of homosociality that were not explicitly homoerotic. Herdt references work by Maurice Godelier (1986) who, in reporting on his research into the neighbouring Baruya, observed that the idealised and preferred sexual object of beauty and attraction in many Melanesian cultures is not the female but the male. Not only is the male the most sexy and ornamented person, but also to desire him is normal and natural — for both genders.

Herdt writes of the

> deeply avoidant tendency in the heterosexist and masculinist positionality of white male ethnographers to feel uncomfortable with these male Melanesian secrets. They were uncomfortable with male intimacy and homosociality in general and might have avoided anything that smacked of homoerotic events or settings. (2011:269, referencing views he expressed initially in Herdt 2003:230–31)

Herdt concludes: ‘Sexuality continues to test society, and probably always will, because it contains the possibility of the greatest liberation and the greatest oppression for the individual in the social contract that is culture’ (2011:270).

Reflecting on Herdt’s work, Bruce Knauft (2003) writes of the ritualised homosexuality or boy insemination of the Gebusi, in PNG’s Western Province. He writes of a same-sex sexual practice (he uses ‘MSM’) with young men aged 16–20 being inseminated by older men, but observes that these young men also engaged sexually with each other in the months leading up to their insemination. The practice was not hidden, but it also seemed not to be compulsory in order for boys to become men. Knauft describes it as a ‘relatively flexible, open, and light-hearted complement to generalizations that indigenous MSM in Melanesia was anxiously secret from women, hedged with powerful proscriptions and taboos, associated with traumatic if not brutal initiation … and divided generationally’ (2003:141). Knauft observes a diversity of MSM practice and experience, affirming his observation (Knauft 1993) that, ‘the south coast of New Guinea in particular exemplifies a diverse and overlapping range of heterosexualities, homosexualities and bisexualities’ (1993:58). Knauft writes of the rapid change experienced by the Gebusi in the 16 years between his original documenting of MSM practices and his 2003 reflections, including greater absorption into Christian fellowships, access to state-funded education and involvement in modern trade and commerce. He observes the disappearance of MSM practices and attributes this more to a desire for modernity than a moral crusade: ‘Older flexibilities of sexual orientation can easily seem old fashioned or backward against the heteronormativity of a modern present’ (2003:151). But not only have the MSM practices ended, but memory of them has also disappeared. (How much harder, then, for MDS in PNG as they grapple with questions of their historical place within PNG community?)

Jenkins (1996) writes that traditional peoples of PNG did not have specific terms to designate one type of sexual orientation as opposed to another, although a term to cover altered gender identity can be found in a few of the nation’s more than 800 languages. Jenkins observes that sexual identity is not, in PNG, so much a contested issue. In general, sexuality is configured in such a way as to leave great flexibility in desire and its manifestations, at least for men. Jenkins writes:

> Specified and delineated sexual categories have little relevance to the real essences of sex as experienced and thought about by Papua New Guineans … These real essences are social, erotic, emotional, moral and ethical and, perhaps for some, magical. The actual sexual act is often of secondary significance and the gender of the participants may not play the critical role it does in many other sexual cultures, certainly not a critical role in the attribution of sexual identities. (192)

Jenkins writes that the embarrassment and shame concerning homosexual desires that are so much a part of contemporary narratives were definitely not present in many pre-Christian New Guinea traditions. Her research indicated, however, that where sexual customs offended the Europeans, they could be 'suppressed into deep hiding very quickly' (1996:193, referencing work done by Parkinson 1907). Jenkins writes that lots of factors have contributed to the current place in which homosexual desire finds itself located in PNG: Christian missionaries, the colonial state, the emerging cash economy, fundamentalist charismatic Christian sects, HIV, HIV researchers and pornography. It is a big list, and it includes the abuse of white colonial power to sexually exploit both men and women. 'Homosexuality' in this sense has been perceived as a western abuse of power.

In considering the research on ritual homosexuality, Jenkins concluded that homosexual rituals were in fact practised by only a small proportion of Papua New Guineans, far fewer groups than implied by the more sensational claims that there is evidence of ritualised homosexuality in 10–20 per cent of all Melanesian cultures; claims Jenkins attributes to Herdt (1984). Jenkins observes that these ritualised practices are almost totally non-existent now, but that they remain important: in some areas where homosexual rituals once existed, non-ritual homosexual relations were also important (Ernst 1991). She recalls her own research findings (Jenkins 1994) that young male sex workers in Port Moresby are often from Papuan coastal societies which had ritualised homosexuality or whose neighbours did. As I have noted earlier, these stories of ritualised homosexuality remain important to MDS and trans women in the modern age. Many of my interviewees found these stories affirming and legitimising, while acknowledging the range of views about prevalence of these practices.

Jenkins (1996) writes about the kinds of bisexuality she observed around her in PNG: men who purchase sex from male and female sex workers, men who enjoy sex simultaneously with a woman and another man, and the patron-lover relationship where the older, wealthier man (often white) might engage in a long-term relationship with a younger man who may marry during the course of it, all the while continuing to give and receive sexual pleasure while receiving money and other support. She also writes about the practice in PNG of men having sexual intercourse with a woman in the presence of other men, leaving the possibility open for homosexual intercourse to take place at the same time. Jenkins's work is about the conduct of homosexual sex, as distinct from homosexuality. She observes that these sex acts do not indicate homosexual identity and that, while they may involve homoerotic elements they may take place within a heterosexual framework.

It is also hard to assess the extent to which my interviewees would be aware of any of the research referred to in the paragraphs above. I regret I did not ask interviewees more questions about their sense of the history of homosexual or homosocial behaviour in PNG. But it is certainly true that the issue was raised by quite a few interviewees who asserted that PNG did indeed have a long history and tradition of sexual interactions between men. Several interviewees cautioned against generalising about the history of homosexuality and transgenderism in PNG, arguing that PNG is an incredibly diverse country and what had been acceptable in some parts of the country may have been taboo in others.

> I think for me, looking back, I mean in my time growing up being a TG person, I think … most of my community base a problem on culture and customs, that is the most important thing because not all of PNG, I mean respective provinces, have their own culture, some they accept TG people, some they don’t … Certain culture in the country, for instance the Papuan Region, they do have a lot of respect on TG and MDS people … but as for New Guinea Highlanders it’s a big no and it’s a bit taboo. So, most of my friends, TG and MDS, they are still in their hidden clothes, if I may say, they don’t really come out. (Natasha, trans woman)

At the April 2016 community report-back, the topic of an historical place for MDS and TG generated energetic debate, with people expressing quite contradictory views. On balance most seemed to think that there was some historical place for homosexual behaviour (if not homosexuals) and trans women. But there was general agreement that many people in PNG would resist the idea that traditional, pre-colonial society had in any way accommodated homosexual or transgender behaviour. This would presumably, at least in part, involve resistance to western definitions of homosexuality and transgenderism. Participants agreed that these community conversations would need to be approached very carefully. There was not agreement with the proposition that acceptance of MDS/trans women would be promoted by pointing to an historical community role for MDS and trans women.

I was really struck at this event by the richness and energy of the conversation. There were strong and divergent views, and many, many people seemed to have one on this issue. But it seemed also to me to be conducted very respectfully and with great regard for the sensibilities of other Papua New Guineans. It also involved very considered reflections on the way the issue might impact on the welfare of the broader MDS/trans community, particularly in the way it might offend the broader population and result in heightened discrimination. I was again reminded of the value in creating safe spaces that enable communities to explore these issues and, to be honest, a little regretful that, over the years of assistance to Kapul Champions, my colleagues and I had not found a way to better enable the community to have this conversation. Regardless of whether or not people thought that MDS and trans women formed part of traditional PNG community, there was agreement that much discrimination was perpetrated against MDS and trans women on the basis that homosexuality and transgenderism were ‘against custom’. Interviewees thought this idea would need to be carefully managed in any MDS/trans-women advocacy.

Perhaps we can borrow one last insight from Herdt (2009), who writes about moral panics and sexual rights. Given the frequency with which my interviewees raised issues of morality, and the focus of my work on rights, it is worth noting Herdt's thinking on these matters. Herdt talks about sexual panic as a form of moral panic, where populations can become totally overwhelmed by conversations about sexual threats and fears. The sexual 'other' is stripped of rights and the majority cultural imagination becomes obsessed with the damage this 'other' might do to 'normal' society. Sometimes the marshalling of intense emotions (like panic) across diffuse groups can result in widespread scapegoating of a sexual group, which Herdt describes as a kind of cultural anger. Many of my interviewees told stories of how their communities perceived them as threats, and I have heard these claims made in PNG media and other contexts as well. It is always confounding when a majority culture expresses fear of minority groups, all the while exercising its almost absolute power to oppress the group by which it is threatened. Several of my interviewees reflected on the irony of it all — they themselves felt very limited power in the face of those claiming to be threatened. But like all forms of panic, sexual panic (or cultural panic) undermines logic.

The influence of Christianity

Many have observed the way that Christianity shapes the understanding of HIV in PNG, and the experience of being HIV-positive. Wardlow (2018) notes that HIV in PNG has long been associated with ideas of immorality, particularly sexual immorality, leading to it being considered as a kind of divine punishment for sexual sin (citing Eves 2008; Hammar 2008; Kelly-Hanku, Aggleton and Shih 2014; Wardlow 2008). Wardlow observes that despite public-health campaigns that have tried to normalise HIV, it remains an exceptional illness, with a moral dimension that sets it apart from other chronic diseases. She observes that ART, despite its impacts, has not dissociated HIV from immoral sexuality for the women she researched.

The importance of the Christian religion was a common theme across interviews, and many interviewees talked about their faith as an important source of strength in dealing with the many challenges of their daily lives. Religion was also mentioned as shaping their experience of stigma, suggesting quite a paradoxical role for Christianity. Thomas, an MDS, believed that MDS and trans women had always been a part of traditional PNG society and that they had lost this role with the impact of Christianity:

> Because the religion came in and really messed the whole thing up. They came in and start labelling people — he's gay, she's lesbian — they are not part of what is stated in the Bible, they don't have a place in Heaven, you should get rid of them or change them and before religion came everyone was included — they had a role to play, they had responsibilities to carry out, so yeah, family first — forget about the Bible … so then we have the religion there telling us that we are sinners and we are bad and

> so, as we are growing up, we always felt we were no good. Many of us killed ourselves, many of us got married and had children even though we are entirely homosexual, we just had to do this.

There were occasionally counter views on the role of the Christian church in shaping attitudes towards MDS and trans women, such as that the Christian value of tolerance encouraged acceptance. But most interviewees who spoke of the impact of Christianity thought that Christian missionaries had undermined traditional acceptance of trans women and MDS and taught communities to think of trans women and MDS as sinful.

> We don’t accept this, if you are a man you get married to a woman, we don’t encourage you to have sex with another man. In our Christian belief, you are a man, you are supposed to get married to a woman, you are supposed to have a relationship with a woman, not a man — you are a man. (Therese, trans woman)
>
> Broadly let me just say PNG is … known generally as a *Christian* country so when you say, I mean you are trying to look at MDS and TG … when you bring this subject up to any general Papua New Guinean they will think, ‘Oh, what’s this, why do we have to recognise them, which way are their rights being abused — I mean — are these really people?’ (Lionel, MDS)

There may be some regional differences

The view was commonly expressed that prejudice against MDS and trans women was greater in some areas than others. This was said to show that some cultures were more open and accepting. People in the Highlands were said to be the least accepting. Others — described sometimes as Papuan but more commonly as coastal or southern people — were thought to be more accepting of MDS and trans women than Highlanders.

> Within the southern region along the central coast they are much more tolerant of the MDS and trans women. I guess it’s just the understanding that southern people are more peace loving and accepting. They are not judgemental how MDS or trans women look or behave. They are accepting. (Rita, trans woman)

Kiteni, another trans woman, agreed that it was much easier in the coastal areas because of the rigid masculinity of the Highlands region:

> I have seen in the Highlands regions and in some parts of Momase there, when you are born man you have to be man and, you know, there is responsibility for [the ways] a male has to be, you are born into it and you have to take all those responsibilities so for you to be like, on the fence, or if you act like a woman, you will be discriminated by the society.

MaryAnne, trans woman, concurred: ‘Provinces have their own culture, some they accept TG people, some they don’t … Certain culture in the country, for instance the Papuan region, they do have a lot of respect on the TG and MDS people.' Kiteni suggested that one factor contributing to acceptance in coastal communities was that these areas had had a longer period of exposure to western influence. But western influence was not the only determining factor, she thought. Kiteni said that while *transgender* may be a western word, that did not make it a western thing. She was among those interviewees firmly of the view that homosexual behaviour had likely been a part of historical PNG society and that trans women had always played some role in traditional community activities.

Dante, a long-time observer of PNG culture, thought it possible that there were regional differences but that more evidence was needed before this could be confirmed as fact. While agreeing that the Highlands region probably constituted a 'no go' zone, he disputed that all coastal areas were comparatively accepting. Thomas, MDS, reflected on the experience of MDS living outside of Moresby:

> They are so scared and because I am so open in the town … they are afraid of even coming up and talking to me … They don't talk about it, they whisper … so these people are hurt and afraid of coming and talking to me but they do text me now and again just for reassurance though, maybe when they are going into crisis. They are living miserable lives … It's a lonely life outside of Port Moresby, we don't have a network, it's not strong enough. Port Moresby, Lae, it is a bit stronger so there is some level of success. You know, kids strengthening each other. Yeah, I probably wouldn't be where I am if I didn't have my friends in Port Moresby especially.

Threading these different views together it seems reasonable to say that many MDS and trans women anticipate a higher degree of acceptance along the coast than in the Highlands, and that acceptance will be greater in the cities than in rural areas. But there is less consensus on the *reasons* for these regional differences. Instead, a range of factors were cited as contributing to the variation: local attitudes towards masculinity, regional propensities for accepting difference, the local presence or absence of a critical mass of MDS/trans women, and length of exposure to western ideas. While my interviewees seemed confident that these geographical differences are real, I am mindful that I have read no research that documents these differences. Even research from those areas of PNG where sexual freedom is generally understood to be greater has not found homosexuality or transgenderism to be culturally embedded as an accepted identity. One such area is the Trobriand Islands, the subject of research by Lepani (2012). Same-sex attraction is not a feature of this work, although it was also never the intended focus.

Class is relevant to the experience of stigma and discrimination

Some interviewees made the point that wealthy MDS were protected in a way that poorer MDS (and all trans women) were not. Several interviewees named MDS who hold high office in PNG and said it was common for MDS to hold such positions of power. These interviewees agreed that, if you have money, you are respected because of your capacity to deliver for your community, and your sexuality is tolerated. Interviewees agreed that this was not an option for people who lack power. They were highly vulnerable to stigma and discrimination in education, employment and health care and were unlikely to be able to attain redress for negative treatment. They would not be able to afford (economically or socially) to take legal action against perpetrators and would be unlikely to seek the protections from police that more powerful people would simply assume. Many interviewees observed that their status as MDS or trans women would be likely to prevent them from getting ahead economically or socially.

HIV is relevant to the experience of stigma and discrimination

The previous section detailed the stigma and discrimination experienced by PLHIV. Many MDS/trans-women interviewees also experienced stigma and discrimination, and not just because some of them were HIV-positive. Some of the HIV-related stigma and discrimination was being experienced because of perceptions that associate MDS and trans women with HIV risk.

There is a perceived interconnection in PNG between transgenderism, sex work and HIV infection. Trans women experience high levels of exclusion and discrimination based on their transgender status. As interviewees observed, this had led to reduced educational and employment opportunities, along with less family and community support. Faced with such limited opportunities, many trans women become sex workers. Sex work is viewed negatively for multiple reasons. It is considered sinful by Christian churches in PNG and this shapes community attitudes towards the industry. But it is also despised because of the way sex work is said to threaten family cohesion (and place spouses in perilous circumstances).

HIV surveillance data confirms significantly higher rates of infection among sex workers as compared with the ‘general population’ (Hakim et al. 2019). It is undoubtedly the case that sex workers are viewed as major vectors for transmission. This can be seen in media reporting, in community views expressed in workshops, and in the way HIV-prevention initiatives have had a serious, arguably obsessive, focus on sex workers. It is also arguably reinforced by HIV-surveillance priorities, which have resulted in data for sex workers but no data for other groups that might warrant consideration, such as clients of sex workers, MPs, businessmen, public servants, and expatriates. This is how surveillance can create and reinforce categories of risk.

Stewart (2010) writes of the 2004 police raid on the Three-Mile Guesthouse in Port Moresby, involving advance notice to the press and other high-profile display tactics intended to show the public what a fine job the police were doing in maintaining social order. These tactics involved violence, looting and rape at the guesthouse, mass arrests of almost everyone on the premises and public parading and shaming of those arrested. Women arrested were forced to chew, swallow or blow-up condoms. The police claimed that the raid was designed to prevent sex workers from contracting and spreading HIV. (Charges against the women were later dropped but only on the technicality that the necessary search warrant had not been obtained.) The story of the raid offers valuable insights into the way sex work is understood by people with power in PNG, and how global discourses on risk shape these perceptions.

As noted, sex workers in PNG are associated with higher HIV risk. They are blamed for its spread. Transgenderism is associated with sex work, which is associated with HIV infection, and it is a fair guess that much of the stigma and discrimination to which trans women are subjected is because of these associations. It is also the case that HIV in PNG is increasingly associated with being homosexual (Hakim et al. 2019). Even before evidence from the *Kauntim Mi Tu* study (Kelly-Hanku et al. 2017) was available, public perceptions already drew a strong association between homosexuality and being HIV-positive. This has been seen all over the world and is true of the PNG situation as well — HIV has been associated with sex work and homosexuality (and transgenderism), so to be one is to be treated as if you were all. As previously noted, the earliest phases of the national PNG response were framed in terms of heterosexuality, but this early framing was lost in the face of a shift towards MARPs and KAPs and subsequent research into these populations.

There is evidence that there are clustered epidemics within trans and MDS communities in PNG (Hakim et al. 2019; World Health Organization 2017; Kelly et al. 2017). As has been noted above, the choice of HIV-surveillance studies often shapes how risk is understood. The studies showing clustered epidemics can be interpreted as evidence that PNG has a concentrated epidemic, where the truth is that the country has multiple epidemics, only some of which are clustered. In some locations, heterosexual sex is the major driver of transmission and women who are not engaged in sex work are at significantly heightened risk. Still, for the foreseeable future, it will not become easier to dissociate HIV from MDS and trans communities in PNG.

Trans women are special

Even though all interviewees agreed that MDS and trans women experience high levels of discrimination, some thought there might still be some recognition that trans women are ‘special’, and not in an entirely negative way. Trans women had these things to say:

> People begin to see that these people, that are more unique, they are more treasured. Why I am saying this is because people begin to see that OK, even though he is different, but he can cook, he can do all the chores in the house. (MaryAnne)

> If we are to go to the garden, especially the ladies call us, they usually call us to go and help them go clean their garden and they usually say that these people are much faster than the ladies. They can, you know, finish this garden by two or three hours rather than the women, you know, and also we attract people to come for these Christmas events or whatever or dance or creative dance, especially Pacific Dance. People like us usually pull the crowd to come and enjoy the Christmas Eve. (Natasha)

> TGs are flexible in everything, like I said, they are kind of like public figures, you know, they … have this, 'I don't care, I don't care who calls me names,' you know, 'I am not bothered by your comments, I am who I am.' (Therese)

> I see that we TG, we not supposed to be left out and we are a blessing to our life. We have a common understanding of developing in a male and a female way and it's of course, it's very unique, and it's kind of treasure in us. (Jasmine)

These strengths are not only recognised by trans women, but also by others in the community. This view of trans women as special also shapes how they think fairer outcomes might be achieved. While some push the line that trans women are the same as everyone else, others argue that trans women are special. This special nature might involve being physically stronger than women yet prepared to do women's work or possessing special skills in dance and entertainment (and here the national popularity of musician Moses Tau comes to mind). These advocates say that this special nature is to be celebrated and recognised as a community resource..

Seeking redress for discrimination and other rights violations

Rita, a trans woman, told an instructive story about the reluctance of trans women to press charges against police. Particularly for young trans women, she said, there was an acceptance that they are, on some level at least, 'criminals', in the sense that through their engagement in homosexual sex or through their expression of transgender identity, they were in breach of recent PNG laws. This, she thought, made police mistreatment, if not acceptable, then at least understandable. Rita also observed that trans women saw gender-based violence all around them, with women being constantly beaten despite laws prohibiting such abuse. In this context, where violence against women was so acceptable, why would they consider complaining about it? As noted above, seeking protection from the police was generally not considered a viable option for trans women.

Awareness of rights was cited as a useful means of combating violations. It was raised repeatedly by trans interviewees as a way of reducing the incidence of rights violations. I found it interesting that this was often suggested by the same interviewees who expressed little confidence in the capacity of the system to provide protection of rights or redress for rights violations. For these interviewees, the mere possession of knowledge of rights was a positive outcome. It may be that these interviewees thought that, armed with greater knowledge of their rights, MDS and trans women would be able to speak out in their own defence with greater confidence and more authority, and that this would limit ill-treatment. Or perhaps interviewees felt a confidence that, over time, if enough victims brought enough cases before the courts (of law or public opinion), then the situation might be changed.

Other evidence supporting interviewee accounts of stigma and discrimination

Before I conclude this chapter on the experiences of stigma and discrimination, I want to note some other sources of data that affirm the stories of interviewees. For example, in 2015 Kapul Champions made a submission to the United Nations Periodic Review, highlighting four key areas of human-rights violations for MDS and trans women, although the report speaks more broadly of the rights of LGBTI people (where LGBTI refers to lesbian, gay, bisexual, transgender and intersex people). These four key areas are education and employment, access to adequate and appropriate health services, recognition of gender identity and the need for law reform.

On the right to education, Kapul Champions notes that the bullying of, and violence towards, LGBTI students in schools is a significant problem resulting in these students being forced out of school. Stigma and discrimination are perpetrated by other students and their parents, and teachers are not sensitised to the needs of LGBTI students. In relation to employment, Kapul Champions notes that LGBTI Papua New Guineans are generally disadvantaged, and that this is especially the case for trans women. Discrimination in employment is rife and LGBTI applicants rarely get jobs. The report notes that this combination of discrimination in education and discrimination in employment means that career options for MDS and trans women are severely limited, and sex work is often the only option available. The report notes the relationship between sex work and vulnerability to HIV infection. In relation to health, the Kapul Champions report states that stigma and discrimination in health-care settings prevents many LGBTI Papua New Guineans from accessing health services. Anticipation of discriminatory treatment causes many LGBTI people to delay or avoid seeking the care they need. This has caused many people with STIs to go untreated and has caused the deaths of several MDS/trans women with HIV. The report states that HIV-positive MDS and trans women have a comparatively lower rate of successful ART than their heterosexual peers. The report refers to cases of clinicians refusing to provide services to LGBTI.

The report also notes the lack of access to hormone therapy for trans women, the unavailability in PNG of pre-exposure prophylaxis (which disproportionately impacts on MDS and trans women due to their increased vulnerability to HIV infection), the lack of doctors sensitised to the needs of trans women and the general lack of mental health services for LGBTI. The report identifies lack of recognition of the preferred gender identity for trans women as another major human-rights violation. Trans women cannot have official birth records amended to record their preferred identity. This has implications for employment and education preventing trans women from formally presenting in line with their true identity.

It is also possible to view stories by independent news services, film makers or development agencies that affirm interviewees' stories. For example, a short story on discrimination against MDS and trans women, *Gay PNG Citizens Face Discrimination,* was produced and broadcast by Australia's SBS World News in 2012. The story references many of the issues reported by interviewees, including the stigma and isolation associated with being homosexual, the public backlash against people seen to be acting against culture, discrimination in employment and the vulnerability of MDS and trans women to HIV. The story refers to the deaths from HIV of multiple MDS and trans women, and to the suicide of others. The influence of Christianity is discussed as a factor preventing greater acceptance of sexual diversity.

A short video, *Addressing HIV-Related Discrimination in Papua New Guinea,* developed in 2013 by the International Development Law Organization and PNG Development Law Association describes a lack of awareness among PLHIV and other affected communities of their human rights. The story reports that these rights are routinely breached but that many of those whose rights are being breached are either ignorant of their rights in the first place or feel powerless to take remedial action. The video reports that PLHIV, and others affected by HIV, experience discrimination in employment, are abused by police, experience discrimination in health care and are exposed to verbal, physical and sexual abuse. The heightened vulnerability of women is noted.

The 2014 documentary by Vlad Sokhin and Roman Kalyakin, *Guava and Bananas: Living Gay in Papua New Guinea,* depicts the lives of MDS and trans women living in Hanuabada. It was featured in a 2014 ABC news story which also explored the lives of these people. The documentary and the story about it reported that up to 30 trans women had made their home in Hanuabada Village and that many experienced a degree of acceptance within this environment. This acceptance was not universal, however, and trans women remained fearful and retained a very cautious approach to movement outside of their immediate community. This fear was well founded according to trans women interviewed for the story. Violence was a common experience for trans women, and trans women had been murdered.

The feature-length documentary on the life and music of trans musician Moses Tau, *I'm Moshanti. Do You Love Me?* (2019) is further compelling evidence of the challenges in living as MDS or trans in the Pacific.

Part Three. Commonalities and Differences in the Experiences of Rights Violations

The groups have much in common

In reflecting on interviewee stories, it is apparent that the lived experiences of rights violations for PLHIV are similar in many respects to those of MDS and trans women. Discrimination against PLHIV, MDS and trans women is rampant. There are no PLHIV, trans women or MDS who do not experience discrimination on a routine basis. They expect it as part of their normal day-to-day life. It is not new for them and many have grown used to it. But while they have grown used to it, or at least are no longer surprised by it, they do not accept it. PLHIV, MDS and trans women recognise violations of their rights and they do not accept them as legitimate or reasonable.

Stigma and discrimination against PLHIV, MDS and trans women take different forms. Stigma and discrimination can be manifested as self-stigma, family rejection, community marginalisation, exclusion from services and opportunities, name-calling and violence. Each of these forms is experienced by all three groups. This discriminatory treatment flows from the stigma associated with being HIV-positive, an MDS or a trans woman. For each of these three statuses there are common elements: sex, gender and disease.

All PLHIV, MDS and trans women experience what they describe as name calling and gossiping. The gossip is extremely negative and generally reflects a disregard for the privacy rights of the subjects. Discrimination very often involves exclusion. Most critically, many PLHIV, MDS and trans women are rejected by their families. This has crushing emotional impacts, but it has economic consequences as well, leaving PLHIV, MDS and trans women especially vulnerable to poverty and exploitation.

PLHIV, MDS and trans women are discriminated against by education service providers, in many cases being denied opportunities to study, and at other times being subjected to poor treatment within institutions once enrolled. PLHIV, MDS and trans women are acutely aware that by being denied access to education they are ultimately denied opportunities to advance in life more generally. The link between education and employment is keenly understood and being excluded or withdrawn from school is understood as often foreshadowing a life of economic hardship.

PLHIV, MDS and trans women experience discrimination in employment. They are unable to gain employment in the first place where their status is known, and they can be forced from employment if their status emerges post-appointment. Interviewees agreed that PLHIV, MDS and trans women are discouraged from applying for roles in the first place, so they self-select out of employment processes in anticipation of rejection. It is likely that employment-related discrimination is underreported.

PLHIV, MDS and trans women experience discrimination in accessing health services. This has detrimental effects on their own health but also impacts on public health. Interviewees reported discrimination within health-care settings taking different forms — it might be perpetrated by doctors and nurses or it might result from the behaviour of other patients. This discrimination might result in PLHIV, MDS and trans women leaving without being provided services, and the anticipation of this attitude from others keeps many PLHIV, MDS and trans women from accessing services in the first place. In some cases, the discriminatory treatment involves clinical negligence. Interviewees agreed that these experiences, or the anticipation of such experiences, could affect the success of ART and that this has serious implications for managing HIV in PNG.

PLHIV, MDS and trans women have all experienced what they often describe as ‘self-stigma’. Many have contemplated suicide, and many interviewees reported suicide to be a real problem within their communities. Among interviewees there was no question that stigma and discrimination has led to suicide amongst their peers. It has also led to other self-harms including alcohol abuse, poor diet, failure to take treatments and a general disregard for their own health and wellbeing.

There are other commonalities across these three groups as well. It is clear that rights violations for PLHIV, MDS and trans women very often involve violence or the threats of violence. Trans women in particular are exposed to routine violence. Violence commonly involves sexual violence.

Interviewees agreed that reducing discrimination involved more information being made available to dispel myths, better inform the population, and enhance greater visibility of all three groups so that their essential humanness could be better appreciated.

Members of the three groups agree that ‘double discrimination’ is a reality and that people who are both HIV-positive and either an MDS or trans women are far more likely to be experiencing extreme stigma and discrimination. Members of all groups agree that there is a gendered dimension to their stigma and discrimination.

PLHIV, MDS and trans women have all drawn support from their own peer groups. Interviewees agreed that it was important that they be able to come together with people who shared their status so that they could discuss issues in common. Beyond being forums for information exchange, these gatherings were also important sources of camaraderie and peer support. These groups were often described as being communities. In some cases, they were described as being families.

Interviewees from all three groups commonly spoke of the impact of stigma and discrimination on their relationships. They regretted the negative impacts of their status on their partners and children, and women with HIV were very focused on limiting the impact of their status on their children. Interviewees also spoke of the ways that restrictions on their movements and opportunities negatively impacted on their prospects of establishing and maintaining relationships. This was sometimes described in terms of not being able to meet up with friends and subsequently being denied the peer support essential for building self-esteem. It was also described in terms of preventing interviewees from finding romantic partners. Several interviewees dreamed of a world in which their rights might be respected, and they would be able to find love — the former would facilitate the latter, they believed.

PLHIV, MDS and trans women recognise that their rights are breached but there is a low level of awareness of what to do in response, and not a great deal of hope that remedies can be obtained. There is some awareness of the PNG Development Law Association and the *HAMP Act,* but not a great belief in the capacity of the current legal system to deliver justice. There is, however, a shared understanding that achieving justice will require multiple reforms. It will involve pressure being applied at multiple points. Communities will need to be better educated about the law (PLHIV, MDS and trans-women communities, as well as the broader population). Police and court personnel will need to be sensitised to the needs of marginalised groups. Individual victims of rights violations will need to demonstrate courage to embark on what will, in many cases, be difficult and protracted processes. It will be necessary for these same individuals to be able to access support to assist them through the process and national laws will need to be changed to create a fairer environment for PLHV, MDS and trans women.

Differences between the experiences of PLHIV, MDS and trans women

PLHIV generally feel that life has improved for their community. While admittedly coming off a low base, there is a commonly held view among PLHIV that levels of stigma and discrimination have reduced, at least in Port Moresby and other major urban centres. By contrast, MDS and trans women do not see significant improvements in the levels of community acceptance.

This difference can be partly explained by the shift in the understanding of HIV. Once people understand that HIV is a manageable health issue rather than a highly contagious death sentence, it can be approached in an entirely different way. PNG traits towards caring and compassion re-emerge and PLHIV can be seen as fellow Papua New Guineans in need of support rather than alien and threatening. But homosexuality is still homosexuality even when people know more about it, and transgender expression is still transgender expression. It seems that many Papua New Guineans remain opposed to these ‘lifestyles’ and compassion is held at bay by a shared distaste for what is perceived by many to be strange or deviant choices. The debate around any traditional place for homosexual behaviour or transgenderism will roll on but, for now, interviewees mostly agree that the general population seems unconvinced that there is a place in contemporary PNG for either. While many MDS and trans women believe strongly that they have always had a place in Papua New Guinean society, even they do not think that continuity with the past will be adequate to support unbiased acceptance of sexual diversity in the present without greater human-rights awareness and advocacy.

The experience of violence for trans women is especially horrifying. Most trans women report multiple experiences of violence, often at the hands of uniformed personnel (police, army officers, security guards), but also at the hands of families and communities. These experiences have often involved sexual assault and rape.

There is a difference between the experiences of MDS and trans women. MDS are likely to be hidden, at least to some degree. Invisibility brings its own burdens, but it affords a degree of protection from the discrimination and violence experienced by trans women. MDS who are ‘out’ are much more vulnerable, and yet still they seem slightly safer than their trans-women friends. It may be that their status as men (albeit transgressive ones) affords them a protection that trans women have forfeited by virtue of their feminine expression. It might also be a simple factor of the physical capacity for self-defence: trans women often described themselves as being more like women than men, including in terms of strength. However, many trans women had obviously demonstrated great physical capacity in defending themselves; some claimed — and indeed appeared to possess — considerable physical prowess; and several reported their value to community in terms of the strength they brought to ‘women’s work’. And of course, women labour hard in many PNG communities, including through arduous gardening, so ‘women’s work’ already requires great physical strength.

MDS and trans women were less likely to report discrimination perpetrated against their partners and children. Trans-women interviewees tended not to be parents, and MDS interviewees with children did not report this issue; again, possibly because they were not always ‘out’ about their status and their families were not subsequently vulnerable.

Not surprisingly, PLHIV were more likely to focus on violations of their rights to health care and ART in particular. Access to secure and affordable ART supplies is critical for PLHIV. It keeps them alive, but it also profoundly shapes the way they are treated within their communities; ART facilitates understanding of HIV as a chronic illness rather than a death sentence, reducing fear of the disease and those infected with it.

Control of information and confidentiality were more likely to be issues for PLHIV and MDS than for trans women. Again, the reason for this is obvious. Trans women are mostly unable to hide their status so are less concerned with privacy. By contrast PLHIV and MDS are very invested in ensuring that information about their status is controlled tightly.

MDS and trans women are more likely to see regional differences in the ways they are treated as an indication of cultural variation. Highlanders are considered less tolerant than people along the coast and in some cases this tolerance can look more like acceptance. By contrast, PLHIV thought their experiences were shaped by the extent to which ART distribution and HIV awareness had penetrated PNG. They argued that in areas where residents possessed a sound knowledge of HIV transmission and where ART was available, discrimination was likely to be lower.

MDS and trans women were far more likely than PLHIV to talk about violation of their right to ‘be themselves’. This was especially the case for trans women.

Trans women were far more likely to talk about being prevented from moving around freely. This was their way of discussing safety, or more pointedly the lack of it as soon as they moved outside of their homes or communities of belonging. This focus on the inability to move around without being threatened or assaulted was consistent with the high rates of violence reported by trans-women interviewees. Clearly, and understandably, this violation of human rights is the one that most preoccupies the minds of trans women.

Stigma and discrimination present challenges for Igat Hope and Kapul Champions

This chapter has illustrated how interviewees experience stigma and discrimination in many domains of their lives. My hope is that the stories demonstrate the real effects of this differential treatment, reaching beyond the over-used, catch-all phrase ‘stigma and discrimination’, to show the grinding, often brutal impacts of being treated in such ways. This chapter has detailed the range and scale of obstacles interviewees are required to overcome in their daily lives just to have the same opportunities that Papua New Guineans enjoy. To extrapolate, PLHIV, MDS and trans women across PNG all experience some form of stigma and discrimination, and for many, this is a constant, pervasive and exhausting experience. As the preceding chapter demonstrated, PLHIV, MDS and trans women know these experiences of stigma and discrimination are examples of a disregard for their human rights. In the next chapter, I will explore the operations of Igat Hope and Kapul Champions, with a particular interest in how the organisations shaped understanding and realisation of rights for their constituencies. In Chapter 6, I will explore whether human-rights frameworks, and the language of human rights, are useful in trying to address the problems this chapter has documented.

As we listen to the upcoming stories of Igat Hope and Kapul Champions, it is appropriate to keep in mind the stories we have heard in this chapter about the exhausting, debilitating impacts of unfair treatment. Igat Hope and Kapul Champions have relied heavily on the voluntary, unpaid contributions of highly marginalised communities, of people excluded from education and employment opportunities and with comparatively poor health. The reduced capacities of these communities to contribute and the disadvantage that the organisations' constituents so routinely experienced are important contextual elements to any analysis of Igat Hope and Kapul Champions.

Chapter Five
Igat Hope and Kapul Champions

This chapter is dedicated to Annie McPherson. Annie was the first ever Executive Director of Igat Hope. Appointed in 2007, Annie was integral to the establishment of Igat Hope as a viable and functional non-government organisation. Annie was a tireless advocate for Igat Hope, and quickly established herself as a highly regarded contributor to the national response to the epidemic. Annie became a great connector of Igat Hope to other HIV agencies. She was trusted by aid agencies and critical to facilitating NAPWHA's ongoing support. She demonstrated incredible capacity to manage sometimes chaotic developments in the HIV response, building the Igat Hope secretariat into a strong and respected NGO. Annie also provided early personal and institutional support for an emergent Kapul Champions. Igat Hope's auspicing of Kapul Champions is a rare example of an HIV organisation playing midwife to a queer one. Annie led the organisation until illness forced her from her role. She died in 2017.

*

This chapter tells the story of the two organisations, Igat Hope and Kapul Champions. It is a big story, parts of which are common to both organisations and parts of which are specific to one or the other. So, as with this thesis in general, there are stories within stories and this chapter is perhaps best conceived of as being three major stories: the story of Igat Hope, the story of Kapul Champions and the story of the organisational model as it operated — and continues to operate — in Papua New Guinea (PNG). The chapter begins by describing the organisational features of the two entities. Both Igat Hope and Kapul Champions reflect an organisational model, seen commonly in the community response to HIV in Australia and elsewhere. It is a community-based organisational model, commonly known as a CBO, and it is important to understand the model when reflecting on the achievements of the organisations. The chapter will explore the ways the model facilitated and impeded achievement of community goals.

The chapter will also detail the achievements and shortcomings of Igat Hope and Kapul Champions. To do this, it will draw on the views of the organisations' members, constituents, employees and supporters, supplementing these with documentary evidence obtained from the National Association of People With HIV Australia (NAPWHA), the Australian Federation of AIDS Organisations (AFAO), Igat Hope, Kapul Champions and other sources. It is important to reflect on these achievements in light of what has happened to the organisations in recent years at the hands of donors. A narrative that questions the achievements of these organisations has been promoted by some donors, and also by some local decision makers in HIV service delivery, yet this chapter lays out compelling evidence of strong performance over many years. In this sense at least, the chapter involves some correcting of the record. In that part, the chapter looks at each organisation separately because they have achieved different things and have had different levels of success across different domains.

Having explored the achievements of Igat Hope and Kapul Champions as independent organisations, the chapter takes a step back to look at those achievements and challenges that are common to both organisations, as a way of understanding the overall effectiveness or appropriateness of the CBO model in PNG. Here I am asking the question whether the CBO model can work in PNG and whether the model that has been utilised by PLHIV, MDS and trans women is the right one for their needs. Finally, I take a close look at the appropriateness of the model as a means of promoting human rights. Chapters 3 and 4 detailed understandings of human rights among PLHIV, MDS and trans women, and recorded their experiences of rights violations. These chapters documented the great desire among PLHIV, MDS and trans women for a world in which their human rights might be better respected. This final part of the chapter explores whether Igat Hope and Kapul Champions helped achieve human-rights outcomes.

Part One. The Igat Hope/Kapul Champions model

Igat Hope and Kapul Champions are a certain *kind* of organisation. They both follow the same model, which in most important respects is adopted from the model of NAPWHA and AFAO. I claim some expertise in this area, having spent practically my entire working life within CBOs in Australia and PNG, as well as in Thailand, India, China, Fiji and Indonesia. The defining characteristics of the model are as follows.

The organisations are community based

Being community-based means that the organisations are established for a particular community of people who can ‘select in’ to formal membership by a process of self-identification. Igat Hope is for PLHIV. Kapul Champions is for MDS and trans women. This very process of self-identification is crucial. To opt in to membership of Igat Hope, people need to know that they are HIV-positive, they have to be able to accept this diagnosis on some level, and they need to be willing to accept some degree of public identification as HIV-positive, with all the risks of stigma and discrimination that this entails. To identify as a member of Kapul Champions’s constituency, people need to be sufficiently comfortable with the nomenclature of MDS and transgender and be willing to accept some degree of public identification with these labels. But arguably, before people can be comfortable with these descriptors, they need to understand them. As discussed in Chapter 1, many men who have sex with other men are unfamiliar with the term MDS or uncertain of its application to them, leaving aside any comfort or discomfort they may have with such a label, and ‘transgender’ is hardly straightforward.

The membership link between Igat Hope and its HIV-positive constituency is slightly less direct than is the case for Kapul Champions and its MDS and trans constituency. Igat Hope is a peak organisation — an organisation of organisations — so its membership is institutional rather than individual. But its member organisations are themselves PLHIV groups located throughout PNG. The Igat Hope Constitution (Rule 6) makes clear that membership is open to any PLHIV organisation in PNG that is, among other things, committed to the organisation's objectives and purpose and has a membership of at least 20 individuals of whom all or most are PLHIV. By restricting membership to organisations with memberships that are entirely or mostly HIV-positive, the 'integrity' of the peer base is preserved. Membership is further restricted to organisations that are committed to Igat Hope's objectives, the first of which is the establishment of a united voice for PLHIV.

Kapul Champions does not specify that its members must be MDS and/or trans women. Not surprisingly, at the time the organisation was incorporated there were fears that members would be exposing themselves to risk by outing themselves as MDS and/or trans women. If the organisation's members *had* to be MDS or trans women, then those filing the application for incorporation would be automatically 'outed'. For this reason, the constitution is silent on the sexuality or transgender status of members. I recall the nervousness of those responsible for lodging registration documents with the PNG Investment Promotion Authority (IPA) and we were prepared for any eventuality. We had practised this argument: that merely by registering the organisation it could not be said that we were owning up to unlawful behaviours. Similarly, those registering Igat Hope must have been somewhat fearful that their own act of registration would out them as living with HIV and subject them to the stigma and discrimination so commonly experienced by people known to be HIV-positive at that time. These registrants showed considerable courage in taking on this risk, and this courage was recalled by many interviewees.

People cannot become members of Kapul Champions unless they have been nominated by existing members and approved by the board. The organisation's original membership (those establishing the organisation and applying for its incorporation) was comprised entirely of MDS and trans women, although members were open about this to varying degrees. Kapul Champions's first and subsequent boards have always been entirely comprised of MDS and trans women. This means that no members have ever been able to join without being nominated and approved by other MDS and trans women, and to the best of my knowledge no non-MDS and trans women have ever been admitted or sought to join. This is an example of how community-based organisations tend to manage memberships: membership is in theory open to large populations but is practically restricted by advertising the option of membership by word of mouth only, or by gatekeepers restricting membership in ways that ensure the organisation remains run by the community intended to benefit from its operation. It sounds a little undemocratic and, indeed, several interviewees questioned the degree to which democracy was fully embraced by the organisations (more of this later), but it is a strategy that can be deployed to help ensure organisations remain peer based.

For each organisation, identification with the respective stigmatised status (being HIV-positive or MDS or a trans woman) is the only real requirement for membership (or in the case of Igat Hope, membership of the organisation's representative groups). As noted, this requirement is an informal one for Kapul Champions although it is, in effect, universally applied.

It is worth noting here that Kapul Champions's membership excludes cisgender women. The MDS category is all about men and the organisation's trans members are, in my own experience, all trans women. There is a single account in Kapul Champions's records of a lesbian attending a Kapul Champions's event and no records of participation by trans men (although the early research work of Wilo Muwadda (2012) did involve interviews with members of this group). I cannot say whether Kapul Champions will expand its membership to include lesbians and/or trans men, however the evolution of the Australian Anwernekenhe National Alliance is worth noting. I have referenced Anwernekenhe before in this thesis and consider there to be significant parallels between the queer Aboriginal and Torres Strait Islander movement and the movement that sustains Kapul Champions. It is important to recall that Anwernekenhe commenced as an association of Aboriginal and Torres Strait Islander gay men affected by or concerned about HIV. It rapidly evolved to include Aboriginal and Torres Strait Islander trans women (sistergirls) and later grew to include any Aboriginal or Torres Strait Islander communities whose marginalisation exposed them to greater HIV risk, specifically lesbians, sex workers, brotherboys (female to male trans) and users of illicit drugs. This evolution has been documented for the Australian Federation of AIDS Organisations (AFAO) by M. Costello and N. Fazulla (2015).

The organisations are democratic and representative

Both organisations have clear rules that empower duly admitted members to elect their institutional representatives. There are procedural requirements relating to nomination but both organisations' constitutions provide that any members (or in Igat Hope's case, representative groups of members) might nominate for election to the board. Elections are democratic processes in which all votes are equal. Once elected, board members act on behalf of the organisation's members, they act with the authority of these members and they are accountable to these members. Election to the board is for a limited period at the end of which board members surrender their positions and, if seeking re-election, must submit once again to the judgement of their peers. Members may, by acting together, remove a board member, provided certain procedural requirements are observed.

The organisations are not-for-profit

Igat Hope and Kapul Champions operate on donor funding, although supplies of this funding have dwindled and, in the case of Kapul Champions, dried up entirely. They do not operate as businesses and are not motivated to make profits. Any funds that are acquired or generated (via fund-raising, for example) are required by the constitution to be applied to achieving the organisations' goals, which do not include profit. Funds acquired or raised by either agency cannot be applied for the personal benefit of any member, except where a member might be a paid employee of the organisation. There are institutional checks and balances to ensure employees are recruited through legitimate processes and that cronyism is prevented.

The organisations are advocacy agencies more than service-delivery agencies

Igat Hope and Kapul Champions are both advocacy organisations. Neither holds itself out as a provider of services to its constituencies, although both operate in the service of their memberships more generally. Of course, this is not always as clear-cut as it sounds. Igat Hope has long struggled to manage the tension between being an advocacy organisation and being a provider of member services. An impoverished membership experiencing frequent ill-health has understandably been keen to attain personal benefits from Igat Hope, and many individuals have sought (and sometimes obtained) cash, goods and medicines from the organisation. This tension has caused significant problems for Igat Hope from its earliest days and remains a source of some disagreement within the membership. While Kapul Champions largely learned from Igat Hope's mistakes here, it too has experienced some pressure to respond to members' demands for direct services.

The confusion around what constitutes a 'service' also complicates things. Both organisations have a focus on providing information and education for members. While this work might be described as health promotion or even advocacy, it is also a kind of service, albeit not the direct kind (cash, food, medicines) that many members continue to seek. Despite these shades of grey, it is now firmly established that Igat Hope and Kapul Champions are advocacy organisations. Each is focused on the system-wide challenges experienced by its constituency and on generating the systemic change needed to facilitate human-rights outcomes. The constitutions of both organisations affirm their advocacy roles. Igat Hope's constitutional objectives are to provide a united voice for PLHIV, to represent PLHIV, to lobby governments and other agencies, to empower PLHIV and to advocate on issues of concern. Kapul Champions's constitutional objectives are to empower MDS and trans women, to strengthen local MDS and trans-women communities, to oppose discrimination, to raise awareness on human rights, to voice concerns, to formulate polices, to represent members and to encourage the participation of MDS and trans women in all the organisation's activities.

The organisations are volunteer organisations

While Igat Hope and Kapul Champions both have employed staff, each is run by volunteers who populate the governance structures. These board members might be paid per diems or sitting fees or other token payments, but their labour, skills and expertise are mostly provided free of charge. The organisations have encouraged members to donate time and service to support their work and many members have provided this support. Members might, for example, be despatched to represent the organisation at a stakeholder meeting or a community event, they might be encouraged to help around the office, to set up a room for a community consultation, to staff a stall at a community awareness event, to prepare papers for an AGM etc.

The appropriateness of reliance upon volunteers is discussed later in this chapter, but it is certainly the case that both Igat Hope and Kapul Champions were established with an expectation that members would volunteer their services in support of the organisations, primarily but not exclusively in relation to governance. This was the expectation of NAPWHA and AFAO as they worked to help build Igat Hope and Kapul Champions. Both NAPWHA and AFAO have relied extensively upon volunteers during their long histories: volunteers have provided organisational governance for NAPWHA and AFAO but have also contributed much, much more. They have been critical contributors to policy development, fund-raising and service delivery.

Part Two. What did the organisations do and achieve?

In this section, I explore the achievements of Igat Hope and Kapul Champions, dealing with each organisation separately. The chapter focuses initially on the actual work undertaken by the organisations before considering influence, and then impact specifically relating to human-rights goals.

Igat Hope's work, 2001–20

This part is necessarily a potted history of Igat Hope since its establishment in 2001. It can be supplemented by reference to a reflection written by Tim Leach and John Rule (2013), which serves as a far more detailed account. The part considers what research interviewees had to say about the work of Igat Hope, what they see as its successes, and how they see where the organisation has failed to meet expectations, or at least fallen short of its potential. The part concludes with an analysis of a commonly reported failing, namely corruption, exploring whether, when understood in context, this 'corruption' might be something else altogether.

Igat Hope was established in 2001 by a small group of HIV-positive Papua New Guineans, with support from Australian activists living with HIV. It was set up without institutional protection and without funding. Very soon after its establishment, however, Australian HIV-positive activists secured support for the fledgling group from NAPWHA. Before long, AusAID (as it was called then, now absorbed into the Department of Foreign Affairs and Trade — DFAT) stepped up with program funding. AusAID (and then DFAT) would go on to provide Igat Hope with some level of financial and technical support for almost a decade, often inclusive of funds to facilitate NAPWHA's mentoring and support functions. The following part considers some of Igat Hope's activities during these periods of funding, using two key funding cycles as a framework. The use of these cycles does not suggest that Igat Hope was only ever a product of its donor's funds; indeed Igat Hope has delivered a range of valued services that were not funded by DFAT or by anyone else. The cycles are used only as a chronological guide to Igat Hope's achievements.

AusAID HIV/AIDS Partnership Initiative (AHAPI) 2005–8

The early work of Igat Hope was conducted under the AusAID HIV/AIDS Partnership Initiative (AHAPI) 2005–8, a program designed to increase participation, capacity and knowledge of HIV among PLHIV communities in PNG. The program supported Igat Hope's early steps towards becoming an effective representative organisation, including by way of strategic planning, governance strengthening and the building of peer capacity. Igat Hope developed annual activity plans and organised annual governance training for the board and ongoing mentoring for board members. Igat Hope drafted its *Igat Hope Governance Kit,* which was recognised by AusAID, NAPWHA and others as an important guide; one of very few governance tools for indigenous CBOs in PNG. The kit was updated twice yearly by Igat Hope's boards. Igat Hope members were supported to take on leadership roles, including via skills development programs, and many participated in a training program for HIV-positive speakers in 2008. Igat Hope delivered workshops to promote healthy living on the part of constituents, commencing with the *Healthy Living Workshop for Positive Peers* in 2005.

One of the most important activities during this period was the expansion of positive groups across PNG. This was aimed at reducing the isolation being experienced by PLHIV outside of the capital and at enhancing Igat Hope's claim to speak for a national constituency. During this period, PLHIV organisations emerged in multiple PNG locations — Tru Warriors in Mount Hagen, Good

Samaritans and Higher Aims in Madang, the Mendi PLHIV Group, Alotau Igat Hope, West New Britain Group, Morobe Group in Lae, Wapenamanda in Enga Province, and Friends Ministry and Positive Care Foundation in Port Moresby. Igat Hope did not establish these groups and not all of these groups were open to a close association with Igat Hope. Different groups had their own 'patrons' including Provincial AIDS Councils, church groups and international NGOs, and there were some significant differences in group objectives — some had advocacy goals while others were purely drop-in social groups. Some of the groups actively competed with Igat Hope for funds, members and mandates. But AHAPI did see the beginning of an important national debate among PLHIV as to how they wanted to be recognised nationally.

During AHAPI, Igat Hope established collaborative relationships with many of the HIV response's most critical stakeholders, including UNAIDS, the World Health Organization and the National AIDS Council. Relationships with international NGOs and charities were also established. An external evaluation of AHAPI-supported work demonstrated that Igat Hope successfully enhanced its organisational skills during this period. At the conclusion of the project, it was a far more structured, capable organisation than it had been in 2005.

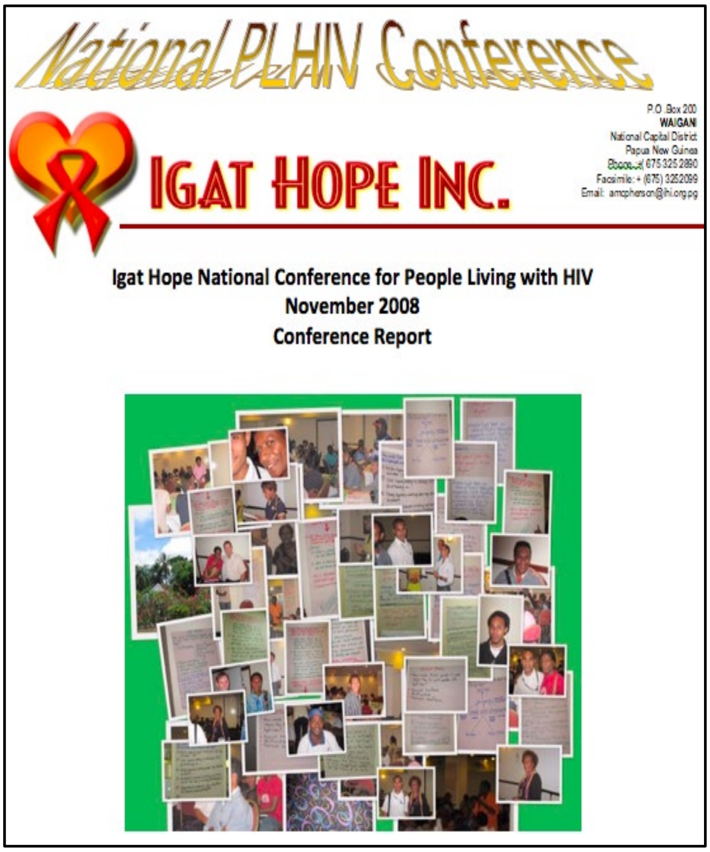
Sanap Wantaim contracts 2009–12

Sanap Wantaim ('Stand Together' in Tok Pisin) was the name given by AusAID to its HIV program in PNG. During this period Igat Hope continued to strengthen its functionality, particularly in terms of the capacity of the secretariat. Work plans for the Executive Director were developed and she twice travelled to Sydney for skills-building programs with NAPWHA. The secretariat expanded its workforce to employ a network liaison officer, an HIV program officer, an administration officer, a deputy director, an NCD provincial officer and financial controller. While its internal capacity grew, the organisation managed to ensure a growing secretariat was properly governed. During this period Igat Hope held a series of successful AGMs at which external observers witnessed elections being held in accordance with constitutional requirements. At each of these AGMs the secretariat reported to the membership — an important act in acknowledging accountability to (and the authority of) the organisation's HIV-positive constituency.

In 2010, Igat Hope formally resolved to become a national PLHIV representative body. This important development was the culmination of over two years' internal reflection and external consultation. The Igat Hope members — at that stage all residents of the National Capital District (NCD) — passed a resolution effectively converting the Moresby-based organisation into a national peak body. In so doing the existing membership divested itself of control over the organisation, which is not something that, in my experience at least, commonly occurs in community movements.

By converting the organisation into a national peak body, the Moresby-based membership gave up control over the organisation’s (then) considerable resources and agreed to adopt a board structure that would conceivably hand power to people beyond NCD. Given the depth of regional allegiances in PNG, and the risk to NCD members that their power and influence would be lost, this demonstrated a real commitment to the creation of a national voice.

During this period, the newly appointed network liaison officer was supported via a mentoring program funded by the Asian Development Bank. This program placed an expatriate adviser onsite for more than a year to deliver one-to-one technical support for the network liaison officer. During this time several emerging PLHIV organisations were supported to formalise operations and ultimately to legally incorporate. This process strengthened regional PLHIV movements, but also helped build a genuinely national network of PLHIV organisations so that Igat Hope could truly claim to be informed by the experiences of PLHIV from right across the country.


National PLHIV Conference

IGAT HOPE INC.

P.O .Box 200
WAIGANI
National Capital District
Papua New Guinea
Phone..:+(675 325 2890
Facsimile: + (675) 3252099
Email: amcpherson@ihi.org.pg

Igat Hope National Conference for People Living with HIV
November 2008
Conference Report

Figure 2. Front cover: ***Igat Hope National Conference Report for People Living with HIV, 2008***
Source. Photographed by author from copy in his possession.

Also, during this period, Igat Hope conducted two national summits. The first, in 2008, ran over four days with more than 80 people attending each day, including a total of 41 from outside Port Moresby. Apart from being an important opportunity for information sharing, the summit also gave PLHIV the space to develop a set of advocacy priorities. These priorities (listed in the conference report, Figure 2) included a greater role for Igat Hope in setting the national training agenda; greater involvement of PLHIV in home-based care; distribution of research findings on treatments use; better understanding and use of the HIV/AIDS Management and Prevention Act; non-discriminatory health care; national campaigns on treatment, care and support; greater availability of HIV treatments; greater church support for PLHIV and treatments; treatments literacy; more consultation with the National AIDS Council Secretariat; more discussion about the role of Igat Hope as a national leader; and the need to involve PLHIV from around the country in the leadership of Igat Hope.

So many elements of this advocacy agenda can be cross-referenced to the experiences of human-rights violations detailed in Chapter 4. Issues being raised in 2008 — the role of *HAMP,* discrimination in health care, access to treatments, the need for more and better information relevant to PLHIV — were repeatedly raised with me by HIV-positive interviewees almost a decade later. This suggests that in the decade between the conference and my interviews, insufficient progress has been made in these areas.

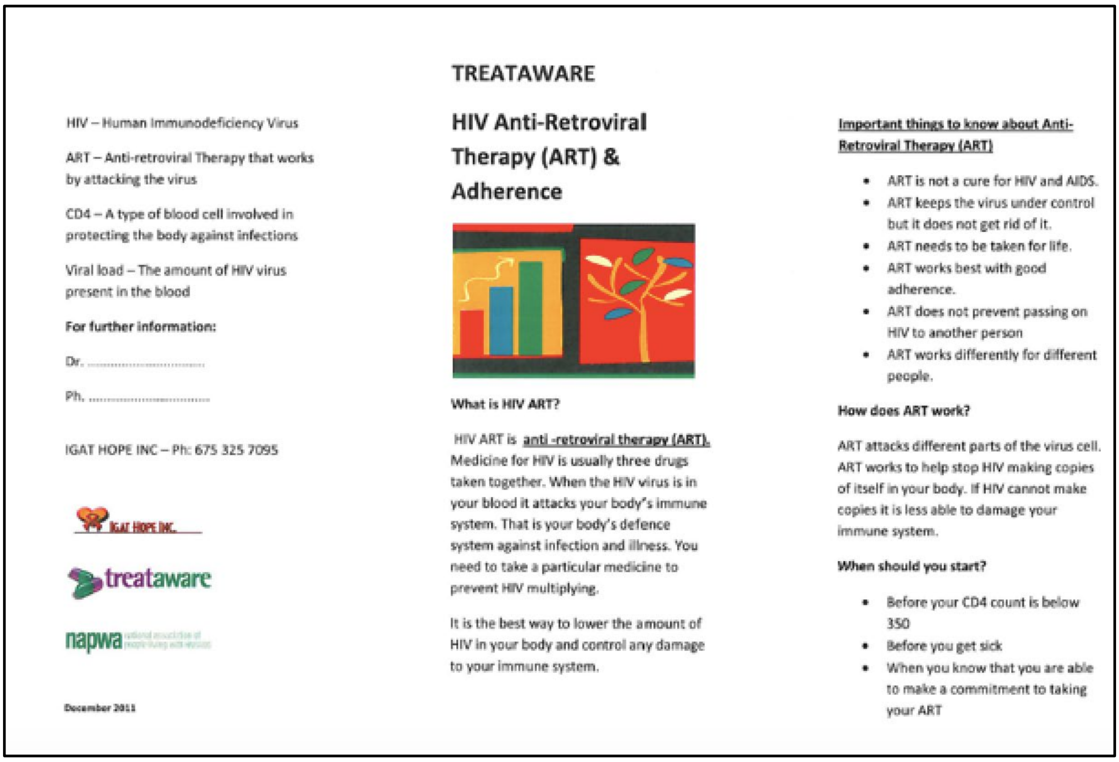
The second national summit took place over three days in 2010. The summit had a focus on treatment, care and support, stigma/discrimination and human rights, and leadership and good governance. Importantly, and in contrast to the 2008 summit, by 2010 Igat Hope was capable of conducting the forum with minimal external assistance.

The Sanap Wantaim period was also marked by Igat Hope’s emerging expertise in advocacy relating to access to HIV treatment. Igat Hope convened PNG’s first national workshop on HIV treatments in 2010. Over 30 people participated in the event including PLHIV; policy makers; doctors, nurses and other health workers; community workers; and development partners such as NAPWHA, AusAID and the Asian Development Bank. The summit focused on identifying barriers to treatment access and ways of delivering better treatment and health services to PLHIV. It culminated in the issuing by unanimous agreement of the *Waigani Statement on HIV Treatment Action 2010*. This was more than just a comprehensive statement of the issues relevant to treatment access. It was a call to action, that offered a roadmap for a better treatment responses, and placed advocacy firmly on the national agenda.

In 2012, Igat Hope convened a follow-up workshop bringing together Igat Hope staff and a dozen workers and volunteers from PNG clinics. The workshop sought to identify ways of kick-starting the advocacy program that the *Waigani Statement* had heralded, but which had failed to materialise. The workshop evaluation indicated a very positive event.

During this period Igat Hope and NAPWHA jointly produced a treatment information brochure, *HIV Anti-Retroviral Therapy (ART) & Adherence* (Figure 3), covering the basic facts about

ART and tips for facilitating adherence. This was the first peer-developed resource about treatments in PNG, more than a quarter of a century after PNG's first HIV diagnosis. Igat Hope also established its Collaboration for Health in PNG (CHPNG) program to embed peer expertise within HIV clinics. A number of pilot programs were conducted under the program whereby people with HIV were employed by HIV and sexual-health clinics to provide advice and support to PLHIV accessing treatments, as well as to clinic workers. The program funded the sharing of peer expertise, which other PLHIV valued greatly. It also helped strengthen the capacity of clinic staff to understand the challenges associated with taking ART, and to better respond to these challenges. This program was eventually picked up by the Global Fund and continues today as a highly regarded Igat Hope HIV intervention.



HIV – Human Immunodeficiency Virus

ART – Anti-retroviral Therapy that works by attacking the virus

CD4 – A type of blood cell involved in protecting the body against infections

Viral load – The amount of HIV virus present in the blood

For further information:

Dr. ....

Ph. ....

IGAT HOPE INC – Ph: 675 325 7095

December 2011

TREATAWARE

HIV Anti-Retroviral Therapy (ART) & Adherence

What is HIV ART?

HIV ART is **anti -retroviral therapy (ART).** Medicine for HIV is usually three drugs taken together. When the HIV virus is in your blood it attacks your body's immune system. That is your body's defence system against infection and illness. You need to take a particular medicine to prevent HIV multiplying.

It is the best way to lower the amount of HIV in your body and control any damage to your immune system.

Important things to know about Anti-Retroviral Therapy (ART)

- ART is not a cure for HIV and AIDS.
- ART keeps the virus under control but it does not get rid of it.
- ART needs to be taken for life.
- ART works best with good adherence.
- ART does not prevent passing on HIV to another person
- ART works differently for different people.

How does ART work?

ART attacks different parts of the virus cell. ART works to help stop HIV making copies of itself in your body. If HIV cannot make copies it is less able to damage your immune system.

When should you start?

- Before your CD4 count is below 350
- Before you get sick
- When you know that you are able to make a commitment to taking your ART

Figure 3. Igat Hope ART brochure, *HIV Anti-Retroviral Therapy & Adherence*
Source. © Igat Hope and Napwha, 2011. This brochure was distributed by both organisations and a digital copy was supplied to me. Used with permission.

Lean times for Igat Hope, 2012–20

From 2012 onwards DFAT's interest in supporting Igat Hope declined. DFAT cited different reasons at different times for its waning interest, including pressures on its aid budget and a desire to deliver support via a different model. The first step in DFAT's defunding process was to conclude funding for NAPWHA's support of Igat Hope. At the time DFAT advised that it had decided to deliver technical support via a different model, specifically the long-term embedding within Igat Hope of an Australian volunteer. No such volunteer was ever sourced or supplied to Igat Hope, leaving it effectively without access to technical support.

After two years, during which Igat Hope had no access to technical support, DFAT introduced a new arrangement whereby technical support would be provided via the agency contracted to manage its aid projects in the PNG health sector. This support was different in two critical ways. First, there was no specific budget for technical support so Igat Hope could not plan ahead for a structured program of assistance. Instead, Igat Hope had to apply for each instance of support as a need emerged, requesting this funding from a generalist stream shared with all DFAT-funded projects within the health sector. And second, the form of support provided was determined as much by DFAT as Igat Hope, so support was often tailored around the donor’s needs rather than those of the organisation. By way of example, support was significantly targeted at institutional reporting and financial accountability rather than building advocacy capacity or facilitating networking. During this period DFAT also reduced its level of core funding for Igat Hope. The staff dwindled to two employees, and then to just the position of executive director.

DFAT eventually determined that from 2017 and beyond it would not fund Igat Hope at all. DFAT implemented a new system of allocating resources to the NGO sector, the PNG Partnership Fund, seeking to fund a selective number of consortia programs in the health and education sectors through a grants partnership arrangement with principal recipients, rather than direct funding to a range of small- to mid-size NGOs. This arrangement aimed to consolidate aid investments and expand coverage of evidence-based initiatives to improve service delivery. Funds were not specifically earmarked for HIV but were instead available for ‘infectious diseases’ and/or ‘sexual and reproductive health’. Consortia were not required to indicate whether or how they would work with, or deliver services to, PLHIV. The PNG Partnership Fund received a lot of initial criticism, including from NAPWHA and AFAO, for the way it disadvantaged local, smaller NGOs in favour of larger international NGOs, which were regarded by DFAT as having more reliable management and accountability systems. Smaller NGOs could not compete and, with limited time and resources, were supposed to ‘negotiate’ their way into consortia with multi-million-dollar international development agencies. The PNG Partnership Fund’s annual review in 2019 stated: ‘PPF will need to be vigilant to ensure that smaller grantees who may not have robust financial and management systems are supported to work in a flexible environment,’ but this support extended only to those that had been able to find their way into consortia which had been fortunate enough to attain funding. Kapul Champions and Friends Frangipani were not among these few, fortunate local groups. Igat Hope joined a consortium with Catholic Health Services and the Burnet Institute, which was successful in securing funding from DFAT for clinical services delivery. As a result, Igat Hope’s highly regarded clinical outreach program continues. Igat Hope also receives modest levels of funding from the Global Fund, that was due to expire in 2020.

The preceding part sought to record what it was that Igat Hope *did*. The following part tries to understand some of the impacts of this work based on the feedback of interviewees and my direct observation. Interviewees were asked to reflect on the work of the organisation and to explain what this work had meant for them. Interviewees had lots to say — some of it was very positive and some was highly critical. I have separated out the wins/successes from the losses/disappointments. When considering the latter, it is critical to keep in mind that organisational efforts must always be seen in context — high levels of need and demand amongst constituents, limited funding and insecurity of resourcing, enormous barriers to success — and there are questions, of course, around who has the right to determine success or otherwise. Still, interviewees were candid about what they saw as things that had been done right and things that could have been done better.

The ability of Igat Hope constituents to reflect critically on the organisation's work is an organisational strength. Interviewees had well-developed views on what Igat Hope should be expected to deliver and considered advice on how organisational performance might be improved. They were all able to look beyond disappointments and lost opportunities to a future in which Igat Hope might operate in a more effective way.

Successes of Igat Hope

The value of 'peer'

Many interviewees talked up the value of the peer connections afforded by membership of Igat Hope. This peer connection was often described as opportunities to share stories and experiences with their 'friends'. The descriptor 'friends' is the term of endearment many PLHIV use to refer to other people with HIV. It works on multiple levels. It conveys the high value that PLHIV place on relationships with their HIV-positive peers, reflects that many of these relationships are friendships and also operates as code: asking if someone is a 'friend' is a discreet way of inquiring about HIV-status:

> When I first joined Igat Hope, one thing that excited me about Igat Hope was seeing my friends and seeing my friends telling me things … It is really nice to get the latest information on what ART is doing to our body. All this and all that, you can't get it elsewhere, you only get it when you become a member of Igat Hope. (Rachel, PLHIV)

Many interviewees reflected very positively on the support they had received from their peers, but they were speaking of more than just friendship. Like Rachel, many referred to the insights into treatment management that they attained via their peers. Some spoke of the value that peers added to the services offered by Igat Hope (and other service providers): ‘I would rather, like, to go to a place that is peer-led with AIDS counselling, treatment and anything to do with PLHIV, but it must be peer-led’ (Matilda, PLHIV).

Identity and the establishment of a national organisation

Interviewees spoke of their pride in Igat Hope. The organisation stood as a testament to their efforts and many took great pride in the organisation’s achievements. The nature of the pride varied a little. Some were incredibly proud that the organisation had been established at all. After two decades of operation, it is understandable that people might forget what an incredible achievement it had been simply to establish the organisation in the first place. But it is worth remembering that it was established at a time when treatments were generally unavailable, when community fear was at its peak, when there were few positive advocates prepared or able to speak out, and that it had absolutely no government support (from PNG or Australia). Interviewees remembered these times and recalled the courage of Igat Hope’s earliest leaders. These interviewees tended also to be very proud of the fact that the organisation had survived, even if they were able to reflect on organisational failings.

Interviewees talked about NGO responses more generally in PNG, noting that different NGOs had at different times done very good work, but that many of them had collapsed or disappeared or otherwise ultimately ‘failed’. By contrast Igat Hope has remained operational, and many interviewees thought the mere fact of its continued existence was something to be celebrated. For some, this institutional achievement was linked to their own identity.

> Okay, in the past years I came on board to join Igat Hope as a very young woman … and at that time HIV was new to the city, full of stigma and discrimination I have been through, but Igat Hope was there. But like we did not have any office, just a name and nothing, and I used to go from one drop-in centre to another drop-in centre and then with our (friends) at Igat Hope. As years goes by we got a woman on board who worked for us and we have office space now to see Igat Hope in good conditions, got staff in place and now becoming a national body. Before it used to be NCD alone but now it is a national body so I am proud, very proud to see that organisation going as well and I think that I am part and parcel of the organisation itself. Now I am [older and] growing old in the organisation. (Elsie, PLHIV)

Elsie hoped for a change in Igat Hope’s approach that would see it delivering more tangible benefits for local PLHIV. On this point Elsie was in the minority, although not alone. Several other interviewees recognised that, by going national, Igat Hope had reduced its focus on the support needs of PLHIV in NCD. However, most interviewees who talked about this change accepted that this was the price of having a national advocacy organisation.

> I used to think that Igat Hope was supposed to be doing this for me, this for me, and then they are not doing much, they are not doing enough, but then I realised that, no, I can't take my status out on Igat Hope, they [exist] just to make sure that they advocate for us in terms of making sure that Igat Hope is here advocating for us in terms of human rights and stuff like that. (Ruth, PLHIV)

Igat Hope constituents who bemoaned the loss of local services that had come with going national could also see the value in Igat Hope having reached beyond the capital. For example, Matilda, a woman living with HIV, had this to say:

> The good thing that they [Igat Hope] have done is like going to the provinces and not only Moresby but other places are coming up as well, like getting organised, having their own groups, talking about what they need, what they want in the places or the communities where they live. I think they [Igat Hope] took the lead to actually bring it out.

Opening up about status

Interviewees talked about the role of Igat Hope in encouraging PLHIV to be open about their status. This was described in different ways. Some reflected that the emergence of greater numbers of positive advocates had given the virus a human face, and they educated the population that PLHIV were everyday members of the community. This had chipped away at the notion of PLHIV as 'other' with a consequent reduction in stigma and discrimination. Interviewees were grateful for Igat Hope's assistance in helping them disclose their status, with many talking about the personal value of 'coming out' as HIV-positive:

> I never came out in telling people about who I was until I joined the organisation and then that gave me confidence in coming out and now I don't feel afraid of talking about HIV and telling people how to look after themselves. (Serah, PLHIV)

In this quote we see both personal liberation and a peer contribution to public health. The interviewee was describing her new role as an advocate for PLHIV and as an educator for her peers, advising them how to manage treatments and live healthy lifestyles. She was not the only one to talk about the way Igat Hope had helped build her confidence. This was a common reflection, and was often associated with an express desire to 'give back' to the positive community: 'I would like to increase the knowledge or gain the skills so I would be there for my other friends' (Matilda, PLHIV).

Treatment access and adherence support

> I think the biggest thing is our treatment, our treatment in the country. Igat Hope has [to] fight a lot for the treatment side of it and now we can see treatment has been rolling out [in] the rural places as well, which in the early days used to be in the city alone and [in] some of the provinces there was no

> ART, but now you can see in the provinces there is ART there, so I am very proud of Igat Hope. (Elsie, PLHIV)

The value of peer support around treatment adherence was often mentioned. There was a high level of awareness of Igat Hope's expert patient trainer/clinical outreach program. Many interviewees cited the program, which employs PLHIV to work with clinicians to deepen understanding among HIV-positive patients of treatments and adherence, as a big success. The peer element of this has been critical to its success, they said, as no one understood the challenges of compliance like a person with HIV.

Many interviewees talked about the importance of the peer element to the quality of Igat Hope's work more generally (beyond just the expert patient trainer program). They talked about it in different ways, but many observed that Igat Hope's services involved a special degree of understanding that could come only from personal experience. It is interesting that this service characteristic was so often cited, given the organisation has never had an HIV-positive executive director and only a minority of the organisation's employees have been PLHIV. While a few interviewees raised the HIV status of employees as an issue, most interviewees seemed satisfied Igat Hope's services have properly reflected the lived experience of being HIV-positive. The fact that all Board members are PLHIV is likely to have been a major contributor to this outcome.

Interviewees talked at length about HIV treatments and exactly what might be going on for PLHIV in PNG, particularly with regards to the widely reported problems with ART adherence. Elsie was asked to explain what might be contributing to non-compliance and offered three possible explanations, suggesting all three were likely to be in play simultaneously. The first was that when people recover and start to look better, they take themselves off treatments. This might be because they have received insufficient information about the importance of adhering to HIV treatments for life. Where PLHIV have not had these facts properly explained they would follow a typical human practice of stopping medical intervention when symptoms disappear. Elsie's second explanation was around alcohol: 'Some they do like alcohol, they go drink, drink, and forget to go and get their medicine or do other things.' Sometimes 'alcohol' was shorthand for a kind of lifestyle that involved heavy consumption of alcohol and associated practices such as smoking marijuana, partying, not eating properly and disrupted sleep patterns. The third reason put forward by Elsie was the desire to hide their status from others. And most often 'others' meant partners:

> They don't tell their partners they are like this [HIV-positive] so they hide this. So it makes them distressed when they are taking medicine with their partner. So I see most of my friends come and we share among ourselves.

A fourth reason was put forward by other interviewees, although not mentioned by Elsie, namely a lack of family support. This was sometimes used as code for lack of community support, or for the kind of rejection and isolation documented at length in Chapter 4. Importantly and very disturbingly, several interviewees expressed concerns around the long-term efficacy of ART. Rachel had this to say about ART:

> I don't know. I keep thinking — I may be wrong, I don't know, it's just that I think that the virus gets smarter. We've been on ART for such a long time and I'm thinking that — I sometimes think that because we are on ART for such a long time our immune system is not as strong as it used to be. It's amazing how I see other expatriates, especially PLHIVs, they can leave and they [are] still around and our friends still get to die and, I don't know, I'm thinking that it's our ARV. I know that we are eating healthy. I'm eating healthy. Is it the food, is it the air I breathe? I am also confused. I have no idea. It's just that I see myself, I am going skinnier and skinnier and I'm thinking is it the ARV decaying my body? I don't know. It's yeah, I think it's the medication is too strong for us.

This references a number of very important issues: a lack of detailed knowledge about ART even among treatment activists in PNG; questions around long-term side effects; resistance and drug failure; poor treatment outcomes compared with PLHIV in developed countries, due perhaps to underlying health inequalities that affect how bodies cope with treatment, or the possibility that the drugs made available in PNG are inferior to those distributed elsewhere. Very unfortunately, there is a view commonly held in PNG that a policy of free ART equates with adequate PLHIV care. As Rachel points out, this is not the case.

Several HIV-positive interviewees spoke about the role of Igat Hope in the advocacy for treatments. Those that spoke of this achievement tended to rate it as the organisation's most significant accomplishment. Alani spoke knowledgeably about the role of Igat Hope in procuring national government funding for ART. Alani described the organisation's work around the time when PNG lost Global Fund resources (because of government failings). The loss of Global Fund support, under Global Fund Round 10, had threatened the free supply of ART but, as a direct consequence of Igat Hope advocacy and lobbying, the national government had stepped up to allocate funding for the procurement and supply of ART (at the time of interview running at a cost of around PGK15 million per year). Igat Hope had effectively prompted the government into action via a mix of pushing, lobbying and shaming, Alani said.

Serah thought that Igat Hope's advocacy plan was a really good foundation for advocacy, but that it had not been actioned. Similarly, the *Waigani Statement* had not been converted into practical action. Serah was not alone in lamenting lost advocacy opportunities; others also thought more could have been done around advocacy for treatments.

Leach and Rule's (2013) report on the NAPWHA–Igat Hope partnership makes some observations on the challenges of treatment advocacy in PNG, and these observations remain relevant to any assessment of Igat Hope's performance. The report notes the peculiar history of ART in PNG that has cast Papua New Guinean PLHIV as passive players in the national drug roll-out. Stakeholders in national drug supply have resisted involving PLHIV in their deliberations and activities, isolating them from processes intended for their benefit. Advocacy for treatments has been further undermined by the enormity of structural health system barriers in PNG, by the failure of in-country agencies to support Igat Hope or to do their bit to implement the *Waigani Statement,* and by the ill-health and untimely deaths of too many HIV-positive activists. The report also notes the challenges involved in *teaching* advocacy, and the real possibility that the model of advocacy promoted by NAPWHA and other well-intentioned donors may not have been sufficiently indigenised.

Stigma and discrimination

Interviewees talked about the impact Igat Hope has had on reducing stigma and discrimination. There had been great value, they said, in PLHIV standing up publicly and presenting the human face of HIV. This had been particularly important in promoting an understanding of HIV treatments and their role in transforming HIV into a manageable condition.

> In the early days, like, people thought that when somebody is infected, like he or she can spread the virus through by sharing eating utensils or sharing the same common bathroom or toilets or by sleeping in the same house or something like that, which now it doesn't. People know that HIV is like a killing disease but it has a medicine, a treatment that can stop it from multiplying or things like that. Through our, to be honest, it's through the advocators — people who come and say, 'Oh hello, so I'm living with HIV and I'm on treatment like this and I can do that and I can do this and I can live — so why don't you just come over like me and be together — that's not how we can get HIV and AIDS it's from that side, it's true that side, it's true this side.' So like we explain to the community and to the people. A lot of awareness has been going on so I think the key people are us.
>
> So I am very proud of Igat Hope too, and also the slowing down of stigma and discrimination in the city and the country as well. I think Igat Hope has done a lot. Now anybody can sit down and talk about HIV in the family homes, community, but it was not like this before. (Elsie, PLHIV)

Rachel, a woman living with HIV, believed she had seen an *increase* in stigma and discrimination, which she attributed to declining media interest in HIV, linked, in part, to the reduced capacity of Igat Hope to stimulate or generate this interest. She affirmed the power of peer testimony in combating stigma and discrimination and recognised this 'human angle' was critical to generating ongoing media interest in PLHIV stories. Even though there was a risk that these stories would be sentimentalised or portray PLHIV as victims, they at least provided coverage of PLHIV issues. Rachel considered the days of easy media coverage to be (regrettably) over: ‘Because there is no more media coverage of people living with HIV talking about their status and telling the public about their rights … I think that stigma and discrimination is slowly rising up.’ Rachel was frustrated that, just at the time Igat Hope needed to increase its advocacy and media work to combat declining media interest, its resources had been depleted to the point it was unable to step up as required. This was contributing to increasing stigma and discrimination, she thought.

Igat Hope challenges

I had the following conversation with Bosai, a man with HIV, in which he identified a number of ‘problems’ with Igat Hope which were also reported by other interviewees.

> Bosai: Why? Things are not succeeded because of leadership failure. Leadership failure cost downfall …. it was the board which we established; they did not play their role properly. Why that happened — because those villagers which we appointed them as board, all of them had different interests and they didn’t go through with the running of the organisation. The relationship which I saw was like, currently now people working in there where no proper relationship or agreement [exists] between the board and the people who are working, so then things can eventuate. Yes, so not agreement between the board and the staff, those arrangements weren’t carried out. From my observation, it’s [the fault of] both the staff and the board. Igat Hope should be coordinating and rolling the activities down to the networks but such things never eventuate. Igat Hope has an office, it has an overseer and then as overseer they do see what other needs or what are the activities are to be carried out … but it never eventuates.
>
> That’s the big issue with Igat Hope. I myself was in with Igat Hope in the office and I really witness it, that is the big issue, mismanagement of funding. To manage that we have to have transparent people who [properly manage] whatever funding is being given, it has to be used for that specific purpose but this which I saw was it didn’t look like it. When funds came in people were diverting it to other activities the very activity which seems to be eventuating — it didn’t turn out. Mismanagement of funding and untransparent. That is the big issue with our office here — Igat Hope.
>
> Me: Do you think Igat Hope should continue in the future?
>
> Bosai: Igat Hope should continue.

I’ve started with this discussion with Bosai because it neatly pulls together so many of the critiques I heard throughout my interviews, while continuing to support the organisation. It is worth noting that not one of my interviewees, many of whom were very critical of Igat Hope, thought the organisation should be wound up. Every interviewee wanted Igat Hope to continue.

The actions of some individuals

When asked about the shortcomings of Igat Hope, most interviewees lay blame squarely on the people involved. These criticisms were general rather than specific, and it was very rare for an interviewee to actually name an individual as having done something wrong. Criticisms took different forms but can be grouped into two categories: motivational/character deficiencies, and skills deficiencies. Motivational deficiencies could be seen by interviewees to exist where an individual put himself or herself ahead of the organisation: ‘We don't have the people to work forward for what we are here for … We need leaders who can … stand up strong … not for a self-individual but for the organisation’ (Matilda, PLHIV).

On the issue of skills, interviewees commonly believed that board members should be educated and literate. One interviewee pointedly blamed Igat Hope’s shortcomings on the appointment of ‘villagers’ to the board. It was interesting that so many interviewees expressed the view that board members should possess baseline capacity in reading (and often in reading English), given the sizable proportion of the membership that would be subsequently ineligible. However not everyone supported this position. A few interviewees emphasised the need for the board to reflect the broader PLHIV community, including the many Papua New Guineans with HIV who had limited formal education and low literacy. Instead, these interviewees said, Igat Hope could provide training for current and potential board members and support them via external advisers. Financial management issues arose often in conversations, but here it was not always easy to tell whether interviewees saw it as a character failing or skill deficiency.

Overall, views on the board and management were mixed. Some interviewees thought the board had inadequately exercised its governance responsibilities; others thought the employees had failed. Each was accused of corruption and each of these allegations was vigorously denied.

Structural problems, and the positive/negative divide

One interviewee with intimate knowledge of the organisation advocated the introduction of board positions for non-PLHIV. She did so for two reasons: as a means of accessing a deeper pool of governance talent, but also because the success of Igat Hope was so obviously dependent on effecting behaviour change within the negative population. In order to understand what the broader community was thinking, and what messages it might be open to, the board would need to hear firsthand from negative members, she thought. Another interviewee felt strongly that the organisation should employ only PLHIV:

> One idea that I always have is, instead of employing very highly paid people that are expat there but they are negative, and then working with the PNG network, I am not agree with, because they have a different idea there and they don’t really understand my basic needs … I want the Igat Hope

> governance to … up-skill a PLHIV who is already in the system, give them some good time frame of training or some courses — I think it would really work. (Juvelyn, PLHIV)

Several interviewees commented knowledgeably about the seemingly endless conflict between the board and the secretariat. This was described in many different ways — as a power tussle, as a fight over effective governance and as a reflection of the divide between HIV-positive and HIV-negative Papua New Guineans. Alani said the dispute was multi-faceted. It involved shared misunderstandings of the ways in which community sector governance was supposed to operate. These misunderstandings meant that people were applying fundamentally different governance approaches to the resolution of problems, and, in such circumstances, disputes could never realistically be settled. Alani thought the board had failed to fully understand its responsibility to provide direction to the secretariat. As a result, the secretariat had wandered off in its own direction pursuing activities it considered sensible or accepting funding for activities that donors prioritised, when these might not match up with HIV-positive priorities. On this analysis, there was no malice on the part of the rival positions, more a failure to understand who gets to call the shots when there are differences of opinion about strategic direction.

Alani said that when the board had sought to stamp its authority on the organisation's direction, it had not always had the governance skills to do it neatly:

> So the secretariat went about doing its own thing and the board was sitting there just complaining … they had the right to go and tell the secretariat ,'Hold on, you're not supposed to do that — you're supposed to do what I am telling you to do. What we are telling you is what the networks are telling us. We represent — the board represents the country'… We had this board who could have given the stronger directions and they didn't do that so that's where all the mismanagement came about … but the real issues about people living with HIV got lost along the way.

Alani was clear that this breakdown in governance was predictable in PNG and that donors and technical advisers had failed to take appropriate steps to prevent or manage the problem. In-country technical support had been required and not provided, Alani thought.

Confusion regarding purpose — advocacy or services?

Igat Hope's evolution from local drop-in service to national advocacy organisation is discussed above as a success, but it was also described by some as a failure.

> The failure side of it [Igat Hope] is like, it really can't help the needs of the members. When I say needs of the members, like financially or physically help them. They can build a capacity, they can do all these things but after all it is nothing, after the training or the workshop it goes back to normal again. Like if somebody is sick and he or she is in the ward or something, there is no funds to take care of these kind. It is sad too but I think it's not in the constitution, it is not funded so it's the difficult

> side of it. Or if some of the members have passed away who don't have family support for [a] proper burial or something like that. (Elsie, PLHIV)

Before she said the words quoted above, Elsie had had many positive things to say about the organisation, including its ground-breaking advocacy work. But here she was talking about where it was perceived by members to have underperformed. Igat Hope has long struggled to manage the tension between being an advocacy organisation and being a service provider and this issue was raised by many interviewees. Several interviewees lamented that Igat Hope did not provide the kind of direct support they sought, such as cash, food, medicines, payment of funeral expenses, payment of family expenses like school fees and the like. It is important to recognise that where interviewees were critical of Igat Hope's failure to deliver the direct services they desired, this often represented a misunderstanding of the organisation's purpose as enshrined in its constitution, or of its funding arrangements. But perhaps the most important element of this criticism is the way that the prioritisation of advocacy or national representation over direct servicing is said to have influenced the organisation's peer supports. It is apparent that interviewees greatly value the peer element of Igat Hope's work. Some interviewees miss the peer connection that flowed from Igat Hope's operation as a local drop-in centre when it was a service for a geographic community (NCD). Igat Hope's evolution into a national advocacy organisation — with a much larger constituency that cannot be serviced via drop-in supports — has reduced its role in facilitating peer connection.

While interviewees acknowledge continuing benefit from the peer elements of Igat Hope's clinical outreach program and its national summits, some interviewees feel they have lost peer support that have not been substituted by other providers. As Elsie complained, while there were still some drop-in centres in Port Moresby, these centres wanted new clients, not old ones. Some of the camaraderie that she had valued had been lost, she said. This tension played out in the ongoing struggle between the board and secretariat. Boards generally included PLHIV who remembered and missed the 'good old days' when Igat Hope was a drop-in service and a source of both connection with friends and valued meals. By contrast, the secretariat (and particularly the executive director) was concerned with compliance with contracts that emphasised advocacy and national reach. It was understandably difficult for many board members, with limited governance experience or training, to support a shift in organisational focus that reduced the services they and their immediate friends had valued.

Inadequate process

Several Igat Hope members talked about the organisation's lack of policy on the things that matter — office procedures, financial management, personnel management etc. This had left the organisation vulnerable, with relatively inexperienced staff and volunteers making decisions in a policy vacuum. This observation was also made often by sector stakeholders, but no one who made the criticism (member or stakeholder) suggested that the organisation was resistant to doing things in a more ordered way. Instead, most interviewees thought the absence of policy and process could be addressed over time. However, several people commented that the development of additional policies would not necessarily make things better, observing that even where Igat Hope had *had* a policy — such as its advocacy strategy and the *Waigani Statement* — it had not been able to convert the policy into practical action.

What future Igat Hope?

The model of a representative organisation for PLHIV retains widespread support among interviewees and is seen as still being a critical part of the national HIV architecture.

> Igat Hope is from the Government level to the donor level. They are recognised and Igat Hope is the national PLHIV network in PNG. Without Igat Hope you can't make any policy, without Igat Hope you can't make any decision, without Igat Hope you can't change the HIV infections. (Juvelyn, PLHIV)

Alani stepped through the challenges confronting the organisation, beginning with the challenge of retaining appropriate focus on PLHIV in the national response. To the outsider this may seem an odd challenge to have, as how could it possibly be the case that PLHIV are missed in a national HIV response? But my experience with HIV responses in several countries has taught me that these responses often struggle with issues of balance and focus and PLHIV often missed out. Some national responses have emphasised prevention over treatment and care, prioritising (candidly or not) the protection of the uninfected majority over care for the infected minority. But Alani was describing a variation on this theme. PNG has undoubtedly seen an increased focus on Most-At-Risk Populations (MARPs) or Key Affected Populations (KAPs). Several interviewees noted that in recent years the national response had been rapidly reoriented towards a focus on MARPs rather than the general population. But somewhat surprisingly, PLHIV are not being seen as a MARP or KAP. As Alani (PLHIV) commented, 'Everyone wants to fund MSM programs, sex workers programs, something to do with TGs, so most of the money is going there.'

This is a risk analysis undertaken exclusively through a prevention lens, where the only question becomes, 'Who is most likely to contract HIV?'. It ignores the social and economic inequities faced by PLHIV which intensify their risk and compromise their health, and which can undermine their critical role in prevention. All interviewees who spoke of this agreed that if PLHIV are not seen as a group at risk, then the future of Igat Hope is most definitely at risk. Put another way, if PLHIV did not remain at the heart of the national response, there would be no ongoing role for Igat Hope. This battle for 'place' within the national response was itself part of a bigger battle to ensure continued focus on HIV in a country with so many health challenges. There was general agreement among interviewees that interest in HIV nationally is on the wane. Whereas HIV had previously been much covered in national media and it had been possible to secure funding for HIV responses, things had changed. Many interviewees expressed concern about reduced funding for HIV and falling levels of public interest in the epidemic. These interviewees observed that, while there had been advances in the national response, there remained much work to do, especially outside Port Moresby. They believed that an effective HIV response would require *more* money, not less. These views indicated to me a solid grasp of the bigger picture. Many interviewees were able to look beyond what Igat Hope could deliver for them personally; they were able to see the organisation within the context of shifting national health priorities.

Alani moved on to the challenge for Igat Hope in rebuilding its reputation among donors and other partners tired of supporting the organisation to address its struggles:

> The organisation has a very bad reputation among a lot of partners and, you know, when we talk about Igat Hope we are talking about PLHIV … so, when partners don't want to work with Igat Hope, who misses out? It's the people living with HIV who miss out on programs and that's a huge worry for me.

Alani thought the reputation of Igat Hope could be rebuilt but that it would take time, and time might be a luxury Igat Hope could ill afford when funding was constantly being reviewed. The organisation would need new systems to manage fraud and governance challenges before partners would agree to provide funding, and Alani believed this would take time the agency did not have.

Interviewees had plenty of suggestions for future Igat Hope work, including promoting adherence programs though all ART clinics; working to reduce stigma and discrimination; national advocacy on human rights; working on ensuring access to new drug options; connecting PLHIV to each other; direct support for members, such as food, medicines and payment of school fees; and national networking. Support for more work in national networking was particularly strong among interviewees. Igat Hope was seen to have achieved significant success in building provincial-level PLHIV groups but, according to many interviewees, it had failed to continue this support. Igat Hope was strongly encouraged to rebuild its support for these groups.

Some observations on corruption

It was common for interviewees to refer to the struggles experienced by both Igat Hope and Kapul Champions in the management of money. Igat Hope, in particular, has had issues with money management and funds have been misused. These occasions have not generally been documented in detail, although this is not because the misuse was not known or was hard to prove. Instead, there was a desire to manage the issue in ways that would limit the negative impacts on Igat Hope. This desire was shared by the organisation, by NAPWHA and, to a degree, by the funding agencies whose funds had been improperly applied. Funds were misused by Igat Hope on at least three occasions, and very possibly more. In attributing blame to Igat Hope, it is worth noting that the misuse mostly occurred as a consequence of employees or board members taking individual actions that were not institutionally sanctioned and which would almost certainly not have been approved by the group. On one occasion the misuse was the result of several people acting together although, again, this was not organisationally sanctioned behaviour. (Funds were misused by Kapul Champions on one occasion, although the organisation was able to retrieve most of the funds from the relevant individual.)

It is easy to describe these incidents as evidence of organisational corruption, although that is not the case. The actions were not institutional and were in fact damaging to the institutions. The institutions, in the form of the boards and paid employees, sought to undo the damage that had been done by individuals, in many cases personally intervening in awkward situations with peers and colleagues in ways that damaged friendships. All these incidences of misappropriation were actions taken by individuals and for reasons that are, on some analyses, absolutely defensible. To begin with, donor money is sometimes seen as being subject to a different set of rules (and not in the way donors might like).

> People are having this mentality of their funds are coming from the donor agencies so it’s free money, that’s what they have in their mind. So, we can use it, even if we are doing HIV work or not, we can just use it. (Serah, PLHIV)

It is obviously difficult to place people experiencing extreme poverty and hardship in charge of funds, to tell them that the funds are for the benefit of their community, and indirectly for their own benefit, but then expect them to understand that they are not allowed to actually personally benefit from the funds in any meaningful sense. When reflecting on these incidents of misappropriation, people involved often expressed the view that they were entitled to benefit from the money because they were PLHIV. This goes back to the tension for Igat Hope between being a service provider and an advocacy organisation. Igat Hope members and constituents struggled to understand why, given their undeniable need, they were to be denied access to funds earmarked for PLHIV.

But the sense of entitlement that interviewees described had another dimension as well. It was grounded not only in their status as constituents, but also because they felt they were *owed* by the organisation. On most occasions those utilising resources were volunteers, people actively and meaningfully contributing to the organisation. It is perhaps not surprising that, in a country that does not have a rich history of CBO volunteerism, volunteers felt a degree of entitlement to utilise available resources as payment for their efforts. And perhaps that is fair enough, as time volunteered to the organisation was time lost to income-generating activities. The PNG ethos of redistribution might also be relevant, where volunteers might see this redistribution (to them) as being an equitable consequence of their contribution to the collective good.

As with all 'corruption', context is everything. Igat Hope was described by some interviewees as corrupt, but far more common was a reference to the corruption of PNG more generally. It was mostly mentioned as a universal truth, evidenced by PNG's poor ranking on different measures of corruption.[1] It was often put forward as a kind of excuse — if PNG is so profoundly corrupt, and at seemingly every level from the national government down, why should Igat Hope or Kapul Champions be expected to be different? This is not an unreasonable question. While interviews were being conducted, the PNG media was full of stories of hijinks at the National AIDS Council Secretariat (NACS) with allegation and counter-allegation of misappropriation and worse (noting that NACS, like Igat Hope and Kapul Champions, is partially funded by DFAT with its zero-tolerance policy on corruption). And all this against the backdrop of corruption allegations being levelled at the prime minister (of the time) and many other PNG parliamentarians. (Indeed, during this period, the Australian press was similarly full of allegations of corruption being levelled at members of Australian parliaments.) All this 'corruption' needs to be seen in a cultural context. What seemed missing from many donor discussions of misappropriation was a questioning of the right to define corruption. Who gets to define it?

In his analysis of various ways of measuring corruption, Peter Larmour (2009) observes, 'Corruption is a complex, secretive phenomenon. Particular acts can be interpreted in different ways, so it is no surprise that it is hard to measure and that measures disagree' (156). Grant Walton (2013) asks whether it is even appropriate to apply western notions of corruption to PNG behaviours, noting that discussion of PNG corruption is almost always framed by mainstream western views. By 'mainstream' he means understandings of corruption as legal (the breach of laws or rules), as public office (abuse of public office for private gain), or as economic (government abuse of its control over resources). Walton observes the mainstream view on PNG corruption as accepting that the country has major corruption problems with extensive non-compliance with rules and regulations. These mainstream perspectives posit that this non-compliance is a subversion of the nation-state (and its rules) by a population that identifies much more with clans than with country.

---

[1] For example, Transparency International uses a Corruption Perceptions Index to measure public perceptions of public sector corruption across nations. Transparency International uses multiple data sources including from the World Bank and World Economic Forum. PNG is currently ranked 137th of 198 countries with a score of 28/100 (where 100 is the maximum score).

This has corrupted the public service (where nepotism outranks merit) and the democratic process (where leaders provide material benefits to followers in return for votes). Walton notes that some scholars (Klitgaard 1991; Rose-Ackerman 1999) have also analysed PNG corruption from an economic perspective, voicing concerns over the government's control of large-scale development projects, particularly in extractive industries.

But Walton prefers the alternative view of corruption, which acknowledges how understandings of corruption are shaped by community norms and power. He considers the moral and critical dimensions of this view. Scholars writing from the moral perspective have noted customary acceptance of the entitlement to a second chance, and the placement of personal relationships above the rule of law and state. Some have described corruption as a weapon to be used by the weak in response to poverty and inequality. More common, however, has been the critical perspective, which highlights how definitions used by anti-corruption agencies marginalise competing definitions and how DFAT's approach has sidelined alternative local responses, giving cover to 'boomerang aid' (aid that returns to the country providing the aid, often providing more economic outcomes for the donor than the recipient). While acknowledging the dominance of mainstream views, Walton notes that local scholars have pointed out the marked differences between PNG and western perspectives on corruption, and the availability of local Papua New Guinean responses that may be better suited to fighting corruption than the responses utilised by DFAT. He observes a problematic shift away from seeing PNG cultural values as a strength in fighting corruption, and a conflating of the 'Melanesian way' with a tendency towards corruption.

Stakeholder interviewee Dante reflected on his work with Igat Hope and Kapul Champions before speaking at length about corruption in PNG. His comments related to both organisations, but also more generally to the operation of all organisations in PNG. Dante observed that Igat Hope and Kapul Champions, in most cases, attracted people at the margins of society. These were people who had been largely kept away from power and opportunity. They had less formal education, were less likely to be employed, were more likely to be poor, and were less likely to have supportive networks affording them opportunities to study or make money. These were people who had not had opportunities to acquire the skills necessary for running an organisation, so was it any wonder that they struggled to deliver governance? He also observed that in the absence of training in other methods, people were likely to replicate what they saw in the world around them. And what was being modelled around the country, Dante said, was corruption at all levels. So why would anyone expect the volunteers of Igat Hope and Kapul Champions to be any different? Dante was asked whether the behaviours routinely described by donors as corrupt might, in context, be something else. He returned to the matter of reflecting the social behaviours that are modelled and identified two practices that underscore the complexity of identifying corruption: nepotism and theft. What is modelled, he said, is reciprocity. This underpins the *wantok* system and means that if you give something, you get something back. But he added that, under the *wantok* system, giving is shaped by expectation. It is not really a case of you choosing whether or not to give; the social expectation is that you will give as requested and that failure to comply will have negative consequences. In this context, Dante asked, how could we expect people not to employ their *wantoks* into vacant organisational roles? And when things go missing around the office, or small amounts of money disappear, might it not be the case that employees are seeing organisational property as being in some way communal?

> Why would it be a surprise that a grassroots-based organisation with members with very little social capital, who have been ostracised, whose whole life has been about survival and survival means you cut corners, you break rules, however you can get something you get something, you lie, you steal, you do those things because that's what you do to survive, so why would we be surprised that that might infect an organisation on the ground? (Dante, stakeholder)

Dante was asked whether there might be a better way of donors managing these issues. Apart from being sensitive to cultural factors at play, Dante could not see a better way. It was important to acknowledge culture and traditional practices, but it was also the case that contemporary organisations operate in a rapidly modernising capitalist system where donors are bound by rules (local and country of origin) and best-practice guidelines. And at some point, argued Dante, corruption is corruption and theft is theft, even in traditional contexts.

> The other thing I would say is — how would you construct an organisation that allows for so-called *corruption*? [So] if we are saying that the western model is *cultural imperialism*, what is the alternative because I am not apprised of a model that is significant that allows for an organisation to actually do reasonable and accountable work in the community that is based on nepotism or corruption or cronyism or other elements that we would stand against.

I considered Dante's reflections illuminating. He had sought to be mindful of cultural factors while acknowledging the world of donor expectations in which we live. He had sought to identify a line in the sand beyond which no behaviour, regardless of its cultural dimensions, might be defended. It is a balancing act I've seen many development workers try and perform, trying to shape local practices whilst managing the disconnect between 'this work' and 'blanket rules' developed in different countries for different circumstances, and still seeking an ethical way forward.

Kapul Champions's successes

FREQUENTLY ASKED QUESTIONS:

What is an MSM?
MSM (Men who have sex with men) refers to men who feel sexual and emotional attraction to other men, as well as men who have sex with other men but also have sex with women. MSM may include men who have an identity as gay or bisexual and men who identify as straight.

What is a transgender person?
Transgender (TG) is a hard to word to define in the PNG context. We use the term transgender to describe someone who was born with one sex (male or female) but feels like a member of the other sex. Most of Kapul Champions TG members were born male but feel more comfortable living or acting as female. Some do this all the time while others do it only occasionally.

What is stigma and discrimination?
Stigma refers to prejudice, negative labels or attitudes that takes away from a person's (or group's) character or reputation. Stigma causes much suffering and can be a barrier to health care, education and employment.

Discrimination means treating some people worse than others. This may include social exclusion such as rejection from family and community, or refusal to provide employment, education, or health services. Many people in PNG discriminate against TG and MSM.

What are human rights?
We use this term to describe the rights and protections that all people have no matter where they live. These rights and protections are described in international laws that apply to PNG. MSM and TG have human rights.

WANT TO KNOW MORE?

Contact:

Kapul Champions

Kapul Champions Secretariat,
P.O. Box 200, Waigani, NCD, and
Phone: 325 7095,
Digicel # 72 954990.

Igat Hope

Igat Hope Inc. secretariat,
P.O. Box 200 Waigani, NCD, PNG.
Phone: 325 7095.

Frangipani

P.O. Box 963, Boroko, NCD,
Phone: 311 2575,
Digicel # 71008971.

NACS

Varahe Street, Gordons
P.O.Box 1345
BOROKO, NCD, PNG.
Phone: 3236161

Kapul Champions is proud to be affiliated with:

WELCOME TO

KAPUL CHAMPIONS
THE NATIONAL NETWORK FOR TG AND MSM FOR PNG

Supported by:

Figure 4. Brochure: *Welcome to Kapul Champions*
Source. © Kapul Champions provided me with both hard and digital copies of this brochure. Used with permission.

> It's a formal, it's an institution and it is representing a voice of a marginalised group of people and we are speaking as a collective voice … a member can say the same thing but they cannot do it if they are speaking as an individual, but being affiliated to KC and we say the same words but it will be viewed differently by the different [stakeholders] be it media, a politician or whoever change-maker that we are advocating to, and I think that is the beauty of KC … We can talk about issues that are, you know, [issues] people or policy makers don't usually talk about and are considered taboo, but when we talk, we are respected because people know that we are coming from a public health perspective and human-right perspective and not from promoting [a] promiscuous activities perspective because it's a formal institution organisation presenting the view. (Esther, stakeholder)

Voice and space

Many interviewees commented that Kapul Champions provides MDS and trans women with a voice (Figure 4):

> It is the national voice of our community and advocates [for] partnership with other stakeholder organisations … especially on human rights … So far Kapul Champions has now been established as an organisation and become a strong foundation and the voice for TG and MDS in PNG (Natasha, trans woman).

> I am very happy because KC has really made this an organisation for all of us to come together and to put our voice as one, we need to speak out and tell the whole world that we are here to stay and, um, even with the great work KC is doing because it is an advocacy organisation for human rights for TGs and MSDs, which is a really good work that they are doing. (Marta, trans woman)

> I think that maybe we should come out and maybe tell the community that we are here and we should tell them that — I mean we are not here by chance or choice, I mean, we are here. I think we should advocate more. I think that our organisation Kapul is … moving in that direction … we need to get people of PNG to hear our voices and us doing it and not somebody else from the community. (Chris, trans woman)

> So most of our community now know that we have voice in the country in terms of our rights and our welfare … What Kapul is looking at, we don't want to duplicate, what we are looking at is to have one voice and to have one big word — human rights — that's it. (MaryAnne, trans woman)

Others expressed the view that Kapul Champions had created a space where MDS and trans women could gather and be safe. It was the combination of these factors — the gathering of peers and the opportunity to do this in a safe way — that was really valued. Interviewees talked about the different ways they connected with other MDS and trans women. They might connect online or by phone app, but this offered limited opportunities for peer support; these connections were by their very nature one-to-one and often very sex focused. Alternatively, they might mingle in the bars where trans women sometimes perform, although it is important to note that the presence of trans women performers did not make these venues gay bars. Indeed, they were generally not safe places for MDS or trans women, although they did afford opportunities for MDS and trans women to connect with peers, or opportunities to meet people for sex (who might not be peers and may well identify as heterosexual). But unlike these venues, Kapul Champions offered a safe space where MDS and trans women could gather in numbers and be themselves. This made Kapul Champions unique.

> They have created a safe space for people to come forward, I think … I think it's allowed a space for people to come together, for people to learn from and support each other, and for people to advocate for their rights, which [space] didn't exist before. (Jamie, stakeholder)

It became apparent to me that when interviewees were talking about Kapul Champions providing a safe space for MDS and trans women they were not only talking about the Kapul Champions's office, although many members did use the office as a social drop-in space. They were describing the range of spaces being established by Kapul Champions: forums, workshops, trainings, AGMs and the like. These spaces provided a safe environment for MDS and trans women to be themselves in the presence of their peers. This was critical to helping people overcome their feelings of isolation. In a joint interview Natasha and MaryAnne talked about the important role Kapul Champions had played in bringing people together and helping overcome isolation. Natasha said: ‘Before I was thinking I am the only feminine one here in PNG, there is no one else, but because of KC I am now saying to myself I am proud of who I am because I am not alone.’ MaryAnne agreed: ‘I think Kapul Champions is an organisation that helps … all the TGs and MDS to come together.’

I have not focused on the sexual opportunities generated via these gatherings, although there were some no doubt. However, most gatherings were disproportionately comprised of trans women who were not seeking sex with other trans women but with MDS or heterosexual men. In this context, the spaces may have been sexually disappointing. But whether or not these gatherings provided sexual opportunities, one of their great values was that they provided spaces to just *be* homosexual or trans. Christine Stewart (2014) also writes about safe spaces in Port Moresby. Stewart notes the importance of Poro Sapot as a safe space for gay men (as she describes them), and of the care more generally that gay men take when identifying these spaces. She writes also of the special role of Hanuabada, a village adjacent to Port Moresby Harbour where gay men feel safe to be themselves and dress as they wish. Several of my own trans interviewees lived in Hanuabada and I have often heard it spoken of as a place of safety. And as noted in the previous chapter, its story is nicely told in the documentary *Guava and Bananas: Living Gay in Papua New Guinea* (2014).

Advocacy and law reform — Kapul Champions is about advocacy, not service provision

Many interviewees talked positively about the value of having an organisation to undertake advocacy. Whereas individual advocacy might have limited impact, interviewees thought that an organisational voice was far more powerful. It was more powerful for multiple reasons. Its institutional status gave the agency authority to speak on taboo subjects whereas an individual would not have been given permission to do so. This was partly about the authority that comes with being an institution. A lawfully incorporated organisation with donor funding had some legitimacy — in the eyes of the PNG IPA (the agency responsible for approving incorporation of associations), the government and international agencies — that an activist group did not possess. This is probably in good part because these stakeholders know that, as a legal entity, an institution is bound by rules that promote financial accountability (such as auditing requirements), and consequently consider their money safer with an institution than with a group of individuals.

And, of course, the collective nature of the voice was important. The fact that Kapul Champions could speak on behalf of members gave it a voice that individuals lacked. It provided institutional protection for people who would have otherwise been fearful to speak out, facilitating and amplifying their advocacy. Interviewees were proud of the organisation’s membership (several hundred) and the number of people accessing its private Facebook group (over 750 as at October

2020), with many interviewees describing the membership and broader Facebook community as a kind of mandate. Interviewees rarely used the word 'mandate' but, as evidenced by the quotes above, they spoke often of the organisation as the voice for their community. Kapul Champions's institutional status also gave it an authority to speak beyond its membership (or Facebook following). Where individuals might have struggled to claim a mandate, Kapul Champions was entitled to speak for all MDS and trans women, even those that were not members. This was a view commonly expressed by MDS and trans-women interviewees and no one expressed the view that Kapul Champions might *not* be entitled to claim a national mandate. The organisation was routinely described as *the* voice of the community, not *a* voice. Among interviewees, the authority of Kapul Champions was unchallenged.

Kapul Champions was also seen as having a legitimate perspective that was greater than the self-interest of individual advocates. Whereas an individual MDS advocating the right to have sex with other men could be dismissed as simply acting out of self-interest, an organisation's motivation was somehow less compromised. Several interviewees noted that the fact Kapul Champions's primary spokesperson for many years (as its senior employee) was a heterosexual mother also helped address suspicions of self-interest.

Many MDS and trans-women interviewees spoke of the value of Kapul Champions as an advocacy organisation. Kapul Champions's role as an advocacy organisation seemed universally understood and accepted, and its advocacy work was highly valued by interviewees. It was very rare for MDS or trans-women interviewees to express a desire that Kapul Champions deliver direct services (health, support, financial or other) to constituents. This was very different to the mixed views among PLHIV interviewees, a significant proportion of whom wanted Igat Hope to deliver client services. As a general rule, Kapul Champions's advocacy work was valued and encouraged.

> Yeah, KC is really doing a very, very good job. It's really, it's advocating about MDS and mostly the trans women … and I think seriously they are doing a good job and it's amazing to have an organisation like that working close to the advocacy or in the advocacy process (Jasmine, trans woman).
>
> Like KC should be more focused on advocacy and advocacy should be done by the community members ... we need more advocacy even to the service providers and to the government and law enforcers. We need to work with them to create an enabling environment for everybody (Chris, trans woman).

Kapul Champions seems generally to have escaped the troubles experienced by Igat Hope in managing the tension between being a service provider and an advocacy organisation.

> It is important that KC exists because then it can be used as a vehicle to carry the challenges and issues that MDS and TGs face so they can advocate at the national level and the international level for the rights of MDS and TGs. The difference that I see is, PSP [Poro Sapot Project] is a service provider, they help MDS and TGs with facilities for HIV testing, STI checks and roll out of ART, and they have programs that go out into the community to do outreach, to do peer-to-peer outreach to give out information on STI and HIV. With Kapul, it is an advocacy organisation and what Kapul does is to advocate at different levels and using different methods to get the message across to everyone, about the rights of a TG person or a male with diverse sexuality. (Rita, trans woman)

A number of factors may have contributed to this difference between the expectations of Kapul Champions and expectations of Igat Hope. At the time Igat Hope emerged there was no agency operating as service provider for PLHIV (although Heduru Clinic at Port Moresby General Hospital was later to be established to take up the role of specialist HIV clinic). But this was a full 10 years before the birth of Kapul Champions and the intervening decade was a highly dynamic period in the national response to HIV. By the time Kapul Champions emerged, Save the Children's Poro Sapot Project (PSP) clinic was already delivering clinical services targeting MDS and trans women, meaning another well-regarded agency was already occupying the 'service provider space'.

To understand this context, it is useful to have some knowledge of Poro Sapot. The project is well described by Elizabeth Reid (2010b) and by Stewart (2014). Reid describes in considerable detail the emergence of Poro Sapot as a project determined to take on HIV as a values-based and human rights organisation. Following on from PNG's first efforts to understand the impacts of HIV on sex workers, the Transex Project of the late 1990s, Poro Sapot formally commenced in 2003 with a focus on women in sex work, soon supplemented with a secondary focus on men who have sex with men. Reid explains the genesis of the project's name, with *poro* or *poroman* being Tok Pisin words for companion or friend, and *sapot* being the Tok Pisin word for support.

Stewart describes the service that she witnessed in the mid-2000s: a place where gay men and sex workers gathered and rested, socialised and received treatment. Stewart describes the clinic as being, at that time, unique in the Pacific in targeting these communities. She observed at this time an emphasis on one-to-one interaction and on changing behaviour rather than simply passing on information. In this respect, Poro Sapot was a pioneer. I know from my own experience that in the mid-2000s, when I was spending several months each year in PNG, the country was 'awash with awareness' (as my colleague Elizabeth Reid used to say), yet there were few programs effecting actual behavioural change. Stewart also observes an emphasis on human rights, specifically the right to protect yourself from infection, noting that the organisation has not always enjoyed an easy road: 'Its work targets predominantly those with little education and no formal employment, who have the least to lose by admitting their identities and activities' (2014:144).

A second factor contributing to differences between the Igat Hope and Kapul Champions experiences may be that Igat Hope emerged into a service environment dominated by drop-in centres for PLHIV. These drop-in centres varied but most prioritised meals and other practical supports. As the number of PLHIV grew, and the number of drop-in centres declined (because funding disappeared or other priorities took over), there may well have been an expectation that Igat Hope would pick up the slack. Kapul Champions never experienced such an expectation. Another likely factor is that Igat Hope's decade of operation had educated the community about the role of an advocacy organisation, so that what had seemed very strange at the time Igat Hope was established in 2002 seemed far less strange by the time Kapul Champions was forming in 2012. A final factor is that it is likely that Kapul Champions enjoyed the benefit of being able to learn from Igat Hope's mistakes. Many of Kapul Champions's members were also members of Igat Hope and would have witnessed Igat Hope struggling with the tension between being an advocacy organisation and being a provider of welfare services. It would be completely understandable if these observers had determined that Kapul Champions did not repeat the same mistake.

But, whatever the reasons, it was clearly the case that MDS and trans-women interviewees were comfortable with Kapul Champions as an advocacy organisation, and that they shared an understanding of what this meant in practical terms. They understood this focus meant that Kapul Champions would not be delivering welfare services to members — members should not expect cash, food or medicines. This clarity of vision may have contributed to the relative absence of 'corruption' issues for Kapul Champions. There was comparatively little pressure on Kapul Champions board members to distribute resources to organisational members.

A number of interviewees talked about the difference between Kapul Champions's advocacy and the MARPs-related work of other organisations. There was general agreement that other organisations were in the business of delivering services for MDS and trans women. While these services were highly valued, it was understood that these service organisations did not deliver, or seek to deliver, advocacy on behalf of MDS and trans women.

Rita's quote above is relevant to this issue, but Jara, another trans woman, made the same point.

> Save [the Children] only built my capacity and provided me with a … clinic, that's how I see it, but for Kapul Champions, when it came up, like, I felt that this is the organisation that will help me and stand for my rights … I believe that Kapul is going to do something for me in the future on the law reform side … I think they are the ones who will help us — help us to fight.

Around the time I was conducting interviews, DFAT suggested that, rather than fund Kapul Champions as an independent organisation, DFAT would ask Save the Children to manage Kapul

Champions as an auspiced program. Many interviewees would have been aware of this proposal. Interviewees were asked whether the proposed relocation of Kapul Champions to Save the Children would affect Kapul Champions. Several commented that Save the Children would not be able to deliver what Kapul Champions could deliver.

> How could [it?] … I mean here we have some shared principles around values, around justice and rights etc., but there are deeper values held in England where Save the Children originated from and to the general public and how they see Kapul Champions and how they see Save the Children that will suppress Kapul Champions and how it should stand out and speak for the members of its community and the people that receive services from Kapul Champions … Save the Children will only limit [Kapul Champions] because it can’t talk about gay rights and decriminalising law, they cannot be seen doing that and yet they will be the one managing it — I don’t see how that can work. (Thomas, MDS)

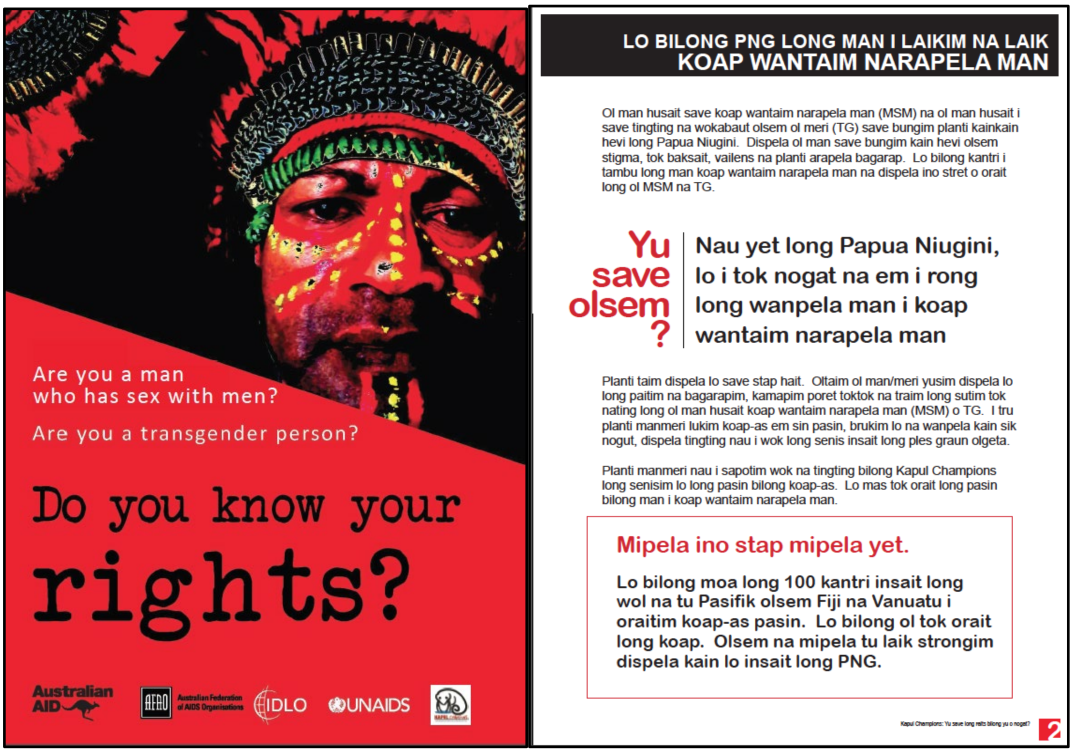
MDS Lionel expressed a slightly different view on Save the Children, saying that he did not want to be associated with an agency that had such a focus on sex workers. On the face of it this looks like anti-sex worker prejudice, and this may have been a factor in the response. But Lionel was also talking about the hidden nature of being MDS. Among MDS there was a shared secret and a shared interest in maintaining that secret. Lionel did not think this extended to trans women who were already openly trans women, nor to sex workers who needed to be ‘out’ (at least to some degree) to connect with clients. Lionel thought this openness would be unpalatable to the majority of MDS who were desperately trying to keep their sexuality a secret.

Kapul Champions’s focus on advocacy was reflected in the development of its strategic priorities in 2012. Among these priorities was the following (at priority 4): ‘Kapul Champions will advocate for the rights of MSM and transgenders. It will focus on the decriminalisation of homosexuality in PNG and for a good national HIV response for MSM and transgenders.’ Kapul Champions had intended to develop these priorities further into a strategic plan but was defunded before it could do so.

Rights education

One of Kapul Champions’s first publications was the *Do you know your rights?* brochure (Figure 5). Published in 2014, this booklet provides an insight into the organisation’s multiple goals. The booklet includes information on human rights as described in the Universal Declaration of Human Rights and the PNG Constitution; rights and responsibilities under the HIV/AIDS Management and Prevention Act; HIV/AIDS messages around prevention of transmission and treatments for PLHIV; and information on law reform and advocacy.

In 2014, Kapul Champions convened a national human-rights workshop, attended by 45 MDS and trans women from around PNG. Conducted over two days, the workshops included a mix of plenary sessions and small group discussions facilitated primarily by Kapul Champions members. The program had been developed through a collaborative process involving Kapul Champions, AFAO and several donor agencies. The workshop was very positively reviewed by participants with 75 per cent of participants rating it as excellent or good. The workshops were groundbreaking in offering MDS and trans women the opportunity to come together in a social space of interaction. For many participants, this was the first time they had ever had the opportunity to be among so many people 'like them'. The workshops also offered some very useful insights into the way rights are perceived.



LO BILONG PNG LONG MAN I LAIKIM NA LAIK KOAP WANTAIM NARAPELA MAN

Ol man husait save koap wantaim narapela man (MSM) na ol man husait i save tingting na wokabaut olsem ol meri (TG) save bungim planti kainkain hevi long Papua Niugini. Dispela ol man save bungim kain hevi olsem stigma, tok baksait, vailens na planti arapela bagarap. Lo bilong kantri i tambu long man koap wantaim narapela man na dispela ino stret o orait long ol MSM na TG.

Yu save olsem? Nau yet long Papua Niugini, lo i tok nogat na em i rong long wanpela man i koap wantaim narapela man

Planti taim dispela lo save stap hait. Oltaim ol man/meri yusim dispela lo long paitim na bagarapim, kamapim poret toktok na traim long sutim tok nating long ol man husait koap wantaim narapela man (MSM) o TG. I tru planti manmeri lukim koap-as em sin pasin, brukim lo na wanpela kain sik nogut, dispela tingting nau i wok long senis insait long ples graun olgeta.

Planti manmeri nau i sapotim wok na tingting bilong Kapul Champions long senisim lo long pasin bilong koap-as. Lo mas tok orait long pasin bilong man i koap wantaim narapela man.

Mipela ino stap mipela yet.

Lo bilong moa long 100 kantri insait long wol na tu Pasifik olsem Fiji na Vanuatu i oraitim koap-as pasin. Lo bilong ol tok orait long koap. Olsem na mipela tu laik strongim dispela kain lo insait long PNG.

Kapul Champions: Yu save long raits bilong yu o nogat? 2

Figure 5. Brochure: Kapul Champions, *Do you know your rights?*
Source. This brochure was produced and distributed by © Kapul Champions, with assistance from AFAO. Used with permission.

National education campaigns

Kapul Champions has developed three poster resources and each has been widely distributed across PNG. The first was a poster aimed at promoting adherence to taking ART medication, a simple image of ART pills in a hand, with the tagline: *Live your Life*. The poster was a first in many respects. It was the first treatment poster to be developed by a community-based organisation in PNG. It was also the first health message to be disseminated by an MDS and trans women organisation in PNG. It marked Kapul Champions as an HIV organisation and placed PLHIV at the centre of the Kapul

Champions's constituency. In this sense it was ahead of its time — even before surveillance data confirmed the high rates of HIV among gay men and transgendered people, Kapul Champions was on the case. Its own membership was well aware of the correlation between homosexuality/transgenderism and infection, with stronger than average awareness of condom use as a means of prevention.

Figures 6 and 7. Kapul Champions's posters promoting ART, in English and Tok Pisin.
Source. These posters were produced and distributed by © Kapul Champions with support from AFAO. Photographed by author from copies in his possession. Used with permission.

It was developed at the same time as a second resource, *Walk With Me — Together We are PNG*. This poster (Figure 8) depicted a trans woman walking hand in hand with two other Papua New Guineans, and invited understanding and inclusion of trans women.

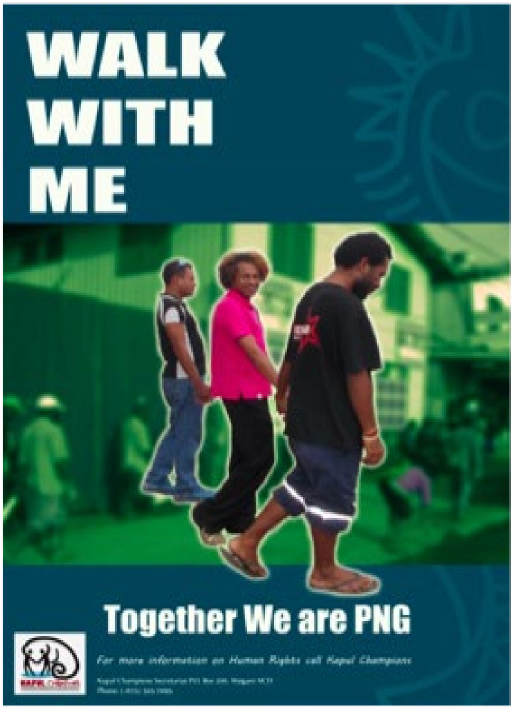


Figure 8. Poster: Kapul Champions, *Walk With Me: Together We are PNG*
Source. © Kapul Champions. Photographed by author and used with permission.

The *Live your Life* campaign (Figures 6 and 7) was launched on World AIDS Day 2014. Kapul Champions invited members and others to be photographed with the resource and then uploaded the photos to the Kapul Champions Facebook page. The campaign was further promoted via radio FM 100 in Port Moresby.

These resources were independently evaluated with interesting results (Chapeau 2015). The evaluator interviewed 36 MDS and trans women about the posters and found that, while the treatment campaign message was mostly understood, the *Walk With Me* message failed to entirely hit the mark. In its efforts to be subtle, it seems the poster lost its visual message. Some of those interviewed for the evaluation thought its message to be very different to that intended. Alternative messages included promotion/encouragement of sexual activity, and isolation of trans women from mainstream community. This second message was suggested because the trans woman in the poster was thought to be walking hand-in-hand only with MDS rather than members of the general community. In fact, this was neither the intention nor the case, as at least one of the models was heterosexual. This feedback suggests it can be difficult to give a message about community with an image that depicts a small number of people; who is representing whom? The poster came with a ‘story’ already known to many in the community. The trans model is well known nationally among MDS and trans women through her leadership role with Kapul Champions, and another of the models is also well known in the MDS and trans community as a performer and advocate. The evaluation noted two common responses to this poster that are particularly interesting. The first was that people interviewed for the evaluation thought the trans woman featured in the poster was ‘not trans woman enough’. The second was that people wanted the trans woman to be holding hands not only with MDS but also with people from the broader community. This feedback underscores the enormity of the social marketing challenge. MDS and trans women (especially trans women) want campaigns that promote their visibility and acknowledge their difference. They also want campaigns that reflect the very high value they place on their relationships with the broader community (or their place in community).

Despite the criticisms of the campaigns, all those interviewed for the evaluation wanted Kapul Champions to continue this kind of social marketing. Kapul Champions was seen as being well placed to reach into the lives of MDS and trans women. Interviewees wanted Kapul Champions to consider campaigns around pre-exposure prophylaxis (PrEP) and self-stigma. People interviewed for the evaluation also thought there might be better ways to reach MDS and trans women, specifically through TV and radio, phone messages and promotional items such as stubby holders and caps.

One of the recommendations from the evaluation was that Kapul Champions engage in more community consultations in the development of future campaigns. Kapul Champions responded to this in 2015 by conducting two consultations in Chimbu and Lae (meeting with 46 MDS and trans women) in the development of a social marketing campaign to promote testing (Evera 2015). This consultation resulted in two important outcomes. First, the consultation afforded further opportunities to reflect on the *Live your Life* and *Walk With Me* campaigns. Overall, the feedback on these campaigns from those consulted was very positive, with the consultation report concluding that both campaigns had been successful. Second, the consultation process resulted in two posters promoting HIV testing. The first was developed to target people from the Highlands using an image of Highlanders gathered at a Kapul Champions event. The second was developed to target trans women from coastal areas. While both are important resources, Kapul Champions's staff and board members were particularly proud of the Highlands resource. Staff and many other interviewees reported very high levels of stigma and discrimination in Highlands areas, and a relative invisibility of MDS and trans women in the Highlands as compared to the coast. In this context, the Highlands resource was particularly valued.

There are some final important points to make about the Kapul Champions's campaigns. They were genuinely community-driven in that the education need was identified by the community via a consultative process; the campaign messages were developed by community members; the images were taken by MDS and trans women and posters featured MDS and trans-women models. The campaigns reaffirmed Kapul Champions's focus as an HIV organisation, promoting HIV testing despite the risks to MDS and trans women that, by being tested, they would expose themselves to stigma and discrimination. The focus on treatments was consistent with a view that, despite the risks of confidentiality breaches and high levels of stigma and discrimination directed towards PLHIV, the advantages of early access to ART make the risks worth taking.

Community forums

Kapul Champions conducted several regional forums for MDS and trans women. For some of those who attended, it was their very first time in a safe space where they could express their identity in the presence of peers. Workshops were conducted in Goroka, Eastern Highlands Province (2013), Mingendi, Simbu Province (2015), Lae, Morobe Province (2015) and Mt Hagen, Western Highlands Province (2015). The forums were organised by Kapul Champions's staff in Port Moresby utilising organisational contacts residing in the locations where the forums were to be held. This is one of the ways that a national entity can demonstrate the utility of its structure — staff worked with the board member/s elected from the relevant regions making use of the local representative's contacts while simultaneously ensuring the event had some national-level authority. Agendas were prepared in advance and invitations issued via contacts and through friends, utilising the local grapevine. Participation involved meals and bus fares, but no other payments were made.

The report of the trip to Mingendi documents some of the impact of these events (Evera 2015). It notes that 10 members attended the Highlands workshop in Goroka in 2013, and that these 10 had continued to meet once they returned to Simbu. Their group had now expanded to over 30 members. This is an important record of a successful community development intervention on the part of Kapul Champions. The report records other important details of the workshop, which was attended by 22 MDS, two trans women and one lesbian. This is the only record of attendance at Kapul Champions events by a lesbian, although, based on my experience with the group, I imagine lesbians would have been welcome at others. Employees of Kapul Champions shared, from time to time, stories of their personal connections with lesbians, although these women remained largely absent from organisational activities.

Participants talked about how to attain supportive services in the area. They agreed that the smartest strategy for obtaining optimal servicing was to present as heterosexual, since presenting as MDS or trans women invited stigma and discrimination. Kapul Champions shared information with participants around safe sex and healthy living, and introduced participants to the organisation’s work plan in an effort to engage members in the work of Kapul Champions, but also to assure them that the organisation was already working for their benefit. Participants completed evaluations at the conclusion of the workshop and the day was deemed a success. All members committed to building the local support group and linking new members to Kapul Champions. Participants were asked to help design a poster to promote HIV testing among MDS and trans women. Interestingly, of the five groups that developed ideas, four related to rights-based arguments (my right to get tested) while one referenced getting together with other LGBTI.

Kapul Champions also took the opportunity during the workshop to connect with local health-service providers via a visit to the local clinic. The report notes that health-care workers were pleased to meet with Kapul Champions’s representatives and interested to learn that sex work and homosexuality are common across PNG. Here Kapul Champions would likely have been sharing their experiences of having met with MDS, trans women and sex workers around the country or having met these people in Port Moresby from around the country, bearing witness to their existence nationally.

In April 2015, a closed workshop was held for MDS and trans women living with HIV in Lae (Evera 2015). The workshop aimed to share information on HIV treatment and care, discuss challenges in accessing local services, and discuss how MDS and trans women keep themselves safe. Only five PLHIV attended the meeting. As Nick Evera notes in his report of the event prepared for Kapul Champions, this low number was likely the result of concerns around confidentiality and fear of being publicly known to be HIV-positive. Participants identified the following issues as important:

need for accessible health services and staff sensitisation; fear of stigma and discrimination and lack of regard for human rights; need for better sensitisation of police and better relationships with police; importance of family and peer support; safety risks involved in being MDS and trans women and PLHIV. The workshop was very positively evaluated by participants. Some may be tempted to downplay the significance of such a small event, but this was very likely the first time PLHIV in Lae had the opportunity to come together in this format, and it is interesting to see how the issues identified as important in 2015 are similar to the issues raised by interviewees in my research in 2017.

The facilitators identified the following outcomes:

> We generally all agreed that the meeting went well. Participants seemed to appreciate being together as a distinct group, were open and honest, listened to each other, and appeared to benefit in terms of building their confidence, awareness and knowledge to continue their peer work of reaching out to other local MDS and trans-women people. (Evera 2015:9)

Media workshop

In March 2015, Kapul Champions held a workshop for ten journalists and other media employees. Seven attendees completed evaluations with the average overall rating for the workshop being nine out of 10. Responses indicated important learnings: correct terminology to be used when referring to MDS and trans women; understanding of the rights of MDS and trans women; reflection on the experience of stigma and discrimination for MDS and trans women; exposure to MDS and trans women and their stories; and appreciation of the need to prevent discrimination against MDS and trans women. Participants said they would incorporate these learnings into their future work. Several participants said they would try to build awareness of MDS and trans-women issues. Others said they would modify the way they reported on MDS and trans women to promote a more positive image of these communities. Participants commonly reported that they would be more careful about the terminology they used.

The Kapul Champions Advocacy Officer subsequently organised an episode of *Olsem Wanem* on EMTV featuring five members of the MDS and trans-women community (Episode 24, 2016). This was a really significant achievement in sensitising the general community to MDS and trans women. The show was sensitively managed and reached a wide audience, and Kapul Champions has received lots of positive feedback about the show. The show’s producer had been a participant in a Kapul Champions media workshop, and the episode was a direct result of this innovation.

National Dialogue

The National Dialogue is shorthand for the national campaign to amend the country's anti-sodomy laws, a worthy goal as many researchers have noted (e.g. Stewart 2014). I am not aware how the campaign took on this name, but it is completely consistent with the view of many MDS and trans-women interviewees that advocacy needs to be undertaken in ways that engage the mainstream community in non-combative ways, in ways that suggest dialogical exchange and mutual learning. What better phrase, then, than 'National Dialogue'? The process has involved a series of consultations and planning meetings organised by Dame Carol Kidu. Dame Carol is now retired from politics but at the time the National Dialogue process commenced she was the Minister for Community Development. A National Consultation event has been one of the features of the dialogue, involving a keynote address by retired Australian High Court Judge Justice Michael Kirby, and a subsequent workshop. Kapul Champions has been an important contributor to all aspects of the National Dialogue process.

The 2011 National Consultation was preceded by an informal meeting between Justice Kirby and members of the MDS and trans women and sex worker communities. Most community attendees were members of Kapul Champions. A formal dinner involved a dance presentation by trans members of Kapul Champions dressed as women. The performance was not unlike the performances some of these trans women had delivered for nightclub audiences in Port Moresby. The audience included prominent Papua New Guineans from political and judicial circles. As a statement about presence and visibility, that performance was hard to beat. Laurel, a delegate to the event, described it as follows:

> I still remember that evening well. The show took place in the same room in Parliament House where the meeting itself had taken place during the day so it was all a bit surreal because it wasn't a club-style venue. Half a dozen or so of the trans people who had been participating in the dialogue earlier disappeared into a side room and changed into frocks, wigs and make-up. They then came out one by one doing Karaoke singing and dancing to disco music on a little cassette player. As I recall, the response was mixed. Many people didn't know quite how to respond, and they were laughing nervously. Others got right into it and were clapping and cheering enthusiastically. There were certainly people sitting there stony-faced, but my memory is that they were a small minority.
>
> I thought it was an incredibly brave thing for them to do. They were exposing their sexuality completely in circumstances where there was not even a hint of anonymity. And this was after they had been talking earlier in the day about the lengths they had to go to in order to hide their sexuality, and the stigmatisation they experienced if people found out they were gay or bisexual. I guess there was safety in numbers, and maybe they felt it was empowering to be able to do something like this in the Parliament building, but I still feel it showed exceptional courage. And it probably did contribute

> in a very practical way to a greater understanding among the audience of what it means to have diverse sexuality.
>
> It is tragic to think that at least two of them have since died of AIDS, possibly three or four.

The rapporteur's report (2015) details workshop proceedings. Kapul Champions's president presented one of the opening addresses, alongside Dame Carol, the UN Country Director, NCD Governor and US Ambassador. Kapul Champions presented a statement on behalf of itself, Igat Hope and Friends Frangipani calling for law reform. Specifically, the organisations called for:

- repeal of laws that criminalise sex work and sodomy on the basis that these impede the HIV response;
- reform of laws to reflect international human-rights standards; national action to implement rights to non-discrimination; improved HIV prevention, information, education and services; access to HIV treatments;
- freedom from any kind of coercion or violence regardless of a person's sexuality, transgender identity or occupation;
- better monitoring of national progress towards discrimination-free access to health, particularly in relation to HIV prevention, treatment and care;
- investigation of human-rights abuses by law enforcement officers, and training for these officers in human rights, and investment in education and training for sex workers to generate opportunities for economic independence.

The workshop agreed on a set of actions to address the challenges being experienced by marginalised groups. In my assessment, progress against these objectives has been poor. There has been no repeal of anti-sodomy laws, no reform of laws to reflect international human-rights standards and no major anti-discrimination initiatives. As this chapter documents, there has been an undermining of HIV prevention, treatment and care through the undermining of the community HIV response. But poor progress does not take away from the value of having an agreed, documented charter for reform demands with buy-in from donors and acknowledgement from government.

Organisation evaluation

In 2013, I was commissioned by the Australian Federation of AIDS Organisations (AFAO) to conduct an evaluation of Kapul Champions. As evaluator, I interviewed board members, staff, employees of agencies working with MDS and trans women in PNG, and representatives of DFAT and AFAO.

The evaluation (Leach 2013) identified a range of strengths and achievements:

1. Kapul Champions's continued existence is a success in itself.
2. Kapul Champions has a clear sense of its purpose, especially its role as more than an HIV organisation. Kapul Champions has asserted a role in promoting the rights and entitlements of all MDS and transgenders.

3. Kapul Champions has established itself as a responsible organisation and a legitimate player in the national HIV response. It has succeeded in raising its profile and in making a strong case for inclusion in decision-making forums relevant to MDS and transgenders.
4. Kapul Champions has succeeded in reaching out to potential members through community forums, social media and via other means.
5. Kapul Champions has produced several excellent resources.
6. Kapul Champions has contributed to the National Dialogue.
7. Kapul Champions has established good working relationships with key agencies, indicating an important ability to work effectively with partners.
8. Kapul Champions has developed skills in bringing in expertise as required, sensibly accessing different agencies for different supports.
9. Kapul Champions has improved its (still limited) ability in financial management and reporting.
10. The Board of Kapul Champions has improved its performance, especially its internal communication.
11. Kapul Champions has paid staff that bring valuable skills and abilities to their roles.

I intentionally reviewed this evaluation late in my research process. I wanted to hear what my research interviewees had to say about Kapul Champions without my earlier observations (largely forgotten) affecting the way I heard it. I was worried I would look only for affirmation of my earlier conclusions, or perhaps be interested only in what might have changed. But when I returned to this evaluation, I saw further evidence of a pattern of performance. My 2013 evaluation had noted strengths and achievements. Workshop participants in 2015 were making the same observations of Kapul Champions. Research interviewees in 2017 made the same observations and drew the same conclusions. Again, this suggests that I am able to offer more than a moment in time snapshot of Kapul Champions. I can point to a pattern of effective service delivery over a minimum of five years. This consistency of performance also raises development questions about evidence and how evaluation is used. When Kapul Champions was ultimately defunded, I was told by perhaps a dozen people within DFAT and other donors that there was insufficient evidence of Kapul Champions's effectiveness to secure its future. Yet there *was* evidence, far more than many other NGOs that continue to receive DFAT funding have ever been able to demonstrate. The better questions are: what was done with the evidence that was available and was anyone really interested in it anyway?

My view is that DFAT was uninterested in the evidence. DFAT had opted for a new model of assistance that would be administratively easier and was disinterested in any evidence that might be at odds with this new strategy. But even if DFAT had been open to evidence of performance, it would have wanted the kind of evidence that donors, with their instrumentalist views, so often favour; it would have wanted statistics and numbers to demonstrate predetermined outcomes and 'value for money'.

Kapul Champions's challenges

As with the preceding section, here I am considering shortcomings and missed opportunities in the context that these organisations (Kapul Champions and Igat Hope) were tasked with responsibilities they were under-resourced to meet, and that my entitlement to determine what constitutes success and otherwise is limited. But I am reflecting the views of interviewees who were often very candid about what the organisations had and had not achieved.

Communication

Chris, a trans woman, thought that some of the advocacy had missed its mark because Kapul Champions had made the wrong call on how Papua New Guineans communicate. She considered that there was such diversity of language in PNG, and such low levels of literacy, particularly in the rural areas, that posters in English and Pidgin were always likely to have limited appeal. Chris drew support from the evaluation of Kapul Champions's social marketing, which had identified some miscommunications (for example, the confusion around the *Walk With Me* message).

Structure and membership

By and large, Kapul Champions escaped the allegations of corruption that were levelled at Igat Hope. An exception was the testimony of Chris who critiqued Kapul Champions's system of Board voting as a form of corruption:

> So there is always lobbying and at the end the right people don't get voted in or you know because of that corruption in votes … It was really evident at the last AGM where it was really unfair for others who were outside of the province.

Chris was reflecting on the relative advantage given to the community hosting the AGM: the first AGM was held in Port Moresby and the subsequent one in Lae. It is Kapul Champions's AGM practice that votes are cast only by those present (no proxies are permitted). While there are efforts to divide participants up so that regional representatives are elected only by people from those regions, there is still an advantage flowing to the host community. Consequently, at the first AGM the NCD community 'had the numbers', with the Lae community carrying the day at the next. Many interviewees thought that a large, engaged membership would be the best defence against corruption. Where Kapul Champions only had a small membership, they said, it would be easier for a person to curry favour with or otherwise influence sufficient numbers to establish a dominant bloc. This would be less possible with lots of people with different perspectives and multiple leadership contenders. As MaryAnne, a trans woman, explained: ‘I think the most important thing is to keep Kapul strong. We want more membership, more voices, that is the main aim of Kapul Champions.’

Interviewees identified ways in which the organisation had failed on the issue of membership. These criticisms might be divided into three groups: failures of reach, failures of range, and failures regarding MDS. First, there was some commentary among interviewees about the organisation’s reach beyond Port Moresby. Specifically, several interviewees noted that Kapul Champions was strong in Port Moresby but less established outside NCD:

> I think it does exist in one part of the world when I say that Kapul is only known in the city areas only and we need to branch out to nineteen provinces now … if we branch out to the 19 provinces then people … will know what is meant by, you know, MDS and TG people because they will see the coordinating body and they will see the boys, the TG people and all the men with diverse sexualities, so I mean Moresby is okay, I can see changing and understanding, what is MDS and what is TG people, but what about [outside of Port Moresby]? (Kiteni, trans woman)

A second membership-related criticism concerned the *range* of members rather than the reach. In the same way interviewees observed that Igat Hope has failed to engage PLHIV who are highly educated or employed in senior roles, so too Kapul Champions was said to have failed.

> Because like 90 per cent of the TG don’t complete their formal education and there are a few lucky ones that went through and completed their [education]. These working class[2] TG wouldn’t come out and open up with TG that are already here, so we have division among the TG as well and I just want everybody to be together and we all work together. (Chris, trans woman)

In her 2014 observations on Poro Sapot, Stewart writes of how Poro Sapot attracted people with little or no education and how this made it harder for the service itself. Stewart observes that Poro Sapot’s service users are poor, often homeless, with high needs and few employment options. By servicing stigmatised clients, the service has itself become stigmatised, says Stewart. Its connection with stigmatised clients has made it the subject of media attacks and its stigmatised status discourages new service users from contacting the service.

Finally, several interviewees noted that Kapul Champions is comprised mainly of trans women with relatively few MDS. I have noted earlier some of the reasons trans women are more likely than MDS to join Kapul Champions (MDS desire to hide sexuality being the key one), but it is worth noting here that this phenomenon was sometimes couched in terms of a Kapul Champions ‘failure’. Some interviewees thought that Kapul Champions could have done more to reach out to

---

[2] As noted in the preceding chapter, ‘working class’ is often used to describe people in formal employment who might otherwise be described as middle-class or even as ‘elites’. The complexity of class analyses is considered in Chapter 4.

MDS and encourage more MDS to become involved in the organisation. It was suggested, for example, that it could have actively pursued MDS, perhaps by occasionally establishing spaces (workshops, meetings) exclusively for MDS.

Lack of processes and systems

MDS and trans interviewees expressed some disappointment that the organisation had not been able to establish sufficient operational systems and processes as they thought desirable. Interviewees used different terms, but essentially, they were all talking about different kinds of organisational policies. Interviewees often specifically mentioned financial policies.

> And it's a shame to say that up until KC closed, we had no bank account opened, no financial policies or procedures put in place, no organisation's structure in terms of fixed positions sitting in that organisation. (Rossa, trans woman)

The closure to which Rossa was referring was the closing of the Kapul Champions's office, made inevitable by the withdrawal of DFAT funding. In making these criticisms, Rossa suggested that responsibility for the failure should be shared by a range of agencies, namely DFAT, AFAO and Igat Hope. All three had a shared responsibility for building the capacity of Kapul Champions to operate as an independent organisation, and all share ownership of the failure. Rossa thought that Kapul Champions would have been better left as an activity of Save the Children while its processes were established. Only at that point should it have been allowed to seek any level of independent operation, she said. But this 'failure' needs to be seen in context. Policies and procedures are often peculiarly donor concerns. They are often required as evidence that an organisation can manage money, yet plenty of money has been stolen in organisations with financial policies, and plenty of groups with no policies have managed money well.

Even during my last visit to PNG in 2019, much of the discussion around building the capacity of the new Key Populations Consortium Papua New Guinea (the body established by UNAIDS, with support from DFAT, to 'replace' independent organisations such as Igat Hope, Kapul Champions and Friends Frangipani)[3] focused on policies and procedures. They are helpful but, in my experience, policies and processes help only where they are developed in partnership with the organisation and mandate practices that are realistic on the ground and that make sense to the people who are supposed to apply them. Based on my 2019 work in PNG, I observe that these capacities continue to

---

[3] This is a new body which is still sorting out its structure and purpose, but it describes itself as a coalition of key population organisations (specifically Igat Hope, Kapul Champions, Friends Frangipani and Women Affected by HIV/AIDS — WABHA). More can be learned by considering the document, Partnership Network Coalition, A New Way to Work with Key Populations in Papua New Guinea (UNAIDS, February 2018).

have higher priority among donors than among members of Kapul Champions (or indeed Igat Hope and Friends Frangipani).

Failure to plan ahead

Many interviewees spoke with sadness about the defunding by DFAT of Kapul Champions and, interestingly, some saw the loss of all funding as evidence of an organisational failing. Several said that the organisation should have seen the writing on the wall and had failed to properly plan for DFAT's withdrawal. Yet others felt that all was not lost.

> The other thing that we need to do is we need to try to start ... networking with partners and government, you know, other donors, rather than focusing only upon Australian aid, you know. We have European aid. We have USAID and we have other ones there, Society, Foundation … Sometimes different governments, each time the other one comes, and the other one goes, those are the things that can really make Kapul fail, but as I have said, if we have networking and if we have support from the government itself and from other donors, I think Kapul can move on from there. (Kiteni, trans woman)

Evaluation findings

The 2013 evaluation referred to above noted a range of areas where Kapul Champions's work might be improved. The report observed:

- Kapul Champions lacks internal systems and processes.
- Kapul Champions does not document its work well.
- Kapul Champions is not clear about the precise terms of its constitution.
- While the Board was generally functional and able to make decisions, it had expended a lot of energy on internal disputes that had had no positive benefits for the organisation.
- Kapul Champions needed to do more to raise its profile with government and other agencies.
- Kapul Champions was not conducting advocacy well. It did not seem to have a plan for human-rights advocacy.
- The National Dialogue process was observed to be moving too slowly. Kapul Champions should take some responsibility for this lack of momentum, it was suggested.
- There was more work to be done in terms of building membership.
- Kapul Champions requires a bigger staff team to undertake the work required.
- Kapul Champions was not planning appropriately for independence from AFAO or a future independence of Igat Hope (Kapul Champions's auspice agency).
- Board members could take greater care to be role models at all times when they are engaged in Kapul Champions business.

It is interesting to consider the ways these observations from 2013 are reflected in the interviews from 2017. Overall, these observations are very similar to those made by interviewees in

2017 and documented here. To a degree this is unsurprising, as I am the author of both reports and many of the stakeholders interviewed in 2013 were also interviewed for my later research. But I believe there is more to it than this. The problems identified in 2013 were continuing to undermine Kapul Champions five years later. This raises questions about the capacity of organisations to learn from mistakes and to respond to factors threatening their future. It is fair to observe that, on some levels, both Kapul Champions and AFAO failed to address the deficiencies identified in 2013. Of course, this will always be a challenge for an underfunded organisation; for example, how could it hire more staff without more money? Yet other factors such as documentation and attention to internal systems could surely have been addressed more effectively than they were. The observations regarding lack of planning for the future received insufficient attention, to catastrophic effect.

Conclusions

Kapul Champions achieved a great deal over many years. For a modestly funded community organisation operating in a challenging environment, these achievements are significant, and interviewees acknowledge these successes. Activities were undertaken and had an impact, as the stories from interviewees indicate. Community members felt they were given voice; spaces were created where they felt safe and could express themselves freely, amongst friends; important conversations were had nationally that were shaped by Kapul Champions; and people learned to think differently about MDS and trans women. It is not unreasonable to conclude that these impacts made life better for many MDS and trans women (Figure 10). Kapul Champions also showed itself to be a learning organisation. It sought feedback from members and service users and was able to document mistakes or areas where its performance might be improved.

Part Three. Collectively, what did the organisations achieve?

In the preceding pages I have canvassed the achievements of Igat Hope and Kapul Champions. While I have also noted interviewees' concerns about underachievement in some areas, the impression I am left with is of significant achievement and positive impact in the face of big challenges. While I have considered each organisation separately, it is useful to reflect on the shared successes of these two groups as this will be key to understanding how the CBO model works in PNG. Both organisations can claim success in the facilitation of community voice, self-determination, promoting visibility, peer connection, community pride, documentation and contribution to the national conversation.

Community voice

First and foremost, the community-based organisations provided voice for marginalised communities.

> Firstly, Igat Hope is a leading organisation in PNG which has been the face of people living with HIV, been the voice of people living with HIV and … I'll say and we have done well throughout PNG. (Rachel, PLHIV)
>
> Now we have our organisation which is Kapul Champions that advocates for the human rights and well-being of MDS. It's an organisation that now, you know, brings all MDS and trans women in PNG coming into one umbrella. So most of our community now know that we have voice in the country in terms of our rights and our welfare. (MaryAnne, trans woman)
>
> OK, KC is an organisation that I have mentioned, an organisation formally informed by MDS and trans women people here in PNG. It is the national voice of our community … So far KC have now been established as an organisation and becoming a strong foundation and the voice for trans women and MDS people in PNG. (Natasha, trans woman)

Even the organisations' harshest critics acknowledge that they have provided their constituencies with a recognisable and national voice. This voice can be seen most obviously in references to the organisations in the media in PNG. A quick Google search identifies multiple instances of the organisations being reported in the national print media, for example, 'LGBTI Community Wants To Be Heard' (*Post Courier,* 23 June 2017), 'Igat Hope Launches New Website for PLHIV Members' (*Post Courier,* 8 June 2018), 'HIV in PNG Is Now Estimated To Be About 70,000: Igat Hope' (*Post Courier,* 21 June 2018), 'Inspirational women providing HIV care in Mt Hagen' (*Post Courier,* 30 November 2018).

Chapter 4 detailed how exposure as HIV-positive or as an MDS or trans woman carries great risk. In this context, where individuals faced great danger in identifying as HIV-positive, MDS or trans women, or in speaking out on behalf of their issues, the building of a community voice that both amplified their concerns and protected them as individuals deserves recognition as an important achievement.

Several sector stakeholders identified the facilitation of community voice as one of the great achievements of the community organisations. Jamie, an Australian interviewee with extensive experience in the Australian HIV response and community responses more generally, believed the project had been highly successful in the fostering of voice for MDS and trans women. An entity brings people together, he said, and this in itself has benefits. Through the collective sharing of experiences and discussion of shared challenges and goals, voice was generated. The success of the organisation was that it helped channel the voice.

> I mean voice just *adds* … I've seen the impact of it through working with people with disabilities and I think that voice … just really challenges the paternalism, the assumptions, when people just say stuff themselves … but you really do have to let people articulate for themselves — my voice is completely different to their voice, you know.

UN official Anthony also reflected on the role of the organisations in giving voice, including in relation to human rights:

> Well, they generally don't have much human rights. They don't have access to government services the same way as other people. They aren't treated with respect, they have to lead lives that are very hidden, that are very segmented. They can be open with friends, colleagues and sexual contacts and maybe a very few family members, but in general their lives are very fragmented … If people are able to access the kinds of things that human-rights protect, like government services, they don't do it generally as a man of diverse sexuality or transgender or a person with HIV … they don't disclose those things except in the rare cases where people are in an organisation that helps them voice that, you know, so Igat Hope, Kapul Champions has certainly allowed a voicing of concern and a voicing of interest and because we have small numbers of motivated and, in some cases, more highly educated, individuals that can lead them in the process. That is the difference but in terms of people in general, you don't have 'champions' because the social cost is too great.

This collective, institutional voice of Igat Hope and Kapul Champions was subsequently heard in many national and international forums, and gave expression to the views of individuals too fearful to speak out.

Self-determination

The organisations provided another important outcome in promoting self-determination for PLHIV, MDS and trans women. While there were many criticisms of the two organisations, interviewees were largely positive about the degree to which each was community owned. The peer nature of the organisations has never been seriously in doubt. The governance structures for both agencies remained determinedly peer-based, despite some views that this might usefully have been diluted. Community boards were democratically elected at properly constituted AGMs by members that had been admitted to the associations in line with constitutional requirements. While many interviewees were critical of electoral outcomes, the systems by which these outcomes were delivered were not generally criticised as corrupt. Instead, interviewees tended to complain about candidates who had over-promised and under-delivered, of memberships that had cast votes without thinking, or (at worst) of low-level 'bribery'. This low-level bribery, such as it was, mostly took the form of support for members to attend AGMs. This support might take the form of an inflated reimbursement for the bus fare to the AGM (10-kina reimbursement for a 1-kina fare, for example). Or it might take the form of a community BBQ put on by the organisation to thank people for their attendance at the AGM. In this second case, board members, and board executive members (president, vice-president etc.) in particular, might be given credit for the meal and (allegedly) rewarded with re-election. But in comparison to what they saw around them at national and provincial government level, interviewees tended to see these failings as being of a modest order. It is also worth noting that I have seen such practices in Australia and pretty much every other country in which I have worked.

Interviewees generally thought community memberships could have been strengthened, but there were no suggestions of unconstitutional activity or other gross manipulations of the system. A properly admitted membership had cast votes at legitimate meetings, and these votes had been fairly counted. As democratic outcomes go, this all looks legitimate.

That the organisations enjoyed a degree of independence is perhaps best evidenced by their history of disputes with funders and advisers. Had the organisations been less independent, DFAT, NAPWHA and AFAO may well have been more easily able to procure the organisational outcomes they desired. But the organisations were in constant dispute with DFAT and their Australian mentors over organisational direction, strategic priorities, program execution and expenditure. Igat Hope, in particular, experienced multiple disputes with AusAID/DFAT, famously culminating in AusAID unilaterally instituting an organisational review in 2011. While this was perhaps one of the more dramatic moments, there were plenty of lesser disagreements. AusAID resisted, for example, Igat Hope budgets that allowed for per diem payments to board members. This in itself is an interesting example of different cultural perspectives. AusAID argued that such payments would constitute personal gain from organisational funds and that they would not be consistent with the voluntary nature of the board. Igat Hope argued that board members were bringing great expertise to their work and that time spent in board meetings was time not spent in pursuit of income via working gardens or marketing and, consequently, some token reimbursement was reasonable. Besides, said Igat Hope members, no-one at DFAT was volunteering their time in support of the HIV response, so why should they?[4]

For a funded CBO, ‘independence’ is often relative. They are required under contract to undertake certain activities, and these activities must broadly accord with the funder’s priorities. They must behave in certain ways and must generally avoid embarrassing or otherwise compromising the funder. The threat of defunding is routinely used to pull organisations into line. I have seen this in every country I have ever worked, and extensively in Australia across multiple

---

[4] I also heard an alternative explanation, that DFAT was trying to get the PNG Government to ‘step up’ and contribute to the core operational costs of Igat Hope. This is possible, but I maintain its primary concern with payment of per diems was related to notions of corruption and any form or personal gain being ‘evidence’ of the problem.

community sectors. Even so, the fundamental independence of Igat Hope and Kapul Champions was observed by DFAT and other donors. Each operated independently of donors, and of their technical partners (NAPWHA and AFAO). The importance of this self-determination was that the ‘voice’ that Papua New Guineans heard was genuinely a community voice. PLHIV spoke for themselves about the issues that were important to them. Their views were not repackaged and rearticulated by donors, non-PLHIV or outsiders, well intentioned though these people may have been. MDS and trans women similarly spoke for themselves on issues that were important to them.

Visibility

The organisations promoted visibility of constituent groups. Igat Hope became a fixture in multi-sectoral forums planning and implementing the national HIV response, providing delegates to national and regional conferences on HIV and building a significant national media profile. Igat Hope representatives spoke at multiple national meetings and conferences. The organisation produced written resources that were distributed widely. It was quoted in the newspaper and on radio. It organised rallies and marches, it held stalls at community events. Kapul Champions similarly built a solid national profile of its own, engaging with government and donors on HIV issues affecting MDS and trans women, sending delegates to meetings and conferences, having its representatives quoted in media, printing and disseminating posters and other resources.

Through all these activities Igat Hope and Kapul Champions promoted the visibility of their constituencies. The positive impact of this cannot be overestimated. Chapter 4 noted the commonly held view among PLHIV that visibility was a key contributor to the reduction of stigma and discrimination. Only by seeing that PLHIV could live well on ART, and that HIV was not a death sentence, could fear and ignorance be overcome, thus enabling Papua New Guinean traits of compassion and caring to come to the fore once more. Chapter 4 also detailed the view among MDS and trans women that by understanding that MDS and trans women were normal Papua New Guineans, just like everyone else, stigma and discrimination could be overcome. For these three communities, visibility was the key to inclusion. Interviewees agreed that the success of Igat Hope and Kapul Champions in raising their profile and presenting the human face of PLHIV, MDS and trans women, was a critical factor in promoting understanding. They agreed that efforts to promote visibility had already reduced stigma and discrimination.

In summary, Igat Hope and Kapul Champions provided voice for highly marginalised constituencies. This voice was largely democratic and representative, and that made it legitimate in the eyes of government, donors and other stakeholders in the national HIV response. This voice told stories of stigma and discrimination, of rights denied and aspired to. These stories were important contributions to the national conversation about rights. Jamie, a long-term leader in the Australian HIV response who had observed MDS movements in multiple countries, applauded Kapul Champions's achievements. He saw Kapul Champions's work as being all the more impressive because it had to do it alone, without the contribution of any national human-rights authority.

> If there was a human-rights entity in PNG, that's who should be doing this work. The Human Rights Commission in Australia should be working on that, because they are just so behind the eight-ball and it is amazing what they did in terms of the visibility, in terms of the voice and that type of thing, being understood and respected in that role, to have got to there I think is really significant.

Legitimacy with stakeholders

The CBO structure adopted by Igat Hope and Kapul Champions was recognisable to donors. This gave donors, particularly DFAT, confidence to support it. Donors were comfortable with an institutional structure where they would not have been prepared to support an informal group, or an individual. The PNG IPA was able to recognise the model and incorporate it, opening the way for the organisations to assume legal status, open bank accounts and be subjected to legal requirements. The institutional status of Igat Hope and Kapul Champions also delivered seats at decision-making tables for both these organisations.

The PNG national HIV response, in some ways, resembled Australia's own, with a notional partnership between government and affected communities. Where government bureaucrats sought identifiable community partners that could legitimately represent constituencies, they appreciated the existence of Igat Hope and Kapul Champions. Whether Igat Hope and Kapul Champions were ultimately accorded the level of institutional respect to which they might have been entitled is a separate question. But it is undeniable that, as incorporated organisations, they were recognisable to governments and donors, and somehow more respectable than a loose coalition of stigmatised individuals.

Peer connection

Interviewees routinely spoke of the value of their peer connection. At a very basic level this had been valued as a form of support, as a way of dealing with alienation and exclusion. For many interviewees, the organisations had been the original pathway to peer connection. Peer support obviously has an intrinsic value for highly stigmatised individuals. But interviewees also spoke about its contribution to the generation of voice. For many interviewees, peer connection was the means by which their concerns were validated. Their voice was given meaning by cross-reference and was legitimised. It was made more real.

Community pride

> We are proud about what Igat Hope is doing with these peer counsellors in partnership and with partnering with this research foundation … It's a good networking thing that they are doing and good benefits for the patients and young generations to come through, (Miriam, PLHIV)
>
> I think the biggest [achievement] is our treatment, our treatment in the country. Igat Hope has [had to] fight a lot for the treatment side of it and now we can see treatment has been rolling out [in] the rural places as well … so I am very proud of Igat Hope too and also the slowing down of stigma and discrimination in the city and in the country as well. I think Igat Hope has done a lot. (Elsie, PLHIV)
>
> For the KC organisation, I am very proud of the organisation. It's not because I am a board member of KC but as a member of Kapul Champions, and to be honestly, the organisation is doing really, really well on advocating for the rights of TG and men with diverse sexuality to the correct level … and I really applaud the organisation KC, they have been doing a very tremendous and terrific work on the advocacy level. I as an individual TG can see that we are getting good response back from the Government. (Therese, trans woman)

Many interviewees spoke of their pride in the organisation. Even where interviewees were being critical of their organisations, and many of them were, they were often proud of the fact that it had been established and that it had survived. Even where they could see its weaknesses, they also recalled its achievements. This was particularly the case for Igat Hope. While Igat Hope was widely criticised by members, its achievements were also quite easily identified: treatment access, building community awareness, PLHIV visibility, combating prejudice. These were all organisational achievements that could be noted, and the organisation's current or recent failings were generally not seen to have invalidated its past achievements.

The pride that members felt in their organisations was clearly indicated across interviews, and this pride is understandable. The majority of interviewees were highly marginalised. Most had experienced extreme mistreatment individually and understood that collectively their communities were viewed with suspicion or disgust. Yet here were these same highly stigmatised communities having established and sustained organisations in an environment where community organisations generally do not survive. Many interviewees spoke about other community organisations that had failed to endure, and this was particularly the case with stakeholder interviewees, many of whom had worked in or with these organisations. I too had seen, over my many trips to PNG, the emergence and disappearance of NGOs. Not surprisingly, members took pride in the fact that they had defied the odds and the critics, and that their organisations had not imploded, had not been shut down for corruption or other failings or disinterest. Their organisations retained a national profile and institutional legitimacy and were entities in which significant numbers of individuals still had an interest.

It seemed to me, the notion of pride reflected a real personal connection between interviewees and their organisations and a recognition of the challenges that the organisation had survived. Interviewees felt a real sense of ownership of their organisations and the achievements of these organisations, or perhaps it was more a case of these organisations embodying some notion of collective personhood. It prompted me to reflect on whether I would ever describe myself as being proud of ACON or AFAO or the Gay and Lesbian Rights Lobby or the Australian Council for Lesbian and Gay Rights, all organisations with which I have had long associations. I have a fondness for these organisations and think they have achieved great things. I think the communities that built these organisations should be proud of their organisations' achievements. I am proud of some of the work I did through these organisations. But would I say I am proud of *the organisations*? I do not think I would.

A neat way of combining rights, health and community development

Some interviewees commended Igat Hope and Kapul Champions for having very successfully supported human-rights advocacy via a project that was primarily a health-promotion initiative. Jamie noted that it was impossible to do the kind of work Kapul Champions had undertaken by flagging it as 'human-rights' work, but that AFAO had facilitated this work by designing an HIV prevention intervention that allowed for a human-rights dimension. This was an example of the way community development and advocacy could work together; through a recognisable structure, community voice could be fostered, legitimised and channelled for effect. It was one thing to get a seat at the table and build understanding that communities should speak for themselves, but it was quite another to help communities make the most of their opportunities to speak. AFAO and NAPWHA both claimed some success in supporting advocates to make the most of these opportunities.

Jamie, a stakeholder well familiar with the CBO model and its use in human-rights work, thought the model had probably delivered more as a community development project than as a human-rights project. The fact that so little progress had been made on law reform worked against it being seen as a human-rights success, although Jamie conceded the fostering of voice was a human-rights outcome in and of itself. But he worried about what the model had delivered overall and that the defunding of Kapul Champions by DFAT had left the organisation in a difficult place and its constituents disappointed and exposed.

> It is so shocking how quickly it disappears — there are people who have had skills [training] and learned stuff but who are also now pretty pissed off, you know, and feel again let down … this is the pattern, what happens — let down.

Despite the fragility of these gains, Jamie thought the national conversation had been shifted along in a positive direction. Visibility of the MDS and trans-women community had been increased, along with an important shift in understanding that these people were an actual community, not just individuals defined by sexual behaviours. DFAT's understanding had been enhanced, he thought, and important links between Aboriginal and Torres Strait Islander advocates and their PNG counterparts had been facilitated.

In summary

In this chapter I have outlined the work undertaken by Igat Hope and Kapul Champions. I have described what they did, which was significant, and what they achieved, also a lot. I am challenging an alternative narrative, which I have heard from aid providers and others, that the organisations failed to deliver. In the next chapter I explore two related issues. First, whether the organisational model used for Igat Hope and Kapul Champions was appropriate for the needs of their constituents, and second, whether the organisations facilitated progress in relation to the human rights of their constituents.

Chapter 6
The Utility of the CBO Model in PNG and the Organisations' Human-Rights Achievements

This chapter is dedicated to Parker Hou. Parker is famous as an advocate for the human rights of MDS and trans women in PNG. Parker was a member of the Leadership Development Group that laid the foundations for Kapul Champions. Parker was subsequently a member of the inaugural Kapul Champions Board and went on to serve as its president, elected in 2014. Parker has also worked as project coordinator for Friends Frangipani and as a researcher with the PNG Institute of Medical Research, contributing to important research on MDS, trans women and sex workers in PNG. One of the most prominent faces of the MDS and trans response in PNG, Parker has appeared in publications and in a 2014 UNAIDS video, I am Proud of Who I am. *Parker has always brought a critical Highlands perspective to the national work of both Kapul Champions and Friends Frangipani and been instrumental in the strengthening of both organisations. I've always thought Parker has a marvellous combination of strength, warmth and grace, an exceptionally good mix for great advocacy.*

*

The utility of the CBO model

I begin this chapter by exploring whether the organisational model on which Igat Hope and Kapul Champions have been based is appropriate for the PNG context. The model is largely the same as that utilised by NAPWHA and AFAO and, it must be said, not much indigenising was undertaken in formalising the organisational structures. PNG is a communal society and communities mobilise around issues all the time, so this chapter is not about whether communities in PNG can mobilise or establish formal structures. A finding that the CBO model 'does not work' would not constitute failure on the part of either organisation. But it would be a useful learning, likely to shape future efforts to promote human rights in PNG.

Before embarking on this analysis of the utility of the CBO model, it is worth noting that assessment of effectiveness is a contested space. There is no single agreed measurement of organisational functionality and an understanding of organisational and governance strength is changing all the time. The Institute of Development Studies (IDS) (2010) invites people to appreciate that there are very different interpretations of governance performance: 'Western policy makers increasingly recognise that improving governance involves far more than transferring formal institutions from rich to poor countries. Yet they find it very hard to discard developed country models' (2010:1). IDS notes most of these policy makers live in OECD countries, are driven by normative values (rights, democracy, poverty reduction), work for organisations that are supply driven and have short-time horizons and are often so invested in their professional knowledge (of law, investment, program delivery) that they cannot fully appreciate development country contexts; they still see the West as likely to have the answers and still see aid as the primary driver of development. IDS observes a tendency to see political patronage, rent seeking and vested interests as pathologies when the truth is somewhat more complex. The instinctive response of development agencies is to 'manage' the local politics rather than recognise them as being key to finding ways forward. IDS also encourages an understanding of political representation as extending beyond democratic elections to include such things as informal village councils and participatory governance structures.

Many stakeholder interviewees had clear views on the utility of the CBO model. Dante was well placed to reflect on the community-based model, having worked in several such organisations in PNG over many years. It was *possible* to establish a functional and sustainable CBO in PNG, he said, but it would be extremely difficult. He identified a range of factors working against the successful operation of CBOs in the country and these are detailed below. While the subsequent discussion is grounded in Dante's observations, he was by no means the only interviewee to be making these points. There was general agreement that the following matters made successful CBO operation in PNG difficult: social structures regarding gender, age and regional alliances; organisations for marginalised groups tended to attract the most marginalised; time management and the place of work in community life; reliance upon the resources of already burdened communities; and approaches to volunteerism.

Social structures regarding gender, age and local and regional alliances

The kind of community-based model with which donors and westerners are familiar sees a community-based membership and a democratic process that enables any members to assume leadership positions with the support of their peers. This is the theory, of course, when in practice these models often fail to meet goals relating to democratic function and community inclusion within governance structures. Interviewees pointed out that some parts of PNG contemporary social structures do not readily facilitate the assumption of power by women, and youth are similarly excluded, so the democratic elements of the organisation can falter. Interviewees suggested that Big Men, who hold status within their own communities, are likely to expect this to flow through to the way they are treated within community organisations. In my experience, Big Men are often referenced in PNG conversations about power. The power structures relating to Big Men are widely understood, even though the structures do not operate in all parts of PNG. Big Men hold culturally recognised positions of leadership, which they have not inherited and to which they have not risen via formal processes. They have assumed their leadership role by persuading others of their merit, often through the accumulation of wealth which can be demonstrated and shared to the benefit of clans and followers. This power enhances the capacity of Big Men to accumulate more power and wealth.

This expectation reported by interviewees, that Big Men power will inevitably flow through to electoral processes, is not unrealistic. These men are more likely to put themselves forward for positions of authority and they are more likely to be elected. To be fair, Igat Hope has had strong women leaders, including three presidents, and Kapul Champions has had a transgender president. But most interviewees still thought that traditional power structures continued to influence the composition of many boards, privileging older men as a consequence.

Local and regional alliances

Both Igat Hope and Kapul Champions sought to be national organisations, envisaging a national community of Papua New Guineans connected via HIV status, sexuality or transgender status. Yet both organisations struggled to synthesise the bond of status with those other great bonding agents in PNG, the *wantok* system and regional loyalties. While the word *wantok* translates literally as 'one language', it is more complex than that. The word is used to describe a more general notion of local loyalty and is sometimes denigrated (including not infrequently by people working in development) as a form of corruption. These local and regional loyalties played out at every national election for both organisations' boards. When casting their votes members did not always demonstrate regard for skills, values and governance capacity. Instead, they often voted for people from their own community or regional grouping. Regional groups voted as blocs and, in my view, this led to both organisations missing opportunities to enhance their governance.

That said, 'connection' and 'commonality' are common features of many electoral processes. In my experience with Australian national CBOs, regional linkages between candidates and voters often play a role and I have seen many national organisations be mindful of geography when electing boards. Community-based, democratic organisations are not antithetical to kinship structures; indeed there are some similarities. Both can be places where identity and personal connection interconnect and allow for dynamic interaction and variation. Clans are not static identities and acquire meaning when activated by a range of factors including shared struggle and coordination of responses to these struggles, including through political action. The structure shapes the individuals and individual dynamics shape the structure, just as in community-based, democratic organisations. Significant energy was expended trying to ‘manage’ these regional constructs and the ways regions elected their representatives, but perhaps we could have spent less time worrying about this and been more accepting of the fact that voters consider a multiplicity of factors, including their connection with candidates. They often make assessments as to whether candidates will understand their perspectives. These motivations do not necessarily undermine democratic processes. They are not ‘corrupt’.

Each organisation had tried to deal with this challenge in a structural sense. Igat Hope allocated board positions on the basis of regional groupings. Positions were reserved for:

- a board member from the Highlands, to be nominated by a Highlands member but elected by all members;
- a board member from the Islands, to be nominated by an Islands member but elected by all members;
- a board member from the Momase region to be nominated by a Momase member but elected by all members;
- a board member from the Southern region, to be nominated by a Southern region member but elected by all members;
- a board member from NCD, to be nominated by a member from NCD but elected by all members;
- a woman to be nominated from the group Women Affected by HIV/AIDS;
- three members to be elected from anywhere in PNG, to be nominated by any member but elected by all members.

This structure was intended to address regional allegiances by ensuring perspectives from each region, while ensuring that each position was subject to a vote of *all* members. Nominees were to come from a region but were not appointed as representatives of these regions — they were to see their allegiance first and foremost to the *organisation* rather than their region.

The board of Kapul Champions consists of:

- one member from the Southern region who shall be elected by all Southern region members present at the AGM and eligible to vote;
- one member from the Islands region who shall be elected by all Islands region members present at the AGM and eligible to vote;
- one member from the Highlands region who shall be elected by all Highlands region members present at the AGM and eligible to vote;
- two members from NCD who shall be elected by all members present at the AGM and eligible to vote;
- one member from the Momase region who shall be elected by all Momase region members present at the AGM and eligible to vote;
- one member who is living with HIV who shall be elected by all members present at the AGM and eligible to vote.

As with the Igat Hope constitution, that of the Kapul Champions seeks to acknowledge regional groupings, with a weighting for NCD on the basis that the biggest MDS/trans-women community resides in Port Moresby. There is a significant difference, however, in that, for Kapul Champions, regional positions are elected by members from the relevant region. With Igat Hope, *all* members vote for each regional position, although only members from the relevant region may nominate.

Despite this difference, elections for both organisations have tended to see regions voting as blocs. Election processes were occasionally marred by disputes around what it means to be 'from a region', with some members being from more than one region where their fathers were from one region and their mothers from another, or where they were born in one region but lived in another. Both NAPWHA and AFAO received complaints from members that their regional representatives were not truly from their region. Efforts to manage regional bias were largely ineffective. Members tended to vote according to regional groupings and the outcome was ultimately determined by which region had the most representatives at the AGM. This tended to favour people from NCD as most AGMs were held in Port Moresby, although Kapul Champions's AGM in Lae also saw local voters exercise their numerical advantage. Occasionally all the regions would get together to vote against NCD.

It is fair to conclude that constitutional attempts to address regional loyalties were insufficient to manage the issue. Not only were there disputes about who could stand or vote for what position, but there were broader governance issues as well. Regional representatives occasionally struggled to balance their commitment to their region with their legal responsibility to act in the best interest of the organisation, even where the proper exercise of this responsibility might have negative consequences for their region. Again, inadequate resourcing played a role. It is one thing to say that individuals elected from a region must put their allegiance to the organisation before their allegiance to the region. But this goal is undermined when there is no money to bring board members together, and regional board members sit in isolation from their colleagues, frustrated by a sense of being kept away from the locus of decision-making (Port Moresby). It is not surprising that this led to suspicion that regional members were being sidelined.

The organisations attracted the most marginalised of the marginalised

As discussed in previous sections, both Igat Hope and Kapul Champions tended to attract members from those parts of the relevant constituencies with the most need for support and the least to lose by being publicly linked to these organisations. This has meant that constituents with more resources (better jobs, more education, more support, greater access to power, more opportunities) have been less likely to join, and doctors, lawyers, accountants, journalists, teachers etc. have not (as a general rule) joined either organisation. As a consequence, organisations have had limited access to the full range of governance skills required for successful operation. By contrast, when I reflect on all the boards of Australian community HIV or gay and lesbian organisations of which I have been a member, they have been characterised by a disproportionately high number of lawyers, doctors and senior public servants.

Time management and the place of work in community life

PNG custom emphasises the importance of family and kinship. Exercise of responsibilities to family and community may disrupt paid work in different ways — employees may take leave from work for family matters at relatively short notice, and they may be gone for long periods during which they cannot be contacted. International donors can find this frustrating as they seek to impose strict funding and reporting cycles. I know from my own experience that funders were frustrated by the long shut-down periods that characterised Igat Hope and Kapul Champions over Christmas as staff returned to their villages for the festive season. These funders were familiar with working with CBOs in other countries and frustrated that PNG CBOs did not seem to operate in quite the same way.

Reliance on the limited resources of already burdened communities

Jamie, a stakeholder with great experience in the Australian community response and considerable familiarity with Kapul Champions, believed that the incredibly hostile nature of the social and political environment had also undermined the operations of Igat Hope and Kapul Champions, and other CBOs as well. He felt very strongly that reflecting on the performance of a community-based organisation required proper focus on *community*. He observed that PLHIV, MDS and trans women have such difficult lives that they are already hugely disadvantaged when it comes to possessing the capacity to implement programs. We cannot expect a brutalised community to be unaffected by their experience, he said, and we should not mistake the need for a representative voice for the capacity to establish one. This linked to his next point on the perils of leadership in a community such as this. It was difficult, he said, to be a leader in any environment. But to take on this role in a community where so many had been damaged by a lifetime of ill-treatment inevitably exposed these leaders to concentrated lateral violence. This was compounded by an unhealthy degree of jealousy given that this leadership, though unpaid, was seen to involve perks unavailable to others.

Approaches to volunteerism

Jamie felt strongly that the CBO model was flawed in fundamental ways. First, Australia had sought to export a model of volunteerism that simply did not exist in PNG, and could not reasonably be expected to operate. He felt it made no sense, in the PNG context, to expect board directors to provide their services for free. This situation invariably involved them working alongside employees who were paid, often doing exactly the same sort of work as paid employees. How could this not have led to tension between board and staff, and to requests (and worse) from board members that they be rewarded? Jamie (and others) felt embarrassed that Australia had sought to export its own model when the contextual differences made it obvious it was not transferable. While the success of the Australian community response has been internationally recognised, almost all the community volunteers responsible for driving the response in Australia have been in receipt of a salary or government pension. This had obviously facilitated their volunteer contributions. Where did we 'get off', asked Jamie, allowing DFAT personnel on salaries of AUD150,000 per year to demand volunteerism in PNG?

He returned to the theme of corruption, questioning whether the zero-tolerance model could ever operate in PNG where 'corruption' is seen at every turn. He also reflected on the cultural impact on people who have had a life of being devalued, essentially unemployed and in many respects criminalised. He argued that the expectations of DFAT, NAPWHA and AFAO had been unrealistically high. Jamie wondered whether Kapul Champions might have been a little 'set up', having been funded so modestly yet tasked with such a huge challenge—shifting the way the nation thinks about MDS and trans women. This might have been achievable, perhaps, in a country with a stronger level of government support, or at least a government that was more open to the idea of change. It may have been more achievable in a country in which there was a functional human rights commission. But in the absence of these, a small community-based organisation could hope to achieve only so much.

So, given all the potential obstacles, can the community model work?

Having canvassed the many barriers to the successful operation of community-based organisations in PNG, stakeholder Dante said it was essential that everyone — donors, constituents, supporters — take a realistic approach to the situation. It was not realistic, Dante said, to expect the sustainable operation of such organisations over many, many years.

> Yes, I think there is the possibility of sustainable organisations but then you also have to look at the real world. How many organisations within the West that come from a western framework, that have

> been built by people who have western values, how many of those last with the same value set for decades?

While Dante left open the *possibility* that community-based organisations could operate successfully in PNG, on balance he thought it unlikely. Instead, movements could build hope rather than institutions.

> No, no, it's not impossible; I would just say it is extremely difficult. You strengthen relationships and you are able to strengthen peoples' perception of who they are and who they are in the world and what power they may have. But building organisations is really, really difficult.

Anthony had worked in HIV movements in several different countries and talked about the evolution of HIV community-based organisations across the region. He reflected that they are often started by small numbers of highly aggrieved people who may, but often do not, possess the skills to run an organisation. Over time these groups often attract the interest of donors and, at that point, Anthony said, they either attract the people necessary for money management or they do not: 'They either find the talent that will manage the donor money and allow the charismatic activists to do their bit, or the whole thing collapses like a house of cards.' Igat Hope and Kapul Champions were at this point, teetering on the edge, but, in this sense, they were not unlike many other CBOs across the Asia Pacific, he thought.

Jamie was unconvinced that the model could be made to work. Given all the cultural barriers to successful operation, he wondered whether perhaps the community model was the wrong way to go in PNG. Given all the challenges of the community model, why not consider a different kind of approach, he asked. He thought the growth in social enterprise entities might be worth closer study. These would still enable social justice outcomes to be pursued but might find ways of securing support for this work beyond government. He thought a social enterprise might be able to establish a stream of income independent of donors and governments and that this would ultimately offer a sense of security that Igat Hope and Kapul Champions had never truly enjoyed.

Esther also had some interesting views about community ownership of the organisations, Kapul Champions in particular. Drawing on her experience of working with PNG CBOs, Esther observed that, while there was a shared understanding of accountability to the community, the notion of community ownership could be further developed. One strategy, she thought, might be to introduce members' fees. By contributing to the organisation, members would better understand their ownership of it. Monitoring of the organisation's money would in some real sense be a monitoring of their own investment. Of course, the members of Igat Hope and Kapul Champions were more likely than not to be poor, so most would have struggled with even modest fees. The organisations would likely also have struggled with the administrative requirements of fee collection and receipt of payments. Yet knowing these things, Esther still thought the imposition of fees would help. Esther was more optimistic about the CBO model than Anthony, Dante or Jamie, concluding that it could be made to work if the right practical measures were taken to support it. Esther set out the minimum procedural steps that would be required to prevent community-based organisations from failing: a minimum set of operating processes (policies and procedures) and associated staff training; biennial external audit; and agreed communication processes.

These local perceptions of what constitutes institutional strength will be critical. Anna Wetterberg, Derick Brinkerhoff and Jana Hertz (2015) document how development agencies often have an inadequate understanding of how to go about engaging local organisations and building their capacity. The authors make the point that the apparent simplicity of terms like 'capacity' and 'capacity development' mask their true complexity and they call for policy makers and development workers to develop a clearer grasp of these notions and a better understanding of the factors that shape the performance of local development partners. Drawing on research into development projects in Indonesia, the authors note that approaches to CBO capacity building in developing countries are often based on questionable assumptions, including the belief that implementing donor projects automatically builds local capacity, and that local governments will willingly avail themselves of the assistance these local organisations could provide. This first point, in particular, resonates with the experience of Igat Hope and Kapul Champions. There was, absolutely, a belief — on the part of DFAT, AFAO and NAPWHA — that the capacity of these organisations would automatically be built as a consequence of them being contracted to deliver donor priorities. The strategies suggested by Wetterberg, Brinkerhoff and Hertz to mitigate the risks associated with this assumption — simplification of contractual requirements, adjustment of targets and timeframes to reflect starting points, and recognition and reconciliation of competing program goals — could have been much better utilised.

What might have been done differently?

As noted, there were divergent views on whether the type of community-based structure utilised for Igat Hope and Kapul Champions was the right one for PNG. Everyone agreed there were elements of a CBO approach that were very appealing, but not everyone agreed that it was the right model for PNG. On balance, more interviewees thought it could be made to work than the opposite, but there was general agreement that mistakes had been made that had jeopardised the organisations and made success harder to achieve.

Funding

Interviewees agreed that it was a mistake to rely so heavily on DFAT. In some ways this failure is a kind of backhanded compliment to DFAT. AusAID's early support of community HIV movements in PNG was significant and courageous. It was provided at a time when no other donors were showing any interest in supporting these communities and in the absence of any interest in supporting this work on the part of the PNG Government. This support had really demonstrated the Australian Government's commitment to the community response in PNG and there is ample evidence that, at this stage at least, DFAT saw itself as being in some sort of partnership with NAPWHA and AFAO. This partnership was aimed at fostering a national HIV response in PNG that properly engaged marginalised groups.

In fact, the willingness of DFAT (initially AusAID) to step up and lead in the HIV space may have had some negative impacts on the sustainability and ownership of the HIV response (see Carlson et al. 2012). AusAID's leadership had arguably robbed the local HIV community of the time and space to develop its own analysis and direction, and perhaps let the Government of PNG off the hook. But even acknowledging these negatives, DFAT provided a positive factor in developing a national focus on HIV. Its willingness to take on a lead role, some interviewees said, led people to believe that DFAT was in for the long haul. Interviewees had been very surprised to see the DFAT support disappear, and so quickly. Many interviewees said they were shocked that DFAT would so jeopardise its past investments in the community response. But others thought that the Australian organisations and their PNG counterparts had been negligent in relying so much on DFAT. They had failed by insisting on working within their comfort zone — with the donor they knew — and had failed to explore other donor opportunities.

> Where we dropped the ball is in not providing the skills to develop a broader portfolio in funding support. I think … sucking on the DFAT teat has given us all a false illusion that the government of Australia would always have as a priority those communities who are not in the mainstream, and that simply has been false and politics has shown that, and I think that, had we been more contemporary in our thinking about what is happening internationally, we would have provided more skill development to broaden the base and make the organisation more self-sustaining. (Dante)

Jamie took up this line of thinking, arguing that it should have been apparent to all that, 'Australian support was only ever a press release away from collapse'. Governments change priorities all the time, he said, and the community response in Australia should already have learned that from its own experience. He considered it a failure on the part of NAPWHA and AFAO to neglect to impart this important lesson to Igat Hope and Kapul Champions. Anthony agreed with this analysis. While acknowledging the hard work of government development programs (like the AusAID of old), Anthony argued that this work was always subject to the swings and roundabouts of the political system, with shifting priorities within governments and ideological swings between them. An aid program might swing from rights and capacity building to economic development in a few short weeks, and it was hard for any movement to retain support in these changing circumstances. But while the challenges associated with managing these shifts were very real, the shifts themselves must be anticipated, thought Anthony.

On balance, I am inclined to agree that there was a failure to anticipate DFAT's withdrawal of support. By the time DFAT withdrew its funding for Igat Hope and Kapul Champions, I had been working in the HIV sector for more than two decades. I had seen plenty of shifts in government priorities, with often immediate, detrimental impacts on community responses reliant on government funding. This would have been true also for AFAO and NAPWHA. I had also learned from my work in the Australian HIV response, and HIV responses elsewhere, that funding programs are shaped not only by shifting government priorities, but by the individuals that give effect to these government policies. I had already learned that if, and when, these people move on, funded programs need to be re-secured and agreements need to be reached anew, and that it is dangerous to assume a committed and supportive bureaucrat will be replaced by someone with the same interests. AusAID/DFAT's early support for Igat Hope and Kapul Champions was driven by committed people within the AusAID/DFAT team in PNG (and Canberra), but this support did not continue in the same way as time went by. Over time, DFAT seemed to have less time and energy for supporting small-scale community responses. Instead DFAT wanted to be less hands-on, to divest itself of more responsibility for the running of programs, to have fewer contracts. To me it felt like DFAT was finding the management of these organisations too much hard work. It wanted to pay someone else to manage these complex programs. It wanted less mess.

I think we did fail to properly prepare for the changes that were to come. From 2013 the Australian Government was signalling some shifts in aid approaches. In a speech to the Chairs and CEOs of ACFID members in October 2013, the (then) new Foreign Minister, Julie Bishop, outlined the new government's vision for aid:

> Aid is a powerful tool in our statecraft designed ultimately to protect and extend Australia's broader interests and we must use it to make the most significant impact abroad and at home. It is a portfolio of investments and like any professional financier, the government will apply a scientific and methodical approach to our investment decisions so we can achieve the greatest outcomes, the best dividends.

The Minister went on to say, in relation to cuts to the aid budget:

> These reductions will be managed sensibly and methodically with a keen eye on maintaining and improving results with more rigorous and streamlined approaches … the demand for efficiency and effectiveness is clear … I want to see strong performance culture and we'll look to adjust our investment decisions based on effectiveness … we need benchmarks for all our partners and the government recognises the experience and the expertise of NGOs and the critical role of civil society development … we look forward to an invigorated relationship with the NGO sector and we hope for a new discipline and rigour in the way we do business together.

In a subsequent address to the Papua New Guinea–Australia Business Forum in May 2014, the Foreign Minister fleshed out her views (Farrell 2014). A new approach to aid delivery was needed, she said, one that would see the private sector more heavily involved in promoting growth. Bishop lamented the lack of progress in relation to health outcomes, observing that 'despite a significant investment in aid in PNG over many decades, in some vital areas there has been no discernible progress'.

DFAT published its *Strategic Priorities for Australia's International Response to HIV* on 20 July 2014. The document, in many respects, reaffirmed Australia's focus on improving regional health and combating HIV, including through a focus on marginalised groups. But it also noted:

> Economic growth in the region and the slowing growth in donor economies necessitates new approaches to social sector funding … The proportion of domestic public spending on HIV has been increasing … in Asia and the Pacific. This trend is continuing in Asia and the Pacific and should be supported.

Two days later on 22 July DFAT Deputy Secretary Ewan MacDonald addressed the World AIDS Congress in Melbourne and, while lauding the Australian response in general, called for greater focus on sustainability in the aid program:

> Our contributions through our aid program are time bound. They cannot substitute for the commitment and political will of a national government … Australia will support partner countries to allocate funding effectively and equitably and increase domestic funding for health and HIV. Many of the governance and coordination structures set up earlier in our response were designed to manage larger, more generalised epidemics. We will encourage the review of these mechanisms for greater efficiency.

Upon reflection, there were clear warning signs that our reliance on DFAT funding was increasingly high-risk. It is a long distance from Canberra to Port Moresby, but I can draw a link between the new Australian Government's broad policy agenda and the decision to withdraw funding. When Igat Hope and Kapul Champions were defunded, we were told by DFAT representatives — at different times and by different individuals, but told all the same — that the organisations could not demonstrate sufficient performance and that an absence of benchmarking meant the value of their work could not be shown; that they could not demonstrate solid return on taxpayer investment; that they represented old ways of doing things when new approaches might deliver more; that greater private sector engagement would enhance program performance; that DFAT could not be expected to keep funding this work and that it was time for the PNG government to step up. Elsewhere across government departments — in the Department of Health in particular — I was seeing a suspicion of community organisations generally, and of their advocacy work in particular. Increasingly, Australian Government funding to NGOs was being delivered on the proviso that it not be used for advocacy.

So, when I reflect on what happened I recall plenty of warning signs that the funding for the two organisations was in jeopardy. What could possibly be more vulnerable than a small, complex, community organisation with an advocacy agenda but no clear benchmarks or performance indicators, which was using a model developed a decade before and reliant entirely on public money and the expertise of public servants? And so, we failed to plan adequately for the change that was coming. At the very least we failed to appreciate the speed and totality of the change. While there *were* genuine efforts to expand the funding base beyond AusAID/DFAT, clearly these efforts were insufficient.

Local leadership

It was suggested by several interviewees that the Australian organisations should have spent more time identifying and mentoring community members with the skills to lead the PNG groups. This may have helped overcome the problem that those putting themselves forward as leaders were not always the ones with the skills to run an organisation. Interviewees said that NAPWHA and AFAO should have looked for potential leaders — from diverse backgrounds, not just community advocacy — and helped prepare them for governance responsibilities. This leadership issue looped back to the issue of membership discussed previously. By failing to attract members from across the entire constituency, the organisations had robbed themselves of much talent.

In fact, Save the Children in PNG and AFAO *had* endeavoured to build leadership capacity in anticipation of the establishment of Kapul Champions. A two-year collaboration between Save the Children and AFAO — the Leadership Development Group (LDG) Project — is largely recognised as the precursor to Kapul Champions and was focused on building leadership skills among MDS and trans women. An end-of-project evaluation undertaken in 2012 found that the project delivered some important outcomes but was perhaps less successful in building leadership capacity than might have been hoped. It struggled under the weight of factors that have since troubled Kapul Champions: regional loyalties, diversity of membership and lateral violence. The LDG had limited success in engaging those MDS/trans women entrenched within power structures — its members were mostly drawn from the same pool of community advocates that went on to become Kapul Champions members. LDG members experienced some very negative treatment from other members of the MDS and trans community and this prompted several not to stand for election to the inaugural Kapul Champions board, a decision which robbed the inaugural board of the very skills that the LDG project had been fostering. And in any event, participation in the LDG Project did not appear to secure for members positions on the Kapul Champions board. Instead, regional factors came into play at the election for the board and several LDG members did not get elected.

I recall that I and my AFAO colleagues were both surprised and disappointed by this turn of events. We had made some wrong assumptions on several fronts. We had underestimated, indeed failed to see, the impact of lateral violence. It was only after the election, when we asked LDG members why they had declined to stand, that we came to understand many had already experienced a hard time from their communities and wanted no further exposure to this pressure. We also thought voters would see a candidate’s involvement in the LDG as strengthening their claim to election, however this was less persuasive than we had anticipated. Not for the first or last time had I failed to read the electoral mood, further evidence of my outsider status. Conversely, it can be interpreted as a positive that members felt empowered to exercise their democratic rights unfettered by AFAO’s expectations.

Rachel, a highly experienced sector employee and former Igat Hope board member, said that Igat Hope board terms should have been longer because a term of one or two years was insufficient time to learn governance skills. As with national parliamentarians, board members were often voted out after a single term, so the board was perpetually populated by inexperienced people who had insufficient time to build the governance skills required. This proposition raises interesting questions about democracy within Igat Hope and points to a contradiction. There was a general consensus among interviewees that too many board members lacked the governance skills required of their role. There was also general support for the notion that governance training was a good idea and that, over time, most board members could be brought to a point of sufficient governance capacity. Yet many interviewees saw the most effective means of encouraging improved board performance to be the removal (or threat of removal) at an election, and for this threat to be real, elections needed to be sufficiently imminent. This contradiction makes it hard to know what should have been done differently here. While there most definitely could have been more and better training provided in governance, it is not clear whether more frequent elections would have helped or hindered efforts to build governance capacity.

What *is* clear, however, is that more could and should have been done to prepare board members for their role and to support them in the exercise of their governance functions. One-off governance training was always going to have limited benefits, and there was strong support among interviewees for ongoing, in-country mentoring for board members. To be fair, both NAPWHA and AFAO tried to procure this support, but both agencies ran up against the same problem — there is a limited number of successful community-based organisations in PNG and the availability of in-country mentoring for peer-based groups trying to enhance their functionality is similarly very limited.

From his stakeholder's perspective, Damien thought the failure around leadership was really a failure to properly mentor.

> A whole bunch of people, foreigners who are dedicated, who know how to straddle, who understand advocacy and all that stuff and are embedded, but I don't … see a lot of success in them mentoring other people into really strong positions and it may be that that is really hard — I'm sure it is. You know, there was a woman in [organisation's name deleted] who was brilliant, and so she was mentored by [person's name deleted] and she increased the responsibility [of that person] year by year and [that person] now has a much more high-powered job and will be a leader and she is only twenty something. So, you can do it if you get the right person … I think that something that would help would be a kind of community leadership college or institution, or long mentoring program … because I think there is no fostering of emerging leaders who have an interest in key populations.

Damien felt that those who had sought to support the organisations had failed to mentor local activists on how to navigate the spaces where power is exercised, and decisions are made.

A mixed leadership model

There was surprisingly strong support for a kind of 'blended leadership' model whereby boards would be elected by moderated democratic processes. Esther, for example, was supportive of the proposition that positions be reserved for 'educated members'. These would be people who had attained an agreed level of education (possibly university level) and who possessed the kinds of skills the board needed (particularly financial management). She was also supportive of 'advisory members' who might be appointed by the members or by stakeholders. Esther thought this attention to the board needed to be matched by attention to the membership — members needed to be educated about governance so that they could make the best possible electoral decisions. Jamie was similarly open to a different kind of governance structure, perhaps a company or a blend of elected and appointed officials.

Many PLHIV, MDS and trans interviewees were comfortable with a notion of their organisations' boards being supplemented with people possessing the skills required for effective governance, but few had thought it through in any detail. For example, few interviewees had thought about how these people might be elected. Would they need to be peers? Exactly what skills would they be required to have? Would they need to be appointed by the members themselves or might they be nominated by stakeholders? The most commonly suggested sources of people with required skills were NAPWHA, AFAO, DFAT, the National Department of Health, the National AIDS Council and donor agencies.

It was apparent that people supporting these blended governance structures were not seeking to undermine peer leadership: no one seriously advocated a model under which peers would cease to be the majority. Instead, interviewees were speaking of ways to strengthen the peer model so that it might deliver more. Interviewees who reflected on the peer nature of the governance structure were far more likely to affirm it than critique it. Igat Hope members were likely to recall disputes between the board and the secretariat and to conclude that having non-peers in paid positions only works where there is strong peer oversight via the board. Support for blended models appears to be conditional upon peers retaining ultimate control of the governance structure (they must ‘have the numbers’), and upon the non-peers being required to understand the needs and aspirations of the peers they work with and a commitment to the organisation’s goals.

A final point needs to be made on governance. Several interviewees observed that boards had had too few opportunities to hone and exercise their governance skills. At best Igat Hope’s and Kapul Champions’s boards were funded to meet perhaps three or four times per year. Given the national nature of the boards, meetings were expensive with each involving multiple flights. Funds for governance were often reluctantly provided, with donors having a clear preference for *doing* over *meeting*, as if the latter was not critical to the former. Each organisation needed many more board meetings than they were funded to convene. Complex governance issues arose frequently, and the boards could easily have met monthly and still not have dealt with all the issues requiring their attention. Governance problems were left to fester when swift face-to-face discussion may well have resolved them. In acknowledging failings, it is important to recognise that most boards did not have adequate opportunities to properly find their feet.

Less FIFO

The Fly-In-Fly-Out (FIFO) nature of NAPWHA and AFAO’s work was criticised.

> There could have been someone working closely with the board and the secretariat, someone who could be placed in-country and who could be, you know, a link … trying to help them [Igat Hope staff] to see the importance of the work they were doing, the positions they were based in and making them understand their roles. Making people to be really aware that my role is this and I am not supposed to do that. I am not supposed to be going and doing advocacy when really I’m supposed to be doing fundraising — those kinds of things. You know, it’s also about people understanding their roles. If someone could have been really placed … in-country … Yeah, all the time and be present to

> work with us — I know [NAPWHA] tried to do something but it was from far off and having to be closer and working closer with people is much more relevant or much more appropriate. (Alani, woman with HIV)

From his stakeholder perspective, Jamie conceded that the model of support provided by AFAO was an expensive one. It involved AFAO charging a management fee with which DFAT was somewhat uncomfortable, and it involved the payment of salaries for Australian employees who did not spend all that much time in PNG. These were reasonable concerns and they made it more difficult to retain government support for the model. Several interviewees who commented on this kind of support made the point that the model was never put forward as the only, or even the best, model of providing support for community-based organisations in PNG. It was simply the best the Australian organisations could offer at the time. These interviewees tended to agree that the imperfections of the model had obscured its actual achievements. Progress was made, but it inevitably slowed when technical advisers returned home.

> You saw the difference when there was a really well planned out meeting and board meetings and strategic planning sessions and things like that, I thought it was really striking — I was only at a couple of them, but I remember being really struck … and saddened by the fact that really when everyone went home again that lots of momentum would be lost and they would really struggle to carry things forward. (Jamie, stakeholder)

But could you find the right person to take on the role, Jamie asked, because to engage the wrong person in-country would be far worse than having good people fly in and out. He also wondered about the long-term impacts of having someone in-country. There was a risk that this person would take on too much responsibility for driving the organisation forward so that, when he or she eventually left, the organisation would collapse. Only a true community-development approach would work for Kapul Champions, he said, and each model of support for this approach had strengths and weaknesses. The FIFO nature of NAPWHA’s support was considered in a NAPWHA report (Leach and Rule 2013), particularly in relation to efforts on NAPWHA’s part to build Igat Hope capacity around advocacy for treatments. The report acknowledges that capacity would have been more effectively built via in-country mentorship rather than the remote support provided by NAPWHA. NAPWHA concluded that FIFO is probably not the best form of support for organisations such as Igat Hope but noted that this does not mean it does not work. It can work quite effectively for some things. The report notes many achievements of the Igat Hope/NAPWHA collaboration, including the establishment of an effective and enduring partnership, built from FIFO connections (Leach and Rule 2014).

There is a bigger picture here. When people working in development in PNG talk about DFAT personnel, it is often observed that DFAT staff in PNG are ‘doing their time’ before they can earn a more desirable position. There are notable exceptions, of course, but in my own experience this is how postings to DFAT Port Moresby are described. There is, then, a perception of a kind of FIFO element to the DFAT approach. DFAT personnel are seen as being in-country for a while but not long term. And while I have not researched the degree to which this may or may not be true, it was certainly the case that when the decision to defund Igat Hope and Kapul Champions was made; one of the greatest barriers to challenging the decision was that there was no one in DFAT Port Moresby who had any history of the community response in PNG.

Similarly, I have heard expressed by many NGO development workers in PNG a kind of grumpiness that their work had brought them to PNG when really, they would have rather been doing HIV and development work from Geneva or New York, or at the very least from Bangkok. I wonder how this must have been experienced by PLHIV, MDS and trans-women communities in PNG and whether it was seen as being a half-hearted interest in helping local communities. It must surely have impacted on the degree to which these communities saw our work as a ‘partnership’. From my own experience, I would observe that the fact that I was a FIFO worker was relevant. But the fact that, by the time I was conducting this research, I had been coming to PNG for more than 15 years and made more than 50 trips, was also relevant.

Local approaches to volunteerism should have been better understood

Both NAPWHA and AFAO seem to have come to similar conclusions regarding volunteering. NAPWHA identified the problems in its reflection document (Leach and Rule 2013), which notes that it did not make sense to expect that the volunteer element that had been so critical of NAPWHA’s success could be exported to PNG. PLHIV working to establish Igat Hope confronted challenges that NAPWHA’s earliest volunteers had not faced: ‘By virtue of their economic and social circumstances, many of Igat Hope’s initiators had less capacity to give than their Australian counterparts’ (Leach and Rule 2013:17). The report notes that Igat Hope volunteers were often unwell and impoverished, lacking access to even basic health care or a means of supporting themselves. In these circumstances members and constituents had understandably sought to gain personal benefit from their engagement with Igat Hope.

A 2012 evaluation of the Leadership Development Group, undertaken by Paul van Reyk under contract to AFAO, also identified volunteerism as an issue. The report describes volunteerism in PNG as occurring within the context of a gift relationship, whether or not this is formally acknowledged; volunteer contributions to Igat Hope or Kapul Champions were gifts that generated organisational obligations to reciprocate. The report concludes that community development projects such as Kapul Champions should involve a continuum of tangible and intangible benefits that might serve the function of gifts for volunteers in reciprocity for their contributions. These benefits might include training, opportunities to travel, enhanced standing in the community, enhanced prospects for future employment, and yes, even monetary reward. In the social enterprise construct, this might look like a living wage.

A better job of coordinating donor contributions was required

Victor, a stakeholder who has seen the community HIV organisation model rolled out in many countries had many persuasive views on what had happened in PNG. When asked to consider the proposition that the model simply was not fit for purpose in PNG, he had this to say:

> We had to do something. I don't think the model is wrong [but] I don't think that … there was broad ownership of the model. My main criticism is around donor harmonisation … so yeah, it wasn't a bad idea if you were all going to help and support it to get as strong as possible, but that's not what happened.

My own experience supports this view. I relentlessly asked donors to provide financial support for Igat Hope and/or Kapul Champions. I asked many, many times, sometimes wearing a NAPWHA hat, sometimes an AFAO hat, and sometimes another hat altogether. Reasons for not providing funding were many and varied, but the following observations can be made about common points of view. Donors commonly liked the idea of these organisations being funded and thought it appropriate that they *be* funded through some component of the HIV response in PNG. They all accepted that the national HIV response would be enhanced by having some structured way of engaging with PLHIV, and most accepted the value of having a means of connecting with MDS and trans women. But few felt that it was *their* responsibility or that it was sufficiently high on their list of priorities to actually fund them from their own resources. Donors wanted *other* donors to provide the funding. When I pressed donors further, I was generally told one of the following: that there were higher priorities; that they didn't currently have any unallocated funds to make available; or that they didn't provide funding for that 'kind of thing'. The phrase 'kind of thing' generally meant providing funding for core institutional functions. They might be able to source some short-term project funding or resources to hold a workshop or produce a pamphlet or poster or print a t-shirt — indeed anything that could be launched at an event at which a donor might appear to be lauded. But no one seemed willing or able to support the core functions of the organisations. Victor summed it up nicely: 'I think the problem was that the funders didn't get together and figure out that it would need constant capacity development, supervision and support and so the rug got pulled out from under it.'

The organisations' achievements in promoting human rights

In the preceding section it has been suggested that the community organisations achieved some important outcomes beyond simple outputs or activities. But a key question for me is whether the organisations achieved *human-rights* outcomes. If the answer is yes then there is an important follow-up query as to whether there is anything specific to the CBO model that might have facilitated these outcomes, or whether they might have been just as easily achieved via a different structure. This is a complex area of enquiry and it is appropriate to begin by considering how success might be measured.

Measuring rights outcomes

There are multiple reasons why it is hard to measure the success of Igat Hope and Kapul Champions in promoting human rights. Some of these are specific to the histories of Igat Hope and Kapul Champions, and some relate to the more general challenges in developing meaningful measurements of human-rights achievements.

To begin with the specific challenges, while Igat Hope and Kapul Champions are organisations with human-rights agendas, this is not their only agenda. They are also health-promotion organisations, and they undertake community development. These activities are all intertwined, and yet they have distinct objectives and implementation approaches. Many organisations have multiple agendas and are still able to measure progress in relation to each, but it becomes even more complex with Igat Hope and Kapul Champions by virtue of the fact that much of their human-rights work has had to be disguised, or at least embedded so that it doesn't constitute the main focus. It has been hidden (although sometimes in plain sight) from DFAT, from the Government of PNG and from others who might have fought it (including some Christian churches, or elements thereof).

> The importance of human rights is almost imputed in this work, you know, when we do it … you can't really get this stuff progressed in government flagging it as human rights, it's still got to be health and it's got to be HIV prevention and I think that was exacerbated by the fact that the Human Rights Branch in DFAT were completely separate from this work and had no engagement so I think [human-rights work] is critical and I don't think [HIV prevention] works unless you have that sort of a frame on it, but you have to double-speak the government to do the work. (Jamie, stakeholder)

Jamie's observations sounded very familiar. My work in Australia has involved these same challenges. Much of my 'human-rights' work has been dressed up as health initiatives or as something else to get around Government ambivalence (or hostility) towards human rights and the national rhetoric about the UN being a meddlesome outsider on such matters as climate change and refugees. When really, as the argument goes, our decisions should be made here in Australia or, at the very least, shaped by 'Jakarta not Geneva', to quote former Liberal Prime Minister Tony Abbott (Shanahan 2013; Wesley 2013). The partly hidden nature of their human-rights agendas has meant that much of the human-rights work of Igat Hope and Kapul Champions has not been articulated. And where it has not been articulated, measurements have been neither proposed nor applied. Without agreed measurements, and efforts to formally record achievements, it becomes especially hard to evaluate the human-rights achievements of the organisations.

Human-rights progress is hard to measure at the best of times, even where agendas are articulated, and achievements recorded. Progress can be very, very slow. If progress is measured by the actions of states, then the wheels of state often move very slowly. Legislative reform, a useful indicator of human-rights progress, often takes years. And then there is the question of whether these laws are ever applied. Human-rights cases can take years to progress through domestic legal systems, and even longer to make their way through international legal structures. Even allowing for these challenges in measuring human-rights outcomes at a national level, it is a whole new challenge to measure whether any of these changes might be attributable, even in a small way, to the work of Igat Hope and Kapul Champions. A legislative reform, for example, may be brought about by innumerable factors — political machinations, lobbying by dozens of different stakeholder groups, media pressure, evolving community attitudes, individual champions, to name a few. In such cases, what hope is there of measuring the impact on this process of a small community organisation? The challenges, then, occur at different levels. There are the general challenges, experienced worldwide, in finding appropriate measures of human-rights progress. Then there are the challenges in applying these to PNG. And then there are the challenges in working out how they might be relevant to the work of Igat Hope and Kapul Champions. The distance between an international human-rights instrument and a little CBO in a developing country can seem very great.

A person could write an entire thesis on human-rights indicators; I give it only a small degree of focus here. I have been keen to put some framework around my reflections on the human-rights achievements of Igat Hope and Kapul Champions, so at least some attention to indicators is appropriate. Gauthier de Beco (2013) charts the development of human-rights indicators from the 1990s, noting, in particular, the pioneering work of the Office of the UN High Commissioner for Human Rights (OHCHR) in identifying indicators as structural, processual and outcome oriented. Structural indicators measure a state's intention to abide by its responsibilities including by ratification of treaties and their incorporation into domestic legislation. Process indicators measure the efforts made by states to implement human rights. Outcome indicators measure the state's human-rights performance, including its development and implementation of human-rights policies.

De Beco observes that despite work done in the development of indicators, human-rights indicator sets are rarely applied. A key reason for this is their complexity. There are plenty of different human rights and development of a single large set of indicators that can measure progress across such a range is inherently complex. The result, says de Beco, is that ‘human rights indicators are generally inaccessible to non-experts who find them unworkable, not useful and even sometimes suspect. Indeed, such indicators seem more popular within academic circles than with practitioners’ (2013:382). He observes that efforts have concentrated on the development of indicators at the expense of their application, and that their utility might be further undermined by the high expectations placed on such tools. But whatever tools might be developed, de Beco cautions that they should not prompt people to dispense with other ways of monitoring compliance with human-rights instruments, like case studies or interviews, both of which provide invaluable insights into human-rights violations.

De Beco describes a methodology for the development of human-rights indicators, writing that, in practice, human-rights indicators are built by ‘capturing human-rights concepts with quantifiable information’ (2013:382). The information may focus on quantitative or qualitative aspects of human rights, and should ideally focus on both, but the information captured should be quantitative — percentages, ratios, yes or no answers, but not subjective statements which are not quantifiable. This does not mean that it cannot capture qualitative aspects of human rights. Stories, descriptions of events and comments from relevant people complement the indicators by putting them into perspective and illustrating issues under consideration. He continues that indicators need to be adapted according to the national context, particularly regarding the capacity of the state to enable the realisation of rights, for example, rights to health and education. Otherwise, human rights risk becoming measurements of development rather than respect for human rights.

But how might a useful set of human-rights indicators be built? De Beco recommends an approach that begins with an overarching framework applicable to all human rights, such as the OHCHR approach of dividing all rights indicators into structural, processual and outcome oriented (2013:384). Next, tailor the framework to the right being examined. Clarity and order are important, so rights need to be broken down into basic entitlements and each needs to be sourced back to an international agreement. And indicators must address cross-cutting issues, the most essential of which, according to de Beco, are participation, accountability and non-discrimination. De Beco emphasises that any discrimination revealed by a human-rights indicator will demonstrate a state’s failure to meet its human-rights obligations and argues that focusing on vulnerable groups is probably the best way to apply human-rights indicators because it focuses on data collection and easily identifies discrimination.

Thomas Hammarberg (2001) talked about some of these challenges in a 2000 address to an international human-rights conference in Switzerland, subsequently published. Hammarberg notes that some aspects of human rights cannot be quantified and that an understanding of achievement will require facts and figures to be assessed in context, with proper consideration of explanations from affected communities. Despite these challenges he encourages human-rights advocates to avoid what he calls the 'drunken man's mistake' of looking for his lost wallet under the streetlight because that is the only place he can see. Hammarberg reflects on the reasons human-rights data might be incomplete or open to interpretation. He sensibly notes that governments often have little incentive to count rights violations as each violation represents a government failing. He considers that human-rights data is often politicised and might be collected and counted in different ways depending on the political point to be made. He acknowledges that human-rights advocates must often take extreme steps to protect the confidentiality of their informants, meaning much of their best data cannot be released. Despite these challenges, says Hammarberg, 'Promotion and monitoring cannot be separated. No serious donor – bilateral or multilateral – can provide assistance in the field of human rights without having the facts' (2001:6).

Hammarberg reflects upon the inclusion of economic and social rights in the concept of human rights, seeing it as having contributed to a useful conceptualisation of government responsibilities as being threefold: to respect, to protect and to fulfil. The state must respect the human rights of all its citizens, it must protect individuals (particularly the marginalised) against violations of their rights by others, and it must make it possible to realise rights for example to education and health care. He observes that when monitoring the response to these three kinds of obligation it helps to analyse progress by reference to four human-rights principles:

- Non-discrimination. Human rights are non-discriminatory and the experience of the marginalised in any context will offer insights into the observance or otherwise of human rights. Where limited information might be available about the experience of human-rights protections for all citizens, it will be appropriate to focus on the experiences of the disadvantaged.
- Progress in the promotions and protection of human rights.
- Participation is a human right in itself. It is also a key element of enforcing other rights involving freedom to receive and impart information and to have channels of influence.
- Remedies involves the availability of effective remedies for solutions where rights are violated.

Hammarberg concludes that monitoring is key to the realisation of human rights, but that the contemporary systems of monitoring are often seriously flawed. He blames resource deficiencies, lack of experience and absence of political will, but notes the positive role that might be played by NGOs:

> In this picture the non-governmental organizations, again, represent a hope. When they can benefit from international exchanges, when they are guided by a clear policy and detailed guidelines for monitoring, when they are well trained and when they can act without risking their safety and get support when in trouble — then, they can contribute to real change. (2001:12)

Sally Engle Merry (2011) notes the growth in the development of indicators for measuring progress in different social justice and human-rights domains, describing this as an example of the dissemination of corporate thinking into broader social spheres. Merry observes that these indicators, 'introduce into the field of global human-rights law a form of knowledge production in which numerical measures make visible forms of violation and inequality that are otherwise obscured' (S84). But the picture that emerges from these measures is incomplete, she writes:

> Indicators, particularly those that rely on ranks or numbers, convey an aura of objective truth and facilitate comparisons. However, indicators typically conceal their political and theoretical origins and underlying theories of social change and activism. They rely on practices of measurement and counting that are themselves opaque. (ibid.)

Merry observes that this growth in application of performance indicators to social justice and human-rights endeavours has had a big impact on civil-society organisations. Donors want clear indicators of success, but this desire is difficult to satisfy. Merry uses the (very real, in my experience) example of a donor wanting evidence of 'increased awareness of human rights' and writes that an outcome or an impact such as this is extremely difficult to measure. NGOs default to easier activities or output measures like numbers of human-rights training sessions or the like, which in fact do not show a general increase in awareness (although participant evaluation may show that individuals' knowledge has increased).

Merry explores the effects of this adoption of indicators, including what she describes as the knowledge effect, by which numerical measures produce 'a world knowable without the detailed particulars of context or history' (2011:S84). Merry considers this knowledge to be often misleading and incomplete. It may facilitate ranking and comparison, or it may make some donors feel more comfortable, but Merry considers it to be not very meaningful. Merry sees that, 'the expansion of the use of indicators in global governance means that political struggles over what human rights or corporate responsibility means and what constitutes compliance are submerged by technical questions of measurement, criteria and data accessibility', concluding that, 'Like witchcraft, indicators are a technology that exercises power but in a variety of ways, depending on who is using it for what purposes' (S92).

Elizabeth Reid (2010a, 2010b) offers another way of thinking about human rights in the HIV epidemic. Reid observes that human rights in the context of HIV have tended to be viewed through a legal paradigm with international human-rights law providing the legal and theoretical framework for analysis. The discussion of human rights which has ensued has therefore been framed within an analysis of human-rights violations — failings, perpetrators, us v them. This, Reid suggests, has been less effective than we might have hoped in bringing about greater respect, greater dignity or lives less damaged by stigma. Reid offers an alternative framework — a practice of praising that acknowledges and reinforces good behaviour, a practice of respect. Reid notes that respect differs from rights in that respect is not an entitlement that people have or something that can be claimed. It is something that can only be earned. (Although importantly, respect can also be shown or extended. There is an analysis of respect in PNG that sees it as a relational attribute in a reciprocal, collective sense. The Tok Pisin notion of *luksave* captures this mutual, relational understanding of respect on PNG: as the showing of respect as well as the recognition of respectful behaviour). Reid describes an activism of respect and praising that gives hope to those who want to live according to the values embedded in human rights. Another fault with the legalistic framework, writes Reid, is that, with its focus on identifying transgressors and penalising them for violations, there is insufficient focus on the causes of these violations. She quotes Paul Farmer: 'The struggle to develop a human-rights paradigm is one thing; a searching analysis of the mechanisms and conditions that generate these violations is quite another. Without understanding power and connections, how do we understand why rights are abused?' (2003:11).

Almost all interviewees talked about violence, but Reid writes of the need to really look at this violence, not in a lazy, racist way that encourages people to describe Papua New Guineans as lawless and violent, but in a way that enables us to see the factors that shape violent behaviour; in a way that enables us to see structural violence. Reid explores the concept of structural violence in relation to the HIV epidemic in PNG. She begins by noting how the epidemic is often described by observers: a rapidly expanding epidemic; the breakdown of law and order; violence everywhere; corruption seemingly at every turn. But she explains how the concept of structural violence helps us see this in a different way, by understanding how inequity is structured and legitimised, provides us with the ability to see how power imbalances impact on the marginalised.

This alternative perspective enables us to ask a critical question: who are the people in PNG who die before their time — the 'untimely dead'? Reid says the untimely dead

> include the women dead in childbirth, women raped and discarded, those dead of treatable diseases and conditions, the burnt, the children defiled, those killed in ethnic conflict, the murdered, and, increasingly, the dead of HIV. These are the victims of structural violence, those whose rights have been violated in multiple ways. (2010:269)

To this list of people, it would seem reasonable to add PLHIV, MDS and trans women. Many, many interviewees spoke of friends and colleagues gone before their time because of the stigma and discrimination to which they were subjected. The question arises, then, did Igat Hope or Kapul Champions contribute to a culture of praising? Did they help Papua New Guineans develop a deeper understanding of structural violence?

Richard Parker (2010) provides another useful perspective when seeking to measure human-rights outcomes with particular reference to sexual rights. Parker charts the evolution in understandings of the politics and practices of sexuality, noting the emerging view of sexual behaviour as socially scripted, with meaningful sexual practices enacted according to socially determined rules which make possible certain understandings of the sexual world while excluding others. Parker sees that this brings with it an appreciation of the profoundly political character of sexuality, which can be fully appreciated only once sexuality is understood as comprehensively social. Parker observes that understanding of sexual life is contested territory where meaning and power intersect as part of ongoing and political processes. He sees the HIV epidemic as having helped give rise to a new wave of research and activism grappling with the ways established rules on sexuality and traditional modes of thinking have negatively impacted on some groups. Parker sees how this research and activism has caused a rethinking of binary classifications such as male/female and heterosexual/homosexual:

> Sexuality cannot be understood in isolation from the social, political, and economic structures within which it is embedded — or without reference to cultural and ideological discourses that give it meaning. Problems related to both sexual health and sexual rights are never evenly distributed across territories, countries, and population groups. On the contrary, they are systematically shaped by multiple forms of structural violence — social inequalities, poverty and economic exploitation, racism and ethnically based exclusion, gender and sexual oppression, discrimination and stigma, age differentials, disabilities, and other manifestations of disempowerment. (2010:60–61)

This is the environment in which Kapul Champions operates, and its members appear to know this as evidenced by their constant reference to the need for rights promotion to take note of context. Parker sees that one of the most important outcomes of social movements engaged with sexuality (such as, I would suggest, Kapul Champions) has been that they make clear the need to approach sexuality-related research and intervention as extensions of broader struggles for human rights. Parker writes of two types of sexual rights: negative and positive. Many activists have focused primarily on negative rights in addressing harm or protecting minorities, he says, but pleasure is also important, as are freedom for sexual diversity and self-expression. Parker calls on advocates for sexual rights to move beyond resistance and defence against violation, to generate social change that will recognise the full potential of sexual rights, including the positive right to sexual pleasure as a fundamental human right in all contexts. To measure Kapul Champions's contributions to this, we would need to look to any achievements in building understanding amongst members or other Papua New Guineans that sexual rights are human rights and promoting positive attitudes towards homosexuality is a success in itself. In fact, any success in promoting sex positivity more generally (and here Igat Hope also has a role in promoting the rights of PLHIV to fulfilling sexual lives) might constitute success.

These different writings all underscore the challenges in finding the right indicators for measuring human-rights outcomes. It is hard enough to find measurements for the Government of PNG; harder still to find measurements that might be applied to small CBOs. Some principles might be gleaned and subsequently used to give shape to my analysis. I have identified five principles to serve as guides. First, rigidity is often unhelpful. Measurements must be adapted for context. Second, not everything to do with human rights is measurable. Numbers, ratios and percentages may be useful, but they may also obscure the real situation. Stories, case studies and witness accounts will be critical to a proper understanding. Third, an emphasis on the experiences of the marginalised will always be appropriate. Stigma and discrimination will always be relevant. A fourth principle is that progress does not have to be measured by counting a state's failings. A list of perpetrators or a count of violations are not the only ways to understand what is going on. Positive achievements and approaches might also be considered. Finally, there is great value in understanding the factors that shape social interactions and that result in disadvantage for some groups. If the structural reasons for stigma and discrimination are not properly understood, then social disadvantage cannot be properly addressed. What, then, are the indicators to be used in determining whether Igat Hope and Kapul Champions contributed to human-rights outcomes? As noted, there are some dangers in retrospectively measuring the human-rights achievements of Igat Hope and Kapul Champions. No human-rights indicators were ever established for the organisations so there is an absence of agreed measure and no baseline from which to measure change. In such a vacuum there is a natural tendency to try and 'make sense' of what occurred and see if this can be given meaning by using some post-facto indicators, or motivations that leave themselves open to criticism: we see what we want to see; we select the indicators that produce the most favourable results; we ignore indicators that suggest failure. Despite these concerns, I have concluded that the organisations' contributions will be best understood by considering any role they may have played in:

- facilitating a better understanding of the experience of marginalisation in PNG;
- supporting people whose human rights have been infringed to seek redress;
- raising awareness of human rights — whether that be among PLHIV, MDS and trans women, or more broadly;

- monitoring human-rights breaches;
- encouraging Papua New Guineans to demonstrate higher regard for the human rights of PLHIV, MDS and trans women, including by promoting understanding of:
    - the lived experiences of PLHIV, MDS and trans women;
    - the structural factors oppressing PLHIV, MDS and trans women.

Applying measurements to Igat Hope and Kapul Champions

There is evidence of very modest progress on the part of the Government of PNG during the life of the two organisations. This progress includes:

- commentary on the rights of PLHIV as articulated via national HIV/AIDS strategies;
- work undertaken to amend the national sodomy laws. This work is often described as the 'National Dialogue'.

Igat Hope was a contributor to national strategies as a member of strategy development working groups and as an organisation consulted in the process of crafting successive strategies. It can conceivably take some credit for the strategy's emphasis on the human rights of PLHIV, although credit must be shared with DFAT and others. Many interviewees noted that Kapul Champions was also a key contributor to the National Dialogue, including stakeholders unaligned to Kapul Champions. I have seen the contribution that Kapul Champions has made to reform sodomy laws, including membership of working groups, attendance at forums and presentations at different conferences. But did the organisations contribute more generally to human-rights outcomes? Arguably they did, and in multiple ways.

Facilitating a better understanding of the experience of marginalisation in PNG

Igat Hope and Kapul Champions have both focused on stigma and discrimination. This focus is seen in almost all of the organisations' activities and in all documents and resources generated by the organisations. Interviewees routinely referenced the work each organisation has done in this area. The organisations have validated the stories being told by marginalised individuals. They have provided spaces for these lived experiences to be discussed, triangulated and affirmed. These spaces have been many and varied — social gatherings, AGMs, board meetings, workshops. Both organisations have operated their offices as drop-in spaces for members. It was rare for me to call in to either office and not find members onsite, having coffee, chatting with staff, using the Internet or phone, helping out. Within these spaces the organisations gave individuals permission to talk about their experiences of unfair treatment and provided a useful framework to facilitate the conversation — that of stigma and discrimination.

> They [the organisations] have created a safe space for people to come forward, I think … I think it's been a unique placement of giving safe space for people to step forward and, over the years … I think

> it's made a real difference in people's lives … so I think it's allowed a space for people to come together for people to learn from and support each other and for people to advocate for their rights, which didn't exist before. (Jamie, stakeholder)
>
> I think the significant outcomes are two at least. One thing that I have felt often in the work in Papua New Guinea is that we cannot be about the institutions, but we can be about building hope, giving people a sense that there is a possibility of change and that they have a right to integrity and a right to respect, so I definitely think there has been important gains in terms of the community experience of how it sees itself both individually and doing it as a community. I think then that the other part is, more broadly, I believe that the perception of these two groups of people — men and women transgenders is different than it was 10 years ago. There is a general understanding that those communities, those individuals exist within PNG. They may be discouraged, they may be discriminated against, they may be hated, but the recognition that they are present, and they are visible, is greater than it was 10 years ago and I think that's a sustainable contribution. (Dante, stakeholder)

Obviously PLHIV, MDS and trans women did not need organisations to give them a language to understand disadvantage. But the organisations helped and encouraged members to recognise disadvantage in all its forms and to name its different manifestations. It is easy to imagine, for example, that people's understanding of self-stigma might well have been facilitated by institutional acknowledgement of its prevalence. What may have been dismissed by some as indulgent self-pity was treated seriously, as befits a condition that has, by all reports, contributed to the deaths of so many. Giving this a label was only one of many ways that the organisations (particularly Igat Hope) encouraged people to talk about self-stigma. By facilitating the sharing of these experiences, the organisations helped build a shared understanding that stigma and discrimination are multi-faceted, and that discrimination occurs in all areas of community life. Through the stories of individuals, a national picture of stigma and discrimination emerged. This influenced the organisations' constituents — interviewees made this clear. It is reasonable to assume that the effect extended beyond the constituencies to other agencies with which the organisations worked.

Supporting people whose human rights have been infringed to seek redress

It is clear from interviewee accounts that both organisations provided valuable peer support for constituents. Both organisations sought to convey to members an understanding of human rights and how they might be enforced. Human-rights sessions have been a feature of Igat Hope's and Kapul Champions's national meetings. AGMs for each organisation have involved human-rights sessions/trainings, and each of these has involved the sharing of information on enforcement and redress. These sessions appear to have provided useful support for people in building their understanding of human rights, helping them appreciate the different ways in which their rights had been violated and in advising of possible responses. Each organisation has worked in partnership with the (now defunded) PNG Development Law Association (DLA) facilitating referral of aggrieved members to legal support.

While these activities have been useful, it is fair to say that the organisations' support for members seeking redress for rights infringements has been of a modest order. The organisations have not taken legal actions on behalf of any members and their support for injured parties has been more general than specific. The level of knowledge regarding redress options remains low among PLHIV, MDS and trans women.

Raising awareness of human rights among PLHIV, MDS and trans women or more broadly

The organisations can claim considerable success in having raised awareness of human rights among their members. Most interviewees who were connected to these organisations displayed a general knowledge of human rights and were certainly very familiar with the term. As noted in Chapter 3, PLHIV, MDS and trans women have a sound knowledge that they possess human rights and that their rights are not being observed. The notion of human rights has currency among interviewed groups. While some interviewees identified problems with rights-based approaches in the PNG context, there was strong support for the unifying nature of human rights for marginalised groups and for continued rights-based advocacy. PLHIV, MDS and trans women are confident that they have a better understanding of human rights than their fellow citizens and many attribute their knowledge to their connection with Igat Hope and/or Kapul Champions. This is consistent with the heavy rights focus that each organisation has pursued. Interviewees demonstrated an understanding of the interconnectedness of HIV prevention on the one hand, and respect for the human rights of those communities most vulnerable to HIV and its impacts on the other. To the extent this understanding is incorporated into PNG's HIV response, it reflects international best practice.

There is evidence that Igat Hope and Kapul Champions have had an impact on national awareness of human rights. Earlier sections have detailed rights promotion work undertaken by the organisations including through participation in education and information sessions, membership of decision-making forums, development of departmental policies, contributions to national strategies and media work. These activities have had an impact. They have been sufficient to secure ongoing funding for the organisations over many years and, at different times, from several different donors including DFAT, UNAIDS, the Asian Development Bank and the Global Fund to Fight AIDS, Tuberculosis and Malaria. External stakeholders interviewed for this research broadly shared the view that the organisations have positively contributed to rights awareness in PNG. For example, drawing on his UN perspective, Anthony had this to say:

> I think one of the changes is with many of the people who have been involved in those organisations for a period of time. They are increasingly understanding the hook of human rights and using it … it's something that wasn't there a few years ago that's now increasingly there. So, I think those organisations are understanding the value and power of using rights, understanding the importance of the law, understanding the importance of ensuring that state actors respect the Rights and the laws and demanding them — insisting on them being provided.

Monitoring human-rights breaches

The organisations have had success in monitoring human-rights breaches, and this success is all the more impressive given the limited resources available to each. This chapter has canvassed the challenges associated with collecting the data relevant to monitoring human-rights breaches, including the disinclination of governments to collect the information themselves, the likelihood that governments will impede the efforts of others to collect it, and the fact that human-rights organisations often have to protect the confidentiality of their members, so their best data cannot always be released. Data collection also takes time and money. Despite these challenges both organisations had success in monitoring breaches. The public commentary of both organisations — provided through public speaking events, workshops, at World AIDS Day or Human Rights Day events, on TV or radio and in the newspapers — consistently had a stigma and discrimination focus. Through these forums and via these mediums organisational representatives told stories of human-rights breaches, often of breaches of their own human rights. Among my interviewees at least 20 had given some form of public address that had touched on these issues, and I had seen at least a dozen more give such accounts in different forums. This is a form of monitoring in that it provides evidence of breaches and calls to account the Government of PNG for failure to protect the rights of marginalised groups.

Kapul Champions's submission to the United Nations Universal Periodic Review is one obvious example of monitoring, formally documenting the failure of the PNG Government to protect LGBTI rights. Igat Hope's contribution to the Stigma Index is another. But other organisational documentation is also relevant. In each of its funding applications and in each of its reports to funders the organisations have referenced the experience of constituents. Collectively these proposals and reports constitute a significant body of work, charting over time the organisations' understanding of human-rights abuses and their efforts to respond to these abuses. These works were institutionally approved, giving them an important degree of validation. They are not the musings of an individual employee or an Australian NGO; they are organisationally endorsed accounts of the ways in which the human rights of marginalised communities are observed.

Encouraging Papua New Guineans to demonstrate higher regard for the human rights of PLHIV, MDS and trans women, including by promoting understanding of their lived experiences or the structural factors that oppress them

Did the national organisations contribute to a national conversation that recognised the structural factors shaping treatment of PLHIV, MDS and trans women? They did. There is evidence that both organisations approached analysis and discussion of stigma and discrimination with high regard for context, an acknowledgement of complexity and an appreciation of the need for whole-of-community responses to marginalisation. One factor supporting this conclusion is the striking absence of blame being apportioned by interviewees to individual perpetrators of violence. Despite the most tragic stories of degradation and deprivation, of repeated violence, of rejection and exclusion, there was a constant recognition by interviewees of the factors that might have contributed to discrimination and violence: lack of knowledge; lack of access to information; lack of exposure to difference; fear; use of alcohol; culture; custom; history; religion; and geography.

The essential demand by interviewees was not for punishment but for change. And the core component of the change sought was always inclusion. The motivation to be included is seen everywhere in the work of both Igat Hope and Kapul Champions. It is seen in the repeated messaging around inclusion. It is worth noting, again, that the very first social marketing campaign undertaken by Kapul Champions was not a campaign around visibility or rights advocacy or identity or an angry statement of defiance. It was a message about inclusion, we are part of your family. This motivation is also seen in the determined way that PLHIV, MDS and trans women conceptualise their human rights as being inextricably linked to their exercise of community responsibilities. PLHIV, MDS and trans women do not so much demand their rights be respected as ask that they be observed as part of a broader social contract. This can be seen in the way that many MDS and trans women are proud of their historical place in PNG community, and yet modify their claims to historical place out of respect for the views of others. And it can be seen in the excuses made for perpetrators of human-rights violations: they have not had access to information about HIV transmission or the impact of ART; they have not had the opportunity to see that PLHIV on treatments can live healthy lives; they do not understand trans women because they have not had a chance to get to know any; they do not know any MDS because MDS are so hidden; they are victims of culture; PLHIV, MDS and trans women have not been behaving properly and have been setting poor examples. The list goes on.

The commitment to inclusion is also seen in the cautious attitude expressed by so many interviewees towards rights-based advocacy. While there is strong support for its continuation, it is seen as a strategy that must be complemented by others. Interviewees tend to see it as part of an overall strategy that must also include support for the building of resilience among vulnerable individuals and efforts to promote community inclusion of marginalised groups. This then is the very opposite of the adversarial approach so often encouraged by legalistic views of human rights.

Conclusion

It is clear that these organisations created safe spaces where members of marginalised communities might gather and talk about their life experiences and discuss how they might build a better world. The organisations gave constituents a rights-based framework in which their lived experiences might be contextualised. They emphasised that rights might be advanced respectfully, without resort to adversarial approaches. There did not need to be an 'us v them' approach. They supported a national conversation that sought consensus on reform, and that looked for solutions that could be owned and implemented by the whole community rather than just by the marginalised. The organisations absolutely facilitated human-rights outcomes for their members and constituents.

Another observation from IDS (2010) is worth noting before concluding this chapter. It is clear that the CBO model can work in PNG and that Igat Hope and Kapul Champions have successfully utilised this model to deliver for their constituents, including the promotion of their constituents' human rights. These achievements are impressive and deserve to be acknowledged. However, the success of the PLHIV, MDS and trans women 'movements' cannot be assessed by reference solely to the strength of Igat Hope and Kapul Champions. IDS observes that collective action of the kind that benefits poor people does not arise automatically from strengthening civil-society organisations. Existing networks of actors will play a significant role and 'traditional authorities' will be influential, especially when understood as including hugely diverse informal local governance structures: 'Informal institutions and personalised relationships are pervasive and powerful and can contribute to progressive outcomes in poor countries' (2010:70). Here, I am reminded of the absolute priority that interviewees placed on connection with family and community, all while having a sense of pride in the work of their advocacy organisations. Progress will come through the work of Igat Hope and Kapul Champions — the records of achievement by both organisations make it clear that this is so. But it will also come through the myriad family and community structures that exercise influence across all domains of Papua New Guinean life, and through the work of individual PLHIV, MDS and trans women within these structures. That PLHIV, MDS and trans women have refused to choose between these different drivers of reform is a fundamentally good thing.

In the next chapter I take a step back to reflect on the overall utility of human-rights language and frameworks in PNG. Having documented the achievements of Igat Hope and Kapul Champions in relation to human-rights advocacy, I reflect in the next chapter on the question of whether these gains could be pursued using different language and different frameworks. Given the alternatives, just how useful in PNG is a human-rights framework and the language we would ordinarily use to promote it?

Chapter Seven
Using Human-Rights Language and Frameworks in PNG

This chapter is dedicated to Christopher Hershey, known as Topa, who set up Save the Children's Poro Sapot Project (PSP), which really paved the way for so much of the advocacy documented in this thesis. The PSP clinic was established specifically to provide services to men who have sex with men and sex workers. It was a model of ethical practice and of acceptance of marginalisation. It focused on the human rights of its service users from the very beginning, advocating their entitlement to health care and their right to safety. PSP was more than a clinic. It was a drop-in centre and a community hub for people who felt safe in few other places. Topa was generous with his time and expertise, supporting the work of AFAO and NAPWHA as they engaged in the PNG response to HIV. He was a key 'go to' person for insights into MDS and the trans community in PNG, and a committed, passionate and effective advocate.

*

Writing in 2016, Denis Altman and Jonathan Symons ask the question I have been pondering: What's the point of human rights, then? (139). They consider a philosophical approach to human rights; a political conception that both helps explain how it can be that human rights evolve, and that also gives them value even in circumstances where they seem not to be enforced. Rights are produced by political practices, write Altman and Symons. They exist because people and states have agreed that they should exist, and they create a space for debate and discussion around how and when to enforce them. They note that the Universal Declaration of Human Rights included no enforcement mechanisms precisely because states would not have accepted one.

Historically, an important function of international human-rights practice has been to provide governments with a debating forum and to legitimate those voices that are calling for reform (Altman and Symons 2016:142). It is a process, Altman and Symons write, and the value of human rights cannot be judged just in the here and now, but on their capacity to generate outcomes over time. This forum for debate is valued also by Martha Macintyre (2000), who observes the way Pacific women have appealed for justice on the basis of a shared humanity with women (and men) the world over and have appealed to the United Nations as the appropriate institution to assist Pacific women. Internationalist campaigns for human rights have provided an arena for Pacific women's political voice. Again, it is a process, and the fact that human rights cannot immediately be enforced does not rob them of their value.

Engaging communities in human-rights conversations

Interviewees were asked if they thought human-rights advocacy was an effective way of improving their lives. This line of questioning required that interviewees have some understanding of what human-rights advocacy might be. It seemed to me that interviewees did indeed have the requisite understanding. As detailed in Chapters 3 and 4, interviewees demonstrated a sound understanding of human rights and they understood absolutely that their human rights were not respected in PNG. They understood very clearly that the way their human rights were or were not respected was significantly shaped by their HIV status, their sexuality or their transgender identity. Most interviewees had a sound knowledge of the rights-based advocacy work being undertaken by Igat Hope and Kapul Champions. All interviewees understood that it would take significant effort, including advocacy, to move PNG to a place where the human rights of PLHIV, MDS and trans women might routinely be observed.

Against this backdrop, interviewees were able to reflect on the effectiveness of rights-based advocacy as a strategy for bringing about change. There was a range of views overall on the role of human-rights advocacy in achieving change. Most interviewees agreed that while human rights were very important, this did not mean that they were very important to ordinary Papua New Guineans. Countless factors compete for the attention of a citizenry, and if Papua New Guineans cannot even be *engaged* in a conversation about human rights, what does this mean for rights-based advocacy? Here, the regard Papua New Guineans have for their constitution may prove invaluable. There is significant overlap between the rights of all human beings outlined in the Universal Declaration and the rights bestowed on Papua New Guineans by their constitution; so in a sense the distinction between international human rights and national constitutional rights is overstated. Constitutional rights might serve as a very effective hook for engaging people in human-rights conversations more generally. Ultimately, however, the merit or otherwise of human-rights advocacy in PNG cannot be determined by reference to whether the notion of constitutional rights might hold slightly more appeal than international human rights, or an analysis of the similarities and differences between the two. These are important matters, but they are not the most important ones. I recall again the degree to which interviewees were comparatively uninterested in the source of their human rights, and far more interested in their observance and the degree to which they could be incorporated into PNG communal life. The utility of human-rights advocacy will need to be determined by other considerations.

Interviewees generally support the use of human-rights frameworks

Despite differing views on the utility of the international human-rights framework as a vehicle for change, there was strong support among interviewees for Igat Hope and Kapul Champions continuing to use a human-rights framework for organisational advocacy. MDS and trans women interviewees expressed the clear view that they wanted Kapul Champions to continue to advocate for their human rights. There was strong support also among PLHIV interviewees for Igat Hope running an advocacy agenda with a focus on rights.

> I think KC is an organisation that helps TG and MDS [to] know their rights and it helps all the TGs and MDS together and the problems they face when KC calls us for meetings and it helps us go further for the years to come, that is what I think … What Kapul is looking at … what we are looking at is to have one voice and to have one big word, 'Human Rights', that's it. Human rights for all … To me I think the big message that Kapul needs to get to the community is advocacy of human rights for MDS and TG, networking and partnership … Human rights for all. (MaryAnne, trans woman)

> People need to be equipped with information. I think that human rights is really important, it's the way to go … Yes, I believe that Igat Hope is a human-rights organisation because it tries to advocate for access for all, it's trying to advocate for equality. (Natasha, trans woman)

> The most important thing what I think Igat Hope could do better is raise up the flag again for advocacy where we can advocate more on the rights of people living with HIV. (Jonny, trans woman)

> Well, I think Kapul Champions is really doing a great job here in PNG. When I first heard about KC I said, this is it, this is about time we had an organisation that stands up for all the TG and MDS because a lot of us in this country really have a lot of stigma because of shame, lots of violence against the TGs. Many of my good friends have been raped and have been the victims of HIV and have passed away. I am very happy because KC has really made this an organisation for all of us to come together and to put our voice as one, we need to speak out and tell the whole world that we are here to stay and, um, even with the great work KC is doing because it is an advocacy organisation for human rights for TGs and MDS, which is a really good work that they are doing. (Marta, trans woman)

I was initially puzzled by this strong support given that, as this chapter will describe, many interviewees were also critical of human-rights approaches. Interviewees seemed very aware that their representative organisations had limited resources and were also very aware of the limitations of human-rights approaches. I wondered why, in this context, interviewees would be so strongly supportive of their organisations using a strategy with so many perceived limitations. Perhaps it was the case that members see rights-based arguments as *a* strategy rather than *the* strategy for improving their lives and see their organisations as being perhaps the only agencies capable of (or interested in) using this strategy effectively. Theoretically then, Igat Hope and Kapul Champions might pursue rights-based advocacy while other strategies are applied elsewhere and by others. As this chapter illustrates, however, interviewees' support for human-rights advocacy was deeper and broader than appeared at first glance. Support was not always expressed as such. Interviewees sometimes (or initially) appeared to be criticising a human-rights approach, or advocating an alternative strategy, when what they were really doing was arguing for a *kind* of human-rights advocacy; one that would be most effective in PNG; one that is, in fact, Papua New Guinean.

MDS and trans women's views on rights language and the role of rights-based advocacy

Jara, a trans woman, thought that human rights were important, but that the current focus of human-rights discourse was wrong. She thought that they had meaning only for Most-At-Risk-Populations (MARPs). She said that the constant efforts to teach MARPs about their rights were misplaced. This, she said, cut off MARPs from the general population. She thought that human rights would be respected only when the general population understood these rights and their importance. It would not work to educate only MARPs and then rely on some sort of penalty system (court orders, prosecutions, formal findings of violations) to deliver outcomes. Instead, *everyone* had to be brought together to understand human rights and their role. Jara's comments reminded me of the negative impacts of categorical terminology, which can open opportunities — access to HIV prevention and care programs, access to funding — but can also change the way people are considered by healthcare providers, public-health practitioners, governments and others. Jara challenged human-rights advocates to do their work differently, to conduct whole-of-population human-rights education campaigns to build a national consensus around (and support for) human-rights principles. Once this has been done, Papua New Guineans would *choose* to respect the human rights of MDS and trans women, said Jara. And only then would life for trans women improve.

Lionel, an MDS, thought that the approach needed to demonstrate greater empathy and be less abrasive. He thought current approaches amounted to forcing views down people's throats when what was required was a gentler, more inclusive approach that engaged communities in understanding MDS and trans women. This, he said, would build support for marginalised groups at the grass-roots level, in his view a necessary precondition for law reform. Lionel felt strongly that parliamentarians would respond only to community expectation or demand, not to international pressure or NGO advocacy. For this reason, Kapul Champions needed to foster attitudinal change at community level, which would eventually have an impact politically. This view is consistent with the views expressed by Jara, with both interviewees emphasising the degree to which the solution rests with communities *choosing* to think and act differently.

> I mean our approach should be more empathetical. We should sort of blend in with the community. It is not about forcing the issue like, *this is what we feel and this is what we deserve* and, I mean, that

> approach should be more inclusive, it's more about connecting with the people, more connection with the people has to happen. (Lionel, MDS)

Lionel thought Kapul Champions needed to be careful about its approaches to 'community building'. While there was value in facilitating connections between MDS and trans women — via Facebook, for example — Lionel thought the focus needed to be on facilitating connection between MDS/trans women and their own communities, that is, the family and community structures within which they were located and from which they were (in many cases) estranged. This view is consistent with the emphasis many interviewees placed on building relationships within their own communities, and on working hard to demonstrate their value to their own communities.

Chris, a trans woman, thought that the human-rights lens was not the right lens through which to seek reform. She considered that, as most Papua New Guineans did not understand human rights, they would not be persuaded by advocacy on the subject. Human-rights advocacy was just using a language that people did not understand, she thought. Instead, Chris thought it might be better for her peers to talk about themselves as human beings so that people could hear their stories and come to understand they were just like everyone else. She also thought this might open more frequent advocacy opportunities. She saw a tendency to link advocacy to human-rights *events*, such as the UN's Human Rights Day, but said these events were too infrequent to enable any momentum to be built. Instead, if MDS and trans women adopted the strategy of just talking about themselves as 'normal people', they could deploy this strategy at any time of the year in ways that made it all seem less *other*. Both the message and the tempo of its application would emphasise normality. This then reflects a discomfort with squeezing a whole being into a category of marginalisation, a discomfort which was expressed by many interviewees. Some were keen to express identity in its many relational forms, and 'owned' their membership of different categories. Others rejected the notion that accepting categorisation, while perhaps frustrating at some level, was a pragmatic pathway to gain.

Obi, an MDS, thought the matter to be very complex. He thought that few Papua New Guineans had any real understanding of human rights, and that this was true across all levels of PNG society. Even people in government or in the police service, who might reasonably be expected to have some basic knowledge of human rights, were largely ignorant on the matter. Obi continued: even where people had some understanding of rights, the understanding had little practical impact because they saw all around them the disregard for the rights people were said to possess. In no part of PNG society was respect for rights on show, he said: not for women, for the poor, for the vulnerable. Obi argued that for many MDS and trans women, the experience of learning about their human rights just made them aware that these rights were not respected. In this sense the process of discovery was almost counterproductive. What was the value of learning you ‘possessed’ something that you could not really use? You were really only learning of yet another way you were being disrespected. And yet the case can be made that this knowledge has a value in and of itself.

Paulo Freire (1968) writes of the intrinsic value of knowledge, even, indeed particularly, knowledge that deepens people’s understanding of their disadvantage. Freire observes the value of knowledge to people experiencing oppression, including the value of understanding that oppression and who is responsible for it. The goal of the oppressed, he writes, must be to enable all people to become fully human so that no oppression can exist. Beyond an understanding of oppression and oppressors lies the capacity to engage in critical dialogue, between oppressors and the oppressed, which can help society move towards the goal of universal humanisation. Learning yet another way of conceptualising your oppression, in this case learning of human rights that are not respected, must contribute to a deeper understanding of oppression, which on a Freirean analysis is a positive. To transform a system of oppression, Freire writes, you need to understand it.

Freire also suggests thinking of dialogue as more than just a debate, more than a zero-sum-game in which people compete to make others accept their views. In this, he could be speaking for the majority of interviewees who advocated for dialogue over debate, for openness to new thinking over absolutism. I will elaborate on this issue later, but to return to Obi. He concluded, on balance, that there were more positive than negative outcomes for MDS and trans women in learning about their rights. Like a number of other interviewees, he saw the limitations of human rights as an advocacy tool yet could see that human-rights advocacy was still a net positive. Understanding their rights gave marginalised people hope and the basis for demanding a better life, Obi thought: ‘I don't get that from community leaders or police, but for people who are really pushed down in terms of their lives, I think there has been more of a response like, *this is something we can demand.*’

Thomas, MDS, took a slightly harder line than his peers, offering some harsh criticisms of Kapul Champions’s strategies. He thought that the current rights-based approach risked alienating the general population and was being pursued at the expense of the more critical activity, which was building the resilience of individual MDS and trans women. He saw that MDS and trans women had been *broken* (his word) by the society in which they lived. The rejection and stigmatising experienced by MDS and trans women had led, he said, to nothing but self-hate, self-prejudice, lateral violence, drug and alcohol abuse, and suicide. He saw this self-loathing manifested in the refusal of MDS/trans women with HIV to comply with treatment regimes. What was needed, then, was a program to rebuild the self-esteem of MDS and trans women.

> We need to love ourselves. If I love myself, I will not be drinking anymore and I’m not sleeping around with 10 different men. I’m not going to take drugs. I’m going to have a goal and I’m going to achieve it

> irrespective of your hate or little groups around stigmatising me and discriminating — I will get there … Because that's where the problem is, it's down there, the people's attitude, behaviour, because we are broken individuals, so much has happened in our lives it is really hard for us to break free and get up and go forward and compete in the world that is governed and administered and the power and influence are held by those other than the members of our community ... we have limited resources and if I had to choose between changing the laws and helping members of my community to love themselves more, have little goals to help transform their lives, it would be that strategy as opposed to changing the laws. (Thomas, MDS)

PLHIV views on the language and role of rights-based advocacy

Toby (PHLIV) thought that there was a growing appreciation within PNG of human rights:

> Oh yeah, yeah, there used to be police brutality before, it used to appear in the paper and all this, nowadays people on the street know their rights — human rights, so this police brutality is now decreasing and everybody on the street knows I am a Papua New Guinean, I have a right to live on this land, why do you have to fight me? People every day are developing [knowledge of human rights].

Alani, a woman with HIV, had thought quite a bit about this issue. Her experience of community responses to her human-rights advocacy was illustrative and not uncommon. She said that when she raised the issue of human rights with people, she commonly received pushback. She was told that human rights were 'spoiling culture and tradition'. Her critics often said that the doctrine of human rights told people that they could do whatever they liked, but that this was not compatible with traditional PNG ways. She described this view in the following way:

> It's coming and spoiling our culture and tradition. It's telling us that, you know, we all have the right to do this and do that, but our culture and tradition have strict laws on, you know, who is supposed to do this and who is not supposed to do that … That's where a lot of people in the communities are not ready to accept it.

But Alani thought that this response should be resisted. She was strongly of the view that some customs and traditions needed to be challenged because they undermined human rights. In particular she thought that customs and traditions reserved power for men while silencing women and children.

> In terms of leadership ... within the community, it's only men. It's only leaders and, you know, you don't have young people's voices there. You don't have women's voices so, you know, everyone has the right to talk and in meetings women and young people can't talk … and that's where human rights can come in encouraging everyone [to enjoy] equal participation.

Alani reflected that this absence of voice for so many Papua New Guineans was having a negative impact on public health. She observed that old men were making decisions about HIV prevention (specifically condom availability and use) as if they were the only ones engaging in sex. The perspectives of women and young people were critical to this discussion, she said. This observation, like many made by other interviewees, was about power in PNG communities. Alani saw these power imbalances as undermining health, particularly for those without power. She saw the promotion of human rights as breaking down these power structures and giving people like her more voice.

Stakeholder perspectives on the language and role of rights-based advocacy

Sector stakeholders said that Igat Hope and Kapul Champions should continue to make rights-based arguments and saw these as sensible stepping-stones towards reform of laws. The universality of this view among stakeholders is interesting. It is consistent with the view that human-rights arguments have more sway with outsiders, donors and employees of international (or internationally funded) NGOs than they do with ordinary Papua New Guineans. But it would be a mistake to dismiss these views in this way. To begin with, many of these 'external' stakeholders were also HIV-positive, MDS or Papua New Guinean, and they had been invited to bring their whole selves to the interview process. Their perspectives also have value because many possess a broader understanding of how the work of Igat Hope and Kapul Champions has fitted within the national HIV response. They were generally more cognisant of HIV-related work being undertaken by other agencies than were other interviewees and many had also been exposed to rights-based advocacy work in other countries.

Damien (stakeholder) had an interesting take on the use of human-rights advocacy:

> I think it is [useful] but I think it's [also] really troublesome … Mostly in our work [in other countries] we are trying to get things for people affected by HIV or people from marginalised populations. We are trying to get access for them to the things that everyone else is getting, that is a lot of what advocacy involves. In PNG that is not actually meaningful because *no one* is getting *anything* and so it's really difficult, it becomes AIDS exceptionalism … So they can sit in a workshop and they can talk about the things that they know we want to hear them talking about, but it often sounds a bit fake because no one is doing the whole analysis that it is *all* stuffed, you know. And what can we push, and do we need a different framework in that environment, in an environment where violence is so prevalent and where law and order is so lacking, where health services are so fragile and where corruption is so pronounced? And I don't think that is the map that gets used, that is kind of too depressing in a way.

Damien was questioning the point in advocating for the health rights of PLHIV when *no one* gets access to basic health care. He was questioning the value of complaining about violence against trans women when almost everyone in PNG experiences an unreasonable fear of violence, or at least all women do. It is easy to see this as an argument against human-rights advocacy in countries like PNG, but Damien was not speaking against this advocacy. Rather, he was speaking in favour of an approach to human-rights advocacy that acknowledges almost everyone as unfairly disadvantaged in trying to access health care in a country that could reasonably be expected to do more to deliver services for its populace. He was calling for a more comprehensive consideration of power and marginalisation. He was championing human-rights advocacy but warning against the notion of 'AIDS exceptionalism'. This notion of AIDS exceptionalism sees HIV/AIDS as unique, deserving of specialist, uniquely tailored health responses. These days it is mostly referred to in a negative way, with many public-health responses 'moving on' from AIDS exceptionalism to incorporate HIV into broader sexual and health responses. But even advocates of moving on tend to acknowledge that this AIDS exceptionalism was critical in the earliest days of the epidemic, because there were and are things about HIV which make it different to other infectious diseases (see Carlson and colleagues (2012) on the appropriateness of AIDS exceptionalism approaches in PNG).

Anthony (stakeholder) also reflected on the scale and breadth of disadvantage:

> But again in the PNG context, I think that people are so beaten down by the system and so lacking in expectation that the state is going to provide them with anything, and so used to just getting on with their lives in the vacuum which really exists because of the political corruption and administrative and service environment, that that also kind of dumbs down the expectations because, you know, who is going to provide these rights to you other than state actors? And if the state doesn't provide you with anything from an aspirin through to your basic rights then, hey?

But like Damien, Anthony concluded that human-rights advocacy was still worthwhile. He reflected on the advocacy work of organisations like Igat Hope and Kapul Champions and argued:

> I think one of the changes is with many of the people who have been involved in those organisations for a period of time, they are increasingly understanding the hook of human rights and using it … I've seen a lot of people shift from just an angry, you know, *look after me* kind of attitude to a *no wait a minute I have rights, you need to respect me when I come to the clinic, you need to ensure that I have my medication* … that's not the experience everywhere but it is changing and it's, you know, it's something that wasn't there a few years ago that's now increasingly there, so I think those organisations are understanding the value and power of using rights, understanding the importance of the law, understanding the importance of ensuring that state actors respect the rights and the laws and demanding them — insisting on them being provided.

Stakeholder interviewees tended to be supporters of rights-based advocacy, and supporters of the Igat Hope and Kapul Champions taking on this work.

If not human-rights advocacy, then what?

Interviewees who pointed out the shortcomings of human-rights advocacy also recommended a range of alternatives, which might be grouped into three categories. I will begin with a brief description of each of these three (advocacy that promotes commonality and membership of community; a focus on public-health advocacy; resilience programs), before asking the question whether they truly constitute alternatives or, rather, actually point to a *kind* of human-rights advocacy that is preferred in PNG.

Advocacy that promotes commonality and membership of community

One strategy proposed as an alternative to human-rights advocacy was a focus on commonality and membership of community. Membership of community and the importance of contributing to community were important themes to emerge from interviews. Interviewee after interviewee expressed the view that, while stigma and discrimination were real, some degree of community membership was still possible. Some interviewees reported this in terms of building their own community of like-minded people, but more commonly people spoke about it in terms of bringing a community around to a recognition and acceptance that PLHIV, MDS and trans women have a legitimate place within their community, or that they are at least entitled to live safely within their community. This was being done in different ways, but all these strategies seek to show the same thing — that PLHIV, MDS and trans women are not as different as people think. It is worthwhile recalling that the very first resource produced by Kapul Champions was not a rights pamphlet or a statement about difference but a poster about social inclusion: *Together We are PNG*. This issue of collective identity emerged as a major theme in my work.

The damage done by stigma and discrimination to individual PLHIV, MDS and trans women, that was noted by interviewees, could be healed, it was suggested, by families and communities choosing to treat their HIV-positive, homosexual or transgender members differently. So how might these communities be encouraged to treat their stigmatised members in a different way? A significant minority of interviewees want Kapul Champions to refocus away from advocacy and rights and towards what they describe as ‘education’. This is obviously a broad term and could include, for example, education about human rights. But among this minority, ‘education’ was usually code for a role that would see Kapul Champions explaining to the general PNG population that PLHIV, MDS and trans women are ‘just like them’. This view relates to the live debate about the ‘responsibilities’ of

PLHIV, MDS and trans women to ‘fit in’ and avoid confronting their fellow citizens. The goal of the approach is to generate change through recognition of commonality. By convincing people that they are basically the same, PLHIV, MDS and trans women will gain access to the same support and opportunities, which is all they really want. This view also connects to the discomfort that many interviewees expressed regarding being categorised as a MARP, KAP or otherwise. These interviewees did not like the way membership of these categories seemed to exclude them from the memberships they valued more — of family, of community.

I had not previously thought of these as different approaches. After all, is not human-rights advocacy, at its core, just education about the fact that we are all the same, all human ‘just like you’? Yet interviewees seemed to be holding these approaches up as distinct. Upon further questioning and subsequent analysis, it became apparent to me that interviewees were drawing some key distinctions. They were seeing human-rights advocacy as assertive and corrective, in particular as asserting that individuals who may be ‘different’ (minorities, marginalised) have the same rights as those who may be part of the mainstream, and utilising doctrines from outside to make the point. They were seeing this human-rights advocacy as focused on the failures of the mainstream to comply with laws or principles that have been declared by others. By contrast, they were seeing education that emphasises commonality as a very different approach. This kind of education encourages an understanding that people who are ‘different’ are in fact not all that different after all; the differences are less than the unifying commonalities. This education encourages people to learn rather than telling them what to think and feel, and this learning is not imposed by the introduction of thinking from outside. Instead, it is revealed by taking a second look at what is already present. This education results in people choosing to act differently.

It is necessary to critique this advocacy for education that promotes commonality and sameness, this ‘same/same’ approach. First, there are questions here about effectiveness. It is not clear, for example, that the same/same approach will achieve the necessary reform of laws that most interviewees seek. The same/same approach seems almost to suggest that ‘there is nothing to see here, folks’. It is arguably passive, whereas what is required involves some proactive, deliberative reform that must, at some level, be jarring. In all my advocacy work in Australia and PNG, I have never seen law reform on matters of sexuality or gender identity result from a gentle evolution of legislative consensus thinking. It has always been contested. There are other issues to consider as well. For example, it is not clear to me that the constituencies of Igat Hope and Kapul Champions actually *do* want to argue they are the same; and this is particularly the case with Kapul Champions’s members. Many Kapul Champions’s members celebrate their difference and are keen to make the statement that they are here. Many trans women interviewees, in particular, were keen to acknowledge their difference. They were not seeking to hide this difference. Indeed, some argued that it made them special giving them a special value to community. Instead, they simply wanted communities to see this difference in context. Mostly this meant they wanted their difference accommodated within their continuing membership of community.

There are other ways these communities will struggle to run the same/same line. In significant ways these communities *are* different. PLHIV need access to drugs that no one else in PNG will use; they will negotiate sexual connection in a context that is at least in some measure different. They will approach conception and childbirth with different considerations. Some trans women seek access to very specific medical interventions (from hormone therapy to gender realignment surgery) and while these may seem unachievable right now, and *are* unachievable through the public-health system, they remain a goal for some trans women. This goal is shared by no-one else in PNG. In some ways MDS and trans women will never fit into heteronormative society, so same/same arguments may not be appropriate in all circumstances. And yet, in my experience, Papua New Guineans are very proud of their diversity. They are keen to talk about the number of languages spoken across the country and the myriad of cultural permutations routinely on display in different regions. There is a recognition of and respect for these differences and an acceptance that they are all part of the greater PNG society. This belonging — to family, to community — is universally valued regardless of whatever particular subgroup a person might belong to, and it is this universality that converts 'different' into 'same'. It is a twist on the way same/same arguments are often understood, but it makes sense in the PNG context.

A focus on public-health advocacy

Public-health arguments were also suggested as a way forward. Interviewees observed that by demonstrating greater regard for the human rights of PLHIV, MDS and trans women, Papua New Guineans were likely to make themselves safer. Where MDS and trans women were supported to access health services — for HIV testing and to obtain the means of prevention, such as condoms — free of stigma and discrimination, they would be better able to prevent infection and transmission rates would decline. This would mean that transmission from these communities into other communities would also be reduced. Interviewees who touched on this strategy were largely aware that it reflects the approaches taken by many donors and would have heard NAPWHA and AFAO talk about their shared public-health approach, attracted by the availability of evidence. Given the frequency with which international and Australian NGOs talked about public health, drawing on global data, interviewees may have associated this discourse with external players. But acting in the greater good is a core component of Papua New Guinean life, so public-health arguments were not so foreign.

MDS interviewee Lionel was amongst the greatest advocates of a substantial focus on public health. This would be a far more palatable approach for Papua New Guineans, he thought, and Kapul Champions's case was stronger as a public-health argument, he believed. Kapul Champions could rely on research and data and point to the positive health impacts for all Papua New Guineans in protecting MDS and trans women's rights. The result would be a different kind of motivation on the part of Papua New Guineans; the general population would be incentivised to better respect marginalised groups via an understandable (if arguably selfish) desire for personal, family and community safety.

> This is a challenge for organisations like Kapul to really advocate in the way where people understand that we are doing this in the context of HIV/AIDS. When we really try to divert our attention and focus on gay rights and experience and MDS rights, we really want to go this deviation from HIV, then we will sort of create some sort of problem. That's where I'm seeing from a PNG perspective. We really have to put HIV into that to really say to our people — because this is happening, it is proven by research and this intervention to really help people in that context and then maybe, in the long run, maybe we'll truly make progress as people understand. (Lionel, MDS)

There is a problem with this public-health analysis, of course. It potentially becomes a national conversation about protecting the mainstream from an infectious minority. It perpetuates a notion that a community poses a risk, and it emphasises the difference between this community and the rest of society, enforcing a notion of MARP or KAP when many people thus defined are really striving to be part of the broader community. It seemed to me that interviewees who spoke of this approach saw it as *a* strategy and not *the* strategy, and one that is best used in combination with other approaches. I wondered how to reconcile this support for public-health messaging with what emerged as the strongest theme across interviews: that community connectedness is more important than anything. Does not a public-health approach in PNG require some recognition that sub-populations are exposed to greater risk than the broader community, and that they therefore *are* different? Yet interviewees also seemed to be offering a pathway through this tricky terrain: 'public health' means the health of all, and interviewees were only seeking the same as everyone else, that is access to the means of keeping themselves healthy. This is a kind of 'helping us means helping you, and we're part of you' message. It is both complicated, and not.

Resilience programs

Interviewees also advocated for the implementation of programs aimed at building resilience amongst PLHIV, MDS and trans women. Thomas (quoted above) was the most passionate advocate for this focus, but he was not alone in arguing that Igat Hope and Kapul Champions should focus on helping victims of stigma and discrimination cope with the traumas of abuse and rejection. These interviewees argued that the incidence of suicide and self-harm indicated an urgent need for interventions that address the psychological needs of marginalised individuals. Such an approach could accommodate a future in which PLHIV, MDS and trans women might be capable of engaging in rights-based advocacy but would focus on the urgent need for interventions that keep people alive and give them hope.

Cultural barriers to human-rights advocacy are overstated

Many interviewees, in identifying the challenges associated with human-rights advocacy or in explaining why their rights were not respected, pointed to ‘culture’. Some thought culture to be a genuine barrier to rights recognition and some just thought it was an excuse used by others. This question of how culture impacts on human-rights advocacy deserves further interrogation.

Pacific culture and human rights

Margaret Jolly (1996) reports on a 1994 family violence conference in Vanuatu, considering the competing claims of universal human rights and cultural relativism. She notes that the ‘allegedly western character of human rights, with its focus on the individual and civil and political rights, is often contrasted with the non-western stress on collectivities and the rights to economic development and self-determination’ (169). Jolly considers arguments that often pitch culture and tradition as impediments to the realisation of human rights (in the case of the article, women’s rights) and cautions against debates that see human rights as western and therefore easily dismissed as a new form of colonialism. But the greater risk, Jolly warns, is that ‘custom’ becomes code for female subordination and human rights means liberation, which makes for unhelpful discussion. Instead, issues are more complex and nuanced. Jolly observes that what is claimed as custom is not always so, noting that some attempts by men to dominate women in defence of custom represent new power grabs with little traditional precedent. Jolly also sees that while custom may indeed sometimes be a barrier to greater enjoyment of human rights, the solutions to the problem of rights violation might also be found in custom. Custom evolves, it is never static, and new customs can be generated.

Jolly challenges the dumbing down of conversations about universality and cultural relativism, warning it is wrong to suggest that western notions of rights have only ever been about individuals; in fact, they have encompassed the rights of classes, of women and of minorities. At the same time, non-western conceptualisations of human rights accommodate notions of humanity relating to the individual. It is similarly lazy to imagine that developed nations prefer a notion of rights as individual and political while developing nations idealise community rights and economic development. Many nations (especially in the industrialised east) have a comfort with the assertion of collective rights over individual rights, and less interest in a freedom focus than is typical in the west. Of course, this can be a cover for repression, but it does not have to be and is not always so.

In an epilogue to a volume on gender violence and human rights, Jolly (2016) considers the value of human-rights discourse in efforts to reduce gender violence, again considering whether the person-centred nature of human-rights discourse might be incompatible with regional cultures, and whether the translation of human rights into Pacific cultures might be less a jarring insertion of the global into local cultures and more a process of mediation and exchange. On the question of compatibility, Jolly reiterates that western human-rights discourse has always accommodated collective visions of rights and that notions of personal autonomy and equality are not absent from non-western contexts. In reflecting on the difference between the autonomous individual of egalitarian liberal democracies and the ‘dividual’ or relational person of traditional Pacific cultures, Jolly imagines a co-presence and a dialectical relation between the two. She refers to work in PNG undertaken by Holly Wardlow (2006), in which Wardlow explores the question whether Papua New Guineans may possess a relational or individuated mode of personhood, finding that both are co-present. Katherine Lepani (2015) also deals lucidly with this issue of dividuality.

Jolly also references the work of Sally Engle Merry (2006a) in conceiving of the translation of human rights not as a ‘hypodermic insertion’ of the foreign into the local, but as a more reciprocal interaction with a flow of meanings, values and powers. The local cultural context is capable of not only modifying the global text, but, as Jolly says, can ‘also radically transform, distort or even subvert the meanings and values of human rights’ (2016:354). Citing Merry again, Jolly reminds readers that non-western activists from the global south have long been involved in international human-rights discourse, having already contributed to the shape and meaning of rights. As a result, human rights are not foreign to the Pacific. Merry also notes the way in which ‘culture’ can be wrongly perceived and described as a monolithic roadblock to the application of human rights.

Jolly reflects on the indigenisation of Christianity in the Pacific and asks how this might relate to the indigenisation of human rights. She observes that introduced forms of gender hierarchy have combined with indigenous gender hierarchies to produce hardened forms of male domination that are staunchly defended as traditional. Jolly observes that those who seek to oppose gender violence in Pacific contexts often find themselves in perilous circumstances, vulnerable to accusations that they are betraying their culture and consequently subject to violent forms of repression.[1] Jolly notes the impact of international human-rights instruments (specifically CEDAW) on Pacific case law and makes an interesting point, that courts across the Pacific can and have translated the provision of CEDAW into decisions, even where national parliaments have failed to convert the agreement into national legislation. Judges of the highest Pacific courts have been able to find ways of neatly combining international human-rights obligations with customary laws, undermining claims that the latter cannot accommodate the former.

Jean Zorn (2016) also offers guidance on this point. Zorn considers how, for international laws to have effect in nation states, they must be translated or interpreted and subsequently internalised. She observes how this has been done in several Pacific countries, including PNG, by courts reinterpreting local law or assisting to ‘evolve’ it by reference to CEDAW, including in areas such as sexual violence against women and girls, arranged marriages and customary land ownership. This point has relevance to complaints that human-rights frameworks are only as meaningful as the state’s commitment to enacting its international obligations via domestic legislation, and to suggestions that human rights can have little impact where knowledge of these rights within the general population is low.

Jolly’s writings invite reflection on the ways Papua New Guinean PLHIV, MDS and trans women talk about their human rights. Once it is no longer presumed that international human rights and collective societies are incompatible, space is opened up to consider whether the language being used is of jarring insertion or a more gentle exchange. Is the human-rights discourse absorbing, interpreting or being interpreted by local elements? Is the local culture being described in ways that accommodate evolution or variation, or is it being used as a cover for behaviours that have little historical foundation?

Philip Gibbs (2016) offers some valuable insights into how Papua New Guineans might resolve tensions between custom and greater observance of human rights, using the Christian faith as a strategy. Gibbs documented a Men’s Matters program in PNG’s Western Province, through which men of the area reflected on their attitudes towards women and their relationships with their wives. He suggests that ‘in PNG, given that most people profess Christianity, a church-based agency may play an important role in interpreting rights language and values into cultural frameworks meaningful to people in a given local context’ (127).

---

[1] Jolly has cited ni-Vanuatu politician, poet and women’s rights campaigner Grace Mera Molisa, as one such person.

The men engaged in the program came to a realisation that, while cultural traditions had come from their ancestors and deserved respect as a consequence, their ancestors were, still, only people. As such, the men participating in the program were entitled to contribute to culture and make changes to it where necessary. Factors that might warrant changes were considered, including commitment to their Christian faith and the new language of human rights promoting notions of gender equality. Gibbs finds scriptural support for a notion of equality that recognises difference within a common humanity. We are all God's children, he writes, and this is a unifying and standardising observation. Once people fully appreciate that God loves all these children equally, that they are all created in God's image and have the same essential dignity, then it is easier to accept that we must all be treated equally on earth. This is described as a framing of the discourse on equality within a discourse on difference. The vernacularisation of equality is managed through an embrace of Christianity rather than through the secular humanism underpinning western concepts of human rights. Of particular interest in Gibbs's work is his account of how Papua New Guinean men connect rights and duties (or responsibilities), this being an issue that emerged so often in my research. Gibbs observes that these rights and responsibilities are closely related: rights imply a person's claims on society while duties indicate the claim of society on a person. Interestingly, the men in Gibbs's study tended to see duties as applying mostly to men, potentially undermining a view of rights as entitlements to be enjoyed by all members of the community.

Another observation seems particularly pertinent. The men in the Men's Matters group were asked to contemplate a power map that saw *man* placed alongside *woman* rather than over her. The men questioned the degree to which this configuration might be considered realistic, and wanted the *community* also involved in the equation. This way, individuals would have rights and responsibilities not only in relation to each other but also in relation to the community. This accords with the views of the many interviewees who had been uncomfortable with a consideration of rights that did not properly engage community.

Gibbs also refers to the work of Merry (2006a) in conceptualising the layering of frameworks, so that a human-rights framework does not replace other frameworks but adds a new dimension to the way people consider and respond to a problem. Gibbs suggests that the men in the Men's Matters program may have been exhibiting a layering of rights framework over kinship and conjugal obligations, with these frameworks being influenced by a scripturally supported conceptualisation of difference within equality.

I have wondered whether my interviewees might have been engaged in such layering. No interviewee articulated a concept resembling layering to explain how culture, Christianity and human rights could be synthesised in ways that might help them. Indeed, no interviewees offered a vision of Christian faith leading the way to equality, and interviewees who talked about culture often did so in ways that described culture as a barrier to equality. Yet many interviewees talked about rights realisation as inseparable from their continuing role as members of their community. They expressed an expectation that by working with and through their communities (with support) they would be able to generate a new acceptance of their existence and their rights to equal treatment. This is consistent with an understanding of custom as malleable. It also indicates a belief that western notions of equality and human rights are entirely compatible with traditional communal structures, although whether this compatibility is best achieved via layering or evolution of custom (or both) was not clearly expressed.

Lepani (2016) has written about the interrelationship of rights discourse and gender relations in PNG, with particular reference to the impact of the HIV epidemic. She notes that the national HIV program has paved the way for the introduction of human-rights principles into development policies and programs, and that HIV has been the vehicle through which gender violence has been addressed as a human-rights issue. She suggests that these interventions (for HIV and/or gender violence) have tended to isolate the individual and the rights of the individual from their social contexts. Human rights have been positioned within a deficit paradigm with passive victims in need of protection through the enforcement of negative rights (defined in terms of redress for harmful behaviour). What is subsequently lost is the opportunity to pursue these rights in ways that challenge the very power hierarchies that enforce sexual inequality and restrict the expression of sexual identity. By taking this deficit paradigm approach there is a risk, Lepani suggests, that it might contribute to further stigmatisation. Lepani also refers to the work of Merry (2006b) on the vernacularisation of human rights, bringing the global human-rights discourse into direct articulation with local knowledge, and she considers how the universal language of human rights might be translated and activated in PNG, in a country in which, ‘heightened levels of movement and intimate exchanges between people from different cultural groups are generating new regional and national subjectivities in Papua New Guinea’s contemporary social landscape’ (Lepani 2016:169).

Lepani reflects on the dialectical tensions between moral individualism and relational personhood, the way culture sets parameters for individual agency and the way culture provides a framework for mediating new social phenomena. She emphasises the importance of understanding the way in which culture shapes the conceptualisation of rights, and that cultural values might be engaged to *reduce* behaviours that are in some quarters justified by reference to culture. Lepani observes that global discourses on HIV, gender violence, and human rights more broadly, tend to see culture as a kind of static dark force that repels efforts to promote equality. What then of the capacity of PNG culture to inhibit new expressions of sexuality? Lepani suggests that 'modernity has widened the field of imaginable social interaction, and sexuality takes new expressions within this highly charged and exciting landscape' (2016:184). Lepani posits that understanding may be usefully pursued via the articulation of human rights in terms of sexual citizenship:

> The rights and responsibilities of all people to have control over their sexual and reproductive health and to express sexual identity, desire and pleasure in healthy and safe ways, free of fear, harm and force, as an expected part of membership in a shared community. (2016:185)

This, she suggests, opens the way to seeing the positive potential of deeply rooted Melanesian values of sociality and relational personhood as a means of addressing stigma and fear in this new world of HIV.

Kalissa Alexeyeff and Niko Besnier (2014:2) consider the impact of non-heteronormativity on Pacific cultures:

> Non-heteronormative Pacific Islanders are at once part and parcel of their societies and subversive of the social order. They are deeply enmeshed with what many think of as tradition, but they are also the heralds of the new, experimental, and the exogenous. Suspended between the visible and the invisible, the local and the global, the past and the future, and what is acceptable and what is not, they call for a rethinking of morality, what 'acceptance' (or 'tolerance') means, and the very relationship between agents and structures. They bring new ways of being in and thinking about the world, to the delight of some and the indignation of others. Their very existence embodies the contradictions of the contemporary social order.

This description rings true for the MDS and trans women I interviewed. MDS/trans women interviewees emphasised their connectedness to PNG community and many argued that they have an historical place in PNG society. This question of historical place has been considered earlier but it is sufficient to reiterate here that many interviewees believe that trans women were an acceptable part of many pre-colonial PNG communities and that homosexual sex occupied a socially acceptable place among men in at least some pre-colonial societies. But interviewees also called for more than their historical place. They called for change, for something new in PNG culture. They sought the right to publicly present as gay or transgender, to be no longer hidden. Yet they simultaneously hoped for social change that would mean their public presentations would cause less public consternation. In this world they would be both more visible and stand out less.

Aletta Biersack (2016) reflects on efforts to progress women's human rights, particularly the elimination of gender violence, in Fiji, PNG and Vanuatu. She acknowledges the patchy nature of progress, which she describes as frustratingly nonlinear, but concludes that there has been progress across all three countries:

> Even in PNG, institutions and laws (however imperfectly implemented) have been put in place to combat gender violence, and community-based activism now emerges as a key factor in the protection of women and girls and the pursuit of their rights. (318)

Biersack acknowledges the rolling conversation in the Pacific regarding the often-lamented loss of the authority of older, married men, who in the past had monitored and regulated the behaviour of boys and young men. She considers male advocacy programs in all three countries, noting how they create spaces within which the authority of older, married males can be reasserted. She sees this as being particularly true of men involved in Fiji's 'gatekeeper committees' and Vanuatu's Committees Against Violence Against Women. These offer further examples of the interweaving of traditional power dynamics with the novelty of human-rights principles. These men are doubly beholden, writes Biersack, to the human-rights principles they have been trained to promote and also to communal standards of decency. Biersack writes that, 'Such committees, along with the male advocates who sometimes serve on these committees, are crucial to the "vernacularization" of human rights doctrine' (2016:318). Here Biersack refers to the work on vernacularisation of Merry (2006b).

> In this, they are far more than a conduit for external norms, importing human rights principles across cultural borders. They are active synthesisers of local and international norms. The result is not 'pure' human rights principles but a viable merger of 'local structures' and norms with 'imported ideas such as women's rights'. The internormative, intercultural spaces these actors occupy are spaces of global Northern–Southern engagement, through which hybrid principles and practices are spawned. (Biersack 2016:38; referencing Merry 2006b:48)

Biersack considers the commonly held view that 'human-rights ideology streams out from its Euro-American birthplace and heartland towards people and places beholden to alternative principles and values' (2016:272). She prefers alternative analyses. Borrowing phrases from Jonathan Inda and Renato Rosaldo (2008), Biersack writes that such practices do not result in a 'hypodermic'-style transfer of ideology but, rather, in 'customization on the part of the receiving subject' (2016:319). Biersack explains that this customisation has been ongoing for decades, citing work on the 'hybrid' courts of Melanesia that manage to balance introduced law and customary systems, and find ways to balance the individual, rights-oriented ways of western justice with traditional sociocentric approaches to settling disputes. This observation resonates with my own. What my interviewees were speaking of was a kind of human-rights framework that would work in PNG, one that had been indigenised, just as these courts and committees were indigenising women's human rights, and just as Christianity has been indigenised for this very Christian country.

The culture of Christianity and human rights

Any consideration of the cultural embrace of PLHIV, MDS and trans women requires contemplation of Christianity in PNG as embodied by the many and varied Christian denominations of which Papua New Guineans are enthusiastic members. One of the first things you learn about PNG as an outsider is that Christianity is a powerful force in the country. You learn it around the same time you learn the strength and depth of the *wantok* system. These two distinct but fundamentally bonding and guiding systems impact on every aspect of Papua New Guinean life. In a way, it makes no sense to have separate sections in this chapter for 'culture' and 'Christianity', as the latter is now so much a part of the former that it can be hard to see where one ends and the other starts.

Angela Kelly (2009) reflects on the role that Christian churches have played in the PNG HIV response. She begins first, however, by exploring Christianity in PNG as a unifying force, bringing people together in ways that overcome geographical, language and cultural differences. Kelly notes the PNG constitution enshrines customary ways and Christianity as guiding forces. She explores different notions of the word 'body' as contemplated by Christian (particularly Catholic) theology, including the way the term is used to describe the membership of the church, unified as one. Kelly also considers the way the liturgical practices of Baptism and the Eucharist join individuals with the body of Christ so that, as a consequence, Kelly argues, 'the body of Christ has AIDS'.

Mark Mosko (2010) stresses the personal partibility in Melanesian Christianity. He draws on Marilyn Strathern's insights on Melanesian 'dividual' personhood, being the product of relations with other persons. Mosko argues that the sociality of (Melanesian) Christianity is not individualistic in the sense of bounded personhood but consists instead, 'in elicitive transactions between dividual persons, human and spiritual' (222). This speaks to a version of Christianity that has a Melanesian dimension and indicates that, to understand the role of Christianity in the lives of my interviewees, I have had to be alert to the particular kind of Christianity being lived by them.

Anna-Karina Hermkens (2012) observed in the Catholic women of her study both individual and relational/dividual forms of personhood. She writes that the two co-exist, albeit in 'conflictual tension'. More generally, Hermkens sees:

> The influence of Christianity in PNG is profound. Christian values are part of the country's constitution, which states that 'We, The People Of Papua New Guinea … pledge ourselves to guard and pass on to those who come after us our noble traditions and the Christian principles that are ours now.' Moreover, almost all Papua New Guineans say they are Christian and political discourse is saturated with Christian rhetoric and references (Gibbs 2005). In urban areas, the abundance of churches, evangelical rallies and the popularity of gospel music testify to the popularity of Christianity and its pervasiveness in daily life. (2012:138)

Hermkens observes the different ways that the Church has an impact on HIV responses. She observes hospital workers privileging Church policy over government policy by, for example, counselling patients against condom use when the hospital policy is to promote their availability. Hermkens notes that Wardlow (2008) had observed similar practices in her study of HIV in the Huli community, specifically hospital workers arguing that condoms are ineffective in the prevention of HIV and that they encourage illicit sex. She also cites an observation by Naomi McPherson (2008) that the Church undercuts HIV education by emphasising the sinful nature of promiscuity, further decreasing the likelihood that condoms will be used. I witnessed these kinds of Christian interventions many times in my own work. Hermkens notes that this linking between 'immoral' behaviour and HIV implies that those who are infected somehow deserve what they have got. Richard Eves (2003) writes of how, in some parts of PNG, HIV is seen as not only a sign of moral decay but a harbinger of the apocalypse.

Given all this, I had anticipated that interviewees would routinely reference Christianity. I had assumed I would hear people expressing views on the role of the Church in addressing stigma and discrimination. The Christian message of compassion for the suffering is a powerful element of the faith, so I had imagined this commitment to compassion might often be invoked. Yet, while many interviewees spoke of their faith, they mostly did so in relation to their faith as an important source of strength that sustained them in difficult times. Occasionally they discussed the role of the Church in causing or contributing to stigma and discrimination. Faith was discussed as a cause of injury and as an antidote for the pain of stigma and discrimination, but almost never as a means by which damage might be prevented in the first place.

There are some distinctions here between PLHIV and MDS/trans women interviewees. Christian churches in PNG have played an important role in caring for PLHIV. As noted in Chapter 4, the Catholic Church in particular, as a major provider of health services and a leader in PLHIV care, is acknowledged for compassionate approaches to Papua New Guineans infected by HIV. I have worked closely with Catholic Church HIV programs over many years and have seen firsthand the incredible compassion on display towards PLHIV. Through work with the Churches Partnership Program in PNG[2] I have had occasion to observe that other churches have made important contributions to HIV care also. But churches have generally failed to show much compassion for MDS and trans women communities. Indeed, churches have been amongst the harshest and most vocal

---

[2] The Churches Partnership Program was established in 2004 as a collaboration between the Australian representatives of seven international Christian churches and their PNG counterparts. The partnership was funded by DFAT to deliver aid programs, including HIV programs. For a discussion of its effectiveness as an aid delivery mechanism and how engagement with religion can enhance development outcomes (Clarke 2015).

critics of MDS/trans women and their human-rights advocacy. Kapul Champions has struggled to find any church leaders prepared to champion the rights of MDS and trans women, despite significant effort on the part of the organisation and despite the fact that its constituents are predominantly church-going people. This can be contrasted with the important advocacy undertaken by church leaders to promote compassion for PLHIV. The intersection of Christianity and HIV in PNG is well explored by Angela Kelly-Hanku, Peter Aggelton and Patti Shih (2014). The authors note how PLHIV apply Christian morality frameworks to make sense of their own infection, the ways PLHIV often embrace or re-embrace Christianity (sometimes a new brand thereof) in response to sero-conversion, the belief many PLHIV have that God can provide a cure, and that their connection with God and His cure is via their church. While the authors look at religion very much from the perspective of PLHIV, they refer also to several other studies focusing on the intersection between Christianity and HIV (2014:106).

It is clear from interviews that PLHIV, MDS and trans women do not seek pity, and perhaps this is why MDS and trans women so rarely invoked the Christian value of compassion. Perhaps other Christian sentiments — refraining from judgement and engaging with the marginalised — may be more relevant. Yet MDS and trans women interviewees expressed only low levels of hope that the Church might become a champion for their cause.[3]

Despite challenges, human-rights frameworks have utility in PNG

Knowledge of human rights is empowering for PLHIV, MDS and trans women. This was discussed in detail in Chapter 3, in which the voices of interviewees were heard describing the important meaning human rights has for them. This knowledge can come in different ways and at different stages: some interviewees talked about an inherent sense of human rights that they had always possessed; others described it as a kind of learning that might have flowed from a workshop, conference or a conversation with another. True, however knowledge of rights is obtained, the moment PLHIV, MDS and trans women know they possess these rights they also know their rights are commonly disrespected. It is therefore, in that moment of realisation, another example of their marginalisation. But the knowledge is still empowering, unifying and galvanising. The knowledge gives some hope to highly marginalised individuals and provides a degree of affirmation that their hopes are not unreasonable. Human-rights advocacy that builds this awareness among marginalised

---

[3] I was reminded of work by Teresia Teaiwa (2014) on homosexuality in the Fiji military. Teaiwa considered the role of hegemonic Christianity in reinforcing heteronormativity, arguing that this role means any understanding of homophobia in the Pacific will require regard to Pacific Christianity. Teaiwa notes that a liberalising of Fiji's laws on homosexuality became possible only because of the military's dismantling of the Methodist Church's authority following a 2006 coup.

communities is, therefore, already generating positive outcomes, but there are positives beyond this. The galvanising and unifying elements of the human-rights framework also help Igat Hope and Kapul Champions articulate and structure their activities. Members recognise that human-rights advocacy has meaning for all constituents and that all will benefit from effective advocacy around human rights. This contrasts with some other activities, such as trainings and workshops, that are seen as favouring only those who are able to attend.

As noted, the vast majority of interviewees argued for continued human-rights advocacy. But interviewees also indicated support for a *kind* of human-rights advocacy. They have recommendations regarding content and style, and herein lies the key to understanding support for this advocacy. The majority support this advocacy because it is seen as compatible with, indeed potentially inclusive of, the very strategies that are described by some, or interpreted by some, as alternatives. In fact, these ‘other strategies’ are not alternatives to human-rights advocacy, but components of the kind of human-rights advocacy program that will be effective in PNG. Interviewees want human-rights advocacy that is compatible with efforts to educate Papua New Guineans that PLHIV, MDS and trans women are just the same as them — even better if the human-rights advocacy actually incorporates this message of inclusion. This is consistent with a view that human rights and culture are not incompatible. Interviewees largely reject the notion that they should engage in a battle to replace Papua New Guinean culture with a new practice of human rights. Instead, they want to recalibrate culture in ways that both refresh understanding of history (to acknowledge the historical place of MDS and trans women) and embrace a future of equality. This equality will be one that accommodates difference, but that recognises these differences as less significant than the ties that bind. This may well point to a layering of rights and culture, or a peaceful coexistence of the two that allows for the gentle reshaping of each by the other in a peculiarly Papua New Guinean way. But whatever the specifics of the process, the effect is coexistence.

Interviewees want this theme of peaceful coexistence to be reflected in the style of rights advocacy undertaken. Advocacy that encompasses the whole community rather than targeting only marginalised groups. Advocacy that avoids any messages that imply a zero-sum-game, that suggest some people have to give up something so that others may have more. Advocacy that is not abrasive but engaging. Like the content, the style emphasises inclusion. The strong public-health arguments that support the rights of marginalised communities are entirely compatible with such an approach. By joining together to implement a shared agreement to treat each other more fairly, the health of the community can be enhanced. Nobody loses, everybody gains.

Interviewees were perhaps less clear on how this advocacy might engage Christian churches, but here again their defence of culture is instructive. Interviewees largely felt their culture could absorb a new approach to PLHIV, MDS and trans women, one that recognises that they are equal in their difference. To the degree that PNG has indigenised Christianity, it can be assumed that Christianity is considered similarly capable of absorbing these new approaches. Indeed, no interviewees, while seeking greater recognition of their human rights, advocated any form of break with their church. Their expectation seems to be that some sort of interweaving will be possible, and that some form of coexistence can be secured.

Wardlow (2008), Kelly (2009) and Hermkens (2012) all observe the way that HIV has asked Christians in PNG to think differently about the practice of their faith. Wardlow (2008) explores how Christians in PNG have responded to HIV through the lens of their faith, from their sin-based understandings of HIV to the fostering of a postcolonial Christian discourse that can be used to structure the right kind of national HIV response for a Christian country. Wardlow documents how the rules of Christianity, as articulated by religious leaders, can be used to control behaviour in the context of erosion of traditional taboos and restrictions. This instrument of control, writes Wardlow, has been given a new lease on life by HIV. Worried by this new threat, Papua New Guineans look to familiar structures for protection. And yet, writes Wardlow, these structures are being tested by new challenges like promotion of condoms, public acknowledgement of the sexual behaviour of the faithful, and national conversations around the use and abuse of power by men. Other factors are also reshaping how these structures of control are perceived: the long history of missionisation in PNG, the economic decline Papua New Guineans see around them, and the failure of government services to respond adequately to this decline. This then is a dynamic space with religion being examined anew.

Kelly (2009) explores how Christians in PNG (with a focus on Catholics) are responding to HIV, particularly through the three theological values of faith, hope and love. HIV has thrown up new challenges for religious, Kelly writes, requiring priests, nuns and brothers to grapple with sexuality and sexual behaviour in new and sometimes confronting ways. Traditions of caring for the sick and poor have had to be updated with new understandings of matters like confidentiality, counselling and antiretroviral therapies (ARVs), and the call to love one another has been tested anew in the face of fear of HIV and the tendency towards stigmatisation of PLHIV and others impacted by the epidemic. Hermkens (2012) explores devotion to Mary, mother of Jesus, in Madang, and the ways female devotees, particularly members of the Legion of Mary, use their devotion to deal with the violence experienced so often in contemporary PNG, especially institutional and structural violence and the impacts of this in a world where HIV is an ever-present factor. Hermkens observes the considerable capacity of religious movements to address issues seen to have a moral dimension, issues like violence and HIV. She notes how this capacity can be weakened by endless debates over condoms and the morality of sexual behaviour, but that still in PNG, religious practice is being promoted as a means of combatting HIV. Mary is promoted as a role model, and following her path is said to both reduce HIV risk and lead to salvation. Devotees model themselves on Mary as a strategy against domestic violence and other problems, attributing to themselves power and agency. Hermkens sees how devotees not only emulate Mary's virtues of patience and modesty but also see Mary as a strong woman and a leader. By working through the Legion of Mary, women are organising and advocating as a group. Hermkens notes that other groups of religious women in PNG are more obviously successfully exerting agency, challenging power structures that exacerbate HIV risk.

A final observation supports a conclusion of utility. It seems to me that in expressing a view about the kinds of rights-based advocacy to be used, interviewees were already pointing to an indigenising of human rights. Human rights are being envisaged as comfortable within culture. This reflects an understanding of identity in relational rather than categorical terms. But it also calls for a deeper understanding of PNG culture by those engaged in analyses of human rights in PNG. Some of the principles that underpin human rights have also underpinned many PNG societies.

The writers and thinkers considered earlier in this chapter lend support to these conclusions. They reflect diverse views and different areas of expertise, but it is possible to glean some shared perspectives. Collectively they encourage an understanding of 'culture' beyond the superficial, and challenge the notion of culture as immovable, unchangeable, monolithic. They encourage others to appreciate the variation within culture and the subtleties of cultural practice; this is an important first step that must be taken before seeking to determine what culture does and does not accommodate. They suggest that, to the extent that human-rights doctrines constitute an 'other', 'outside' of culture, both culture and human rights might be more flexible than has been suggested, enabling each to influence the other as communities work out how human rights will operate in their lives. Writers use different ways of explaining what happens next — indigenisation of rights, perhaps a peaceful coexistence (at least in some domains) or a gentle blending of rights and culture, a layering of one over the other, or adaptation of each in response to the other. If this all sounds a little imprecise, that is because it is, and we should not necessarily be troubled by the fact. Jane Cowan (2006) explores the interplay of culture and rights, particularly the 'contradictions, ambiguities and impasses', and sees rights processes as ' complex and contradictory. Both enabling and constraining, they produce new subjectivities and new social relations and entail unintended consequences' (2006:9). Cowan, too, is interested in Strathern's analysis of personhood and, in particular, in the agency that individuals exercise when navigating the complex kinship relations that so shape their lives, with Strathern calling for an approach to human-rights analysis that takes account of the multiple ways people see themselves as shaped by their relations with others.

Similarly, while my interviewees held diverse views on many matters, I found strong support for the notion that human rights could be indigenised. My interviewees reported or sought the application of human-rights frameworks that reflected and respected culture. Together they painted a picture of culture as anything but monolithic. They spoke about culture as possessing myriad variations, acknowledged there were aspects of culture about which people would have different views (and here I am thinking particularly of the sensitivities around the historical place of homosexuality for transgender identity, discussed in Chapter 4).

There are lessons in all this. Human-rights frameworks can absolutely be effective in development work, but only where the framework and its application are contextualised and adapted for local culture. This is going to require some understanding on the part of people engaged in this kind of work, particularly development workers, and especially development workers who are also outsiders (like me). This understanding will involve embarking on a cultural learning journey that will never end. There will be a thousand stories about culture that will show its diversity and complexity and outsiders will never fully understand it. Some of the stories they hear will contradict others, which makes sense in the context of this diversity and complexity, and because the educators — the story tellers — will be experiencing their culture in different ways. Any notions that human rights are from outside should be resisted, although these notions are commonly expressed. When utilising human-rights frameworks with communities, it is likely that some concepts will feel foreign and some will feel very familiar, as if they have been a part of local culture for hundreds or thousands of years. Notions that human-rights frameworks do not work in cultures that are structured collectively need also to be resisted. They do. Just differently. Frameworks will be strengthened where they acknowledge and respond to the ways that traditional cultures and human-rights doctrines are interconnecting, modifying each other, blending, coexisting, synchronising, and where they recognise that these processes are happening in real time, right now. Lots of people are working on this right now, discovering different ways that these processes are occurring. This process is best understood by observing it in action, looking beyond your particular project and see how it is unfolding in myriad ways — in tiny community projects, in parliaments and courthouses, in churches, and in all the places in between.

People who are marginalised and stigmatised and who experience human-rights abuses deserve every protection they can get, and the human-rights framework is definitely a part of the solution. Our responsibility is to find a way that enables it to most effectively work in the local setting. My interviewees were not interested in a binary choice between rights and culture. They know culture and human rights need to be considered with reference to each other and they understand that change is underway.

Chapter Eight
Overall Observations and Being Loud About Them

This chapter is dedicated to Nick Morea Evera. Nick served as senior program officer with Kapul Champions and was behind some of its most significant achievements, including its 'Live your Life' and 'Walk With Me' posters. He was key to Kapul Champions's efforts to reach beyond Port Moresby to other provinces and is the author of many of the most important records of Kapul Champions's work. But before all this, he was a member of successive Igat Hope boards, starting in 2005 and serving as its treasurer for many years. Before joining Kapul Champions, Nick worked with FHI 360 as its GIPA (Greater Involvement of People With HIV/AIDS) Project Officer, and before that was a peer educator and counsellor with Save the Children's ground-breaking Poro Sapot Project. He was forever accommodating, caring and congenial. He was highly respected within the PLHIV, MDS and trans communities in PNG. Nick died in 2017.

*

For this final chapter I have fully liberated my inner advocate. In Chapter Two I spent time reflecting on my role in my research and considering potential tensions between my role as a researcher and my other roles, concluding that I was a researcher who remained at heart an advocate. Advocacy and activism have been important themes in my research. I have spent time exploring, documenting and reflecting upon the advocacy work undertaken by Igat Hope, Kapul Champions and the constituencies of both organisations. I have dedicated each of my chapters to a legend of the community response, and one of the strengths shared by all these people is the capacity they have demonstrated as courageous advocates. I have heard most of them described at different times as fearless advocates, but I have always thought this phrase undervalues their contributions. They were not fearless! Indeed, I spoke with several of them specifically about the fear they felt in being so public, but they did it anyway. And that is what, for me, is so impressive about their advocacy. So, duly inspired, I have gone 'full advocate' in this chapter and framed my conclusions as a series of advocacy pieces. These are offered only as examples of what could be done with my research. Any advocacy plan or actual advocacy resources would need to be developed through a proper collaboration with Igat Hope, Kapul Champions and their constituencies, however the following are examples of ways my research could be used.

I begin with a conclusion regarding the experience of stigma and discrimination for PLHIV, MDS and trans women in PNG. I drafted this conclusion originally in the form of a long-form article, perhaps for a magazine, but then decided it would work better as a microsite. The text is set out below and the microsite can be found at Tim Leach, *Widespread Discrimination Based on HIV-Status, Sexuality and Gender Identity* (2020).

*

Observation One

PLHIV, MDS and transgender women experience unacceptably high levels of stigma, discrimination and violence because of their HIV status and/or sexuality and/or transgender status. Their human rights are routinely violated.

Introduction

Recently released research shows that people living with HIV, non-heterosexual men and transgender women in Port Moresby experience very high rates of stigma and discrimination, including very high rates of violence. This is likely to be the story nationwide.

The research has included interviews with 35 people living with HIV (or 'PLHIV'). It has also included 31 interviews with men who have sex with other men (many of whom refer to themselves as 'men with diverse sexualities', or 'MDS') and transgender women (or just 'trans' women, many of whom refer to themselves as 'TG'). Trans women are women who have been born with the physical attributes of males but who live or identify as women.

People might think that PNG has moved on from the hysteria associated with HIV in its earliest days, and this is true in many respects, but the research shows that discrimination against PLHIV, MDS and trans women is still widespread. It is experienced by PLHIV, MDS and trans women regularly and there are no PLHIV, trans women or MDS who have not experienced it. Many expect it as part of their normal day-to-day life. It is not new for them and many have grown used to it.

This discrimination constitutes a violation of the human rights that PLHIV, MDS and trans women possess to live free from unfair treatment on the basis of irrelevant factors such as HIV infection, sexuality or gender expression. The research makes clear that when we are talking about such negative treatment, we are talking about the disrespecting of the rights of PLHIV, MDS and translate women to enjoy the same opportunities as their fellow citizens. This negative treatment is often described as stigma and discrimination and it can take different forms — as self-stigma (or shame), name-calling and vilification, family rejection, community marginalisation, exclusion from services and opportunities, and violence. Each of these forms of stigma and discrimination is experienced by all three groups.

Discrimination is experienced in multiple settings

PLHIV, MDS and trans women experience discrimination in employment. They can be rejected for jobs where their status (as HIV-positive, an MDS or trans woman) is known, and they can be forced from employment if their status emerges after their appointment. Research interviewees agreed that PLHIV, MDS and trans women often self-select out of employment recruitment processes in anticipation of rejection. It is likely that employment-related discrimination is significantly underreported.

PLHIV, MDS and trans women experience discrimination in education, reporting that they have been denied opportunities to study when their HIV status, sexuality or gender identity has been revealed. They also reported being subjected to poor treatment within educational institutions once enrolled, from teachers and other students. This poor treatment sometimes takes the form of violence. PLHIV, MDS and trans women are very aware that by being denied access to education they are ultimately denied opportunities to advance in life more generally. They are easily able to explain the link between education and employment, and many have stories of how being excluded or withdrawn from school made a life of economic hardship unavoidable.

PLHIV, MDS and trans women experience discrimination in accessing health services. This has detrimental effects on their own health but it also impacts on public health. People interviewed for the research reported that discrimination within health-care settings might take different forms — it might be perpetrated by doctors and nurses or it might result from the behaviour of other patients. This discrimination can result in PLHIV, MDS and trans women leaving without getting the care they need, and the anticipation of discriminatory treatment keeps many PLHIV, MDS and trans women from approaching health services in the first place. In some cases, the discriminatory treatment involves clinical negligence. Interviewees agreed that these experiences, or the anticipation of such experiences, could impact the success of HIV treatments in PNG (antiretroviral therapy, known as ART). They agreed this has serious implications for managing HIV in PNG. If people with — or at risk of — infection do not feel they will get decent treatment from a service, they will understandably avoid it. Yet if they do not attend services they cannot get tested and they cannot access ART, and they are far more likely to spread infection and ultimately die than those who get the services they need.

Research interviewees acknowledged the important role being played by faith-based health providers in PNG, particularly the Catholic Church, but saw that some official church doctrines, for example those on condom use, homosexuality and transgender expression, were complicating and in some cases undermining service delivery.

The research has found that the most complained about service was the police service. Many interviewees, particularly MDS and trans women, said they did not trust the police to protect them and would not bother to seek assistance. Police were accused of having perpetrated violence against interviewees, based on discriminatory views on HIV, homosexuality and transgender expression. There were disturbingly common reports by interviewees of police involvement in sexual violence.

The experience of discrimination is shaped by a range of factors

When it comes to factors shaping discrimination against PLHIV, MDS and trans women, class plays a role. PLHIV, MDS and trans women who are 'lower class' (less educated, less likely to be involved in formal employment, more likely to live in a settlement and likely to be poor) are more vulnerable to stigma and discrimination and less able to protect themselves from its negative influence. Wealth and social status provide protection against discriminatory treatment, giving greater access to education and employment and reducing vulnerability. PLHIV, MDS and trans women from lower socio-economic groupings are more likely to need the services and support of community organisations that work with PLHIV, MDS and trans women. Through their membership or association with these communities, they risk being further exposed as HIV-positive, homosexual or transgender. Exposure and access to information about PLHIV (and HIV transmission), MDS and trans women, shapes the ways people think about these groups. People who are less able to access this information are less likely to appreciate that HIV is treatable and relatively hard to transmit. They are less likely to understand that PLHIV, MDS and trans women have human rights that are constitutionally recognised, and they are more likely to remain antagonistic towards PLHIV, MDS and trans women. At the other end of the spectrum, people who are less reliant on the programs offered by Igat Hope and Kapul Champions, such as those in positions of power and those with higher levels of education and in formal employment, can choose to ignore the same information and remain antagonistic from their positions of relative privilege.

The research also raises the possibility that geographic location might contribute to the experience of stigma and discrimination. Interviewees agreed that Port Moresby is safer for all these communities than other areas. Urban areas are considered generally safer than rural or regional areas. This is significantly about penetration of information on HIV and human rights. It is also about the greater reliability in urban areas of HIV treatments, with good treatment outcomes being a key shaper of discrimination against PLHIV. But it is also about greater access to education and the increased visibility of PLHIV, MDS and trans women in urban centres. Interviewees tended to agree that where PLHIV, MDS and trans women communities had reached 'critical mass', this visibility had contributed to the establishment of safer communities. These might take the form of enclave communities, particularly for trans women, or of communities more sensitised to the reality and needs of marginalised groups. Here the research acknowledges its limitations, notably that interviewees were Port Moresby-based and offering quite general commentary on life outside the capital.

Interviewees agreed that reducing discrimination involves more information being made available to dispel myths and better inform the population. Greater visibility of all three groups is crucial so that their essential humanness can be better appreciated.

The research indicates strong support for the notion of ‘double discrimination’ where people who are both HIV-positive and either MDS or trans woman are far more likely to be experiencing extreme stigma and discrimination. Being female involves an additional layer of vulnerability.

Peer support is critical, but alone this will not be enough

The research shows that PLHIV, MDS and trans women draw critical support from their peer groups, greatly valuing opportunities to come together with people who share their stigmatised status. Many PLHIV, MDS and trans women see these groups as safe communities, and in some cases as families.

Interviewees from all three groups commonly spoke of the impact of stigma and discrimination on their relationships. They regretted the negative impacts of their status on their partners and children, and women with HIV were very focused on limiting the impact of their status on their children. Interviewees also spoke of the ways that restrictions on their movements and opportunities negatively affected their prospects of establishing and maintaining relationships. This included not being able to meet up with friends and subsequently being denied the peer support so essential for maintaining self-esteem in the face of community opposition.

Regrettably, even though PLHIV, MDS and trans women understand that they are being unfairly treated and want to push back, there is a low level of awareness of what to do in response, and not a great deal of hope that remedies can be obtained. There is not a great belief in the capacity of the current legal system to deliver justice. There is, however, a degree of confidence that the system could be overhauled with sufficient will and resourcing. This would require education, the sensitisation of police and court personnel to the needs of marginalised groups, legal and peer support for community leaders courageous enough to bring test cases, and law reform.

Differences between the experiences of PLHIV, MDS and trans women

PLHIV, MDS and trans women have plenty in common, but they also experience stigma and discrimination in some different ways. PLHIV generally feel that life has improved for their community, at least in Port Moresby and other major urban centres, and they credit ART for much of this improvement. By contrast, MDS and trans women tend not to see significant improvements in levels of community acceptance. This difference can be partly explained by the shift in understanding of HIV. Once people understand that HIV is a manageable chronic disease rather than a highly contagious death sentence, it can be approached in an entirely different way.

But many Papua New Guineans remain opposed to homosexual or transgender 'lifestyles'. There is an active debate around the degree to which pre-colonial Papua New Guinean culture/s accommodated homosexual behaviour or transgender expression, but the more common community view does not embrace this idea. While many MDS and trans women believe strongly that they have always had a place in PNG society, even they do not think this argument likely to be highly persuasive in the short term.

The experience of violence for trans women is especially horrifying. Most trans women report multiple experiences of violence, often at the hands of uniformed personnel (police, army officers, security guards), but also at the hands of families and communities. These experiences have often involved sexual assault and rape.

Many MDS continue to hide their sexuality, at least to some degree. This brings its own burdens, but it affords a degree of protection from the discrimination and violence experienced by trans women. MDS who are 'out' are much more vulnerable, and yet still they seem slightly safer than their trans women friends.

Not surprisingly, PLHIV were more likely to focus on violations of their rights to health care, especially ART. Access to secure and affordable ART supplies is critical for PLHIV. It keeps them alive, but it also profoundly shapes the way they are treated within their communities.

Control of information and confidentiality were more likely to be issues for PLHIV and MDS than for trans women. Again, the reason for this is obvious. Trans women are, in many cases, unable or unprepared to hide their status, so are less concerned with privacy. By contrast, PLHIV and MDS are very invested in ensuring that information about their status is controlled tightly.

MDS and trans women are more likely to see regional differences in the ways they are treated as an indication of cultural variation; Highlanders are considered less tolerant than people along the coast and, in some cases, this coastal tolerance even looks like acceptance. By contrast, PLHIV thought their experiences were shaped by the extent to which ART distribution and HIV awareness had penetrated PNG. In areas where residents possessed a sound knowledge of HIV transmission and where ART was available, discrimination was likely to be lower. These areas were likely to be urban centres, but the location of the urban centre (Highlands v coast) was not thought to be critical.

MDS and trans women were far more likely than PLHIV to talk about violations of their right to ‘be themselves’. This was especially the case for trans women. Trans women were far more likely to talk about being prevented from moving around freely. This was their way of discussing safety — or more pointedly the lack of it — as soon as they moved outside of their homes or communities (however these communities had been formed). This focus on the inability to move around without being threatened or assaulted was consistent with the high rates of violence reported by trans women interviewees. Clearly, and understandably, this violation of human rights is the one that most preoccupies the minds of trans women.

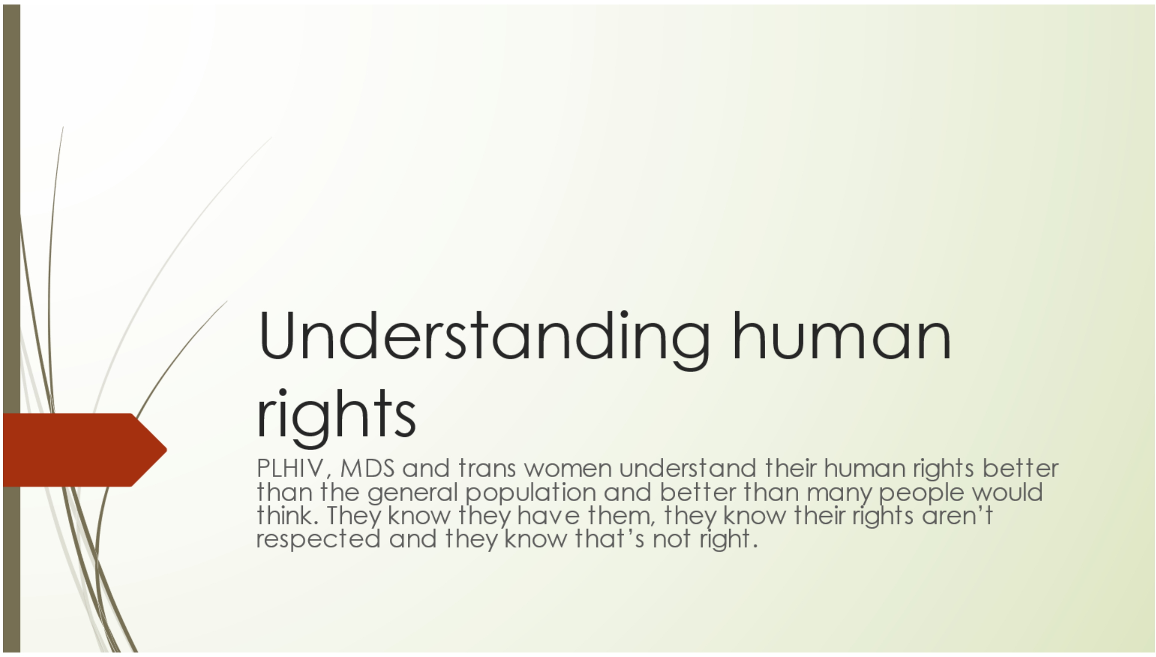
*

Observation Two

These communities understand human rights better than the general population and better than you think. They know they have them, they know their rights are not respected and they know that is not right.

This conclusion is presented in the form of a PowerPoint presentation for delivery by Igat Hope or Kapul Champions. It would be appropriate for a conference or an event such as World AIDS Day or UN Human Rights Day event. The PowerPoint is copied below, and the presentation is attached.

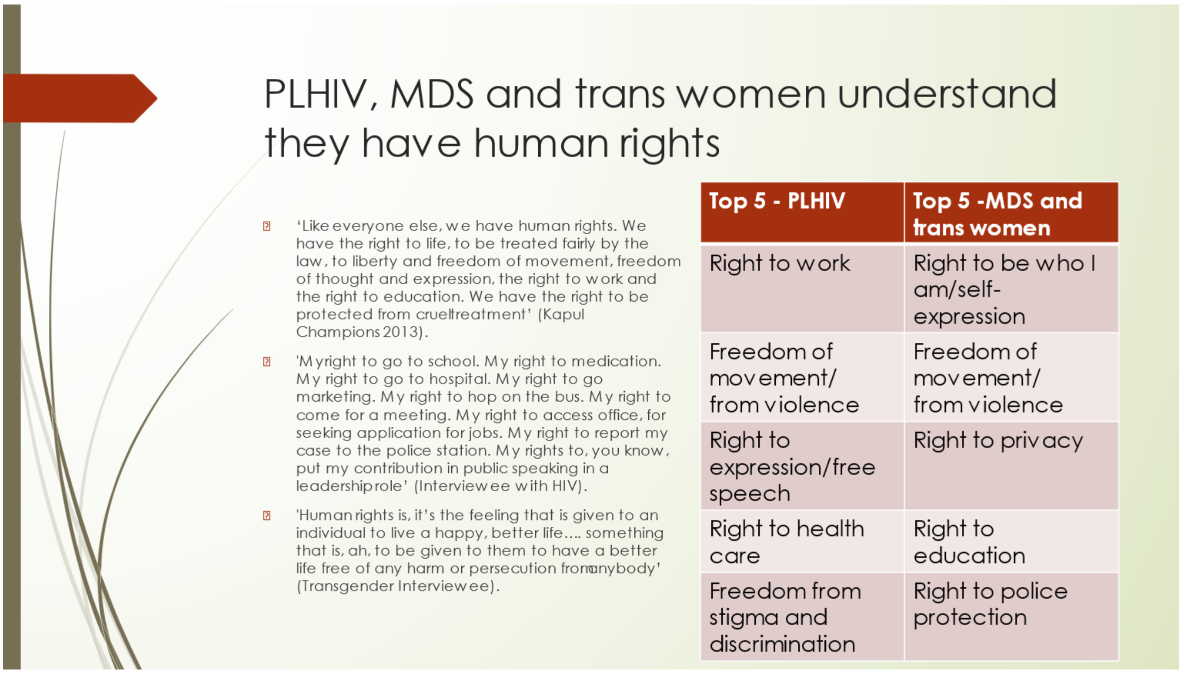
Slide 1.



Understanding human rights

PLHIV, MDS and trans women understand their human rights better than the general population and better than many people would think. They know they have them, they know their rights aren’t respected and they know that’s not right.

Slide 2.

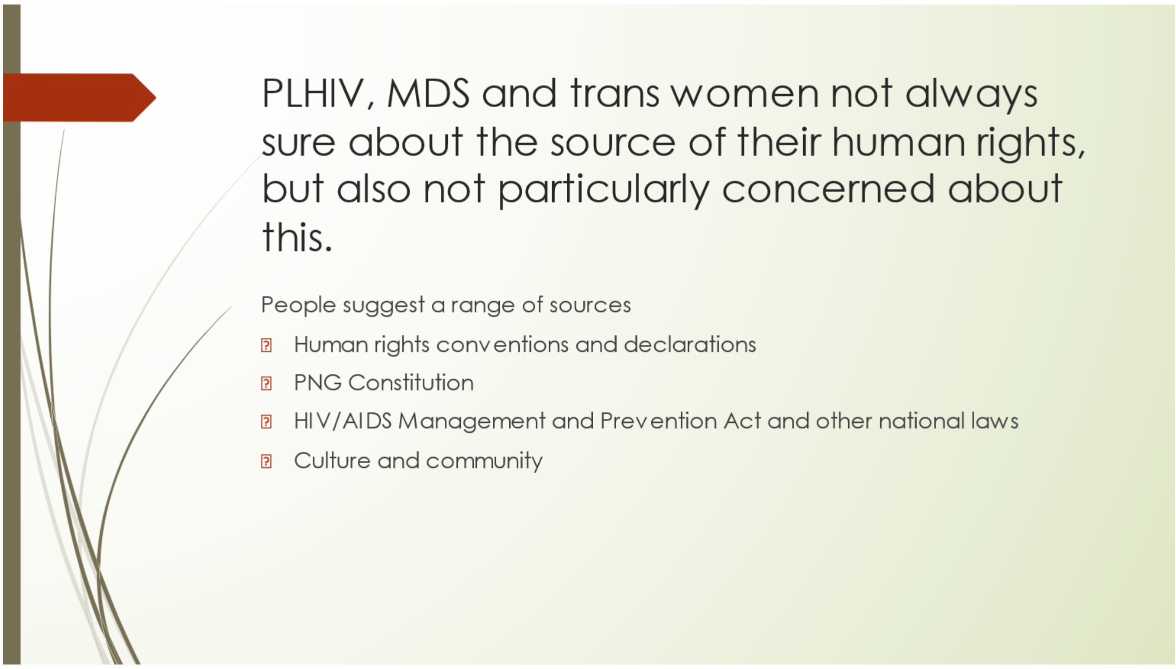


PLHIV, MDS and trans women understand they have human rights

- 'Like everyone else, we have human rights. We have the right to life, to be treated fairly by the law, to liberty and freedom of movement, freedom of thought and expression, the right to work and the right to education. We have the right to be protected from cruel treatment' (Kapul Champions 2013).
- 'My right to go to school. My right to medication. My right to go to hospital. My right to go marketing. My right to hop on the bus. My right to come for a meeting. My right to access office, for seeking application for jobs. My right to report my case to the police station. My rights to, you know, put my contribution in public speaking in a leadership role' (Interviewee with HIV).
- 'Human rights is, it's the feeling that is given to an individual to live a happy, better life…. something that is, ah, to be given to them to have a better life free of any harm or persecution from anybody' (Transgender Interviewee).

Top 5 - PLHIV	**Top 5 -MDS and trans women**
Right to work	Right to be who I am/self-expression
Freedom of movement/ from violence	Freedom of movement/ from violence
Right to expression/free speech	Right to privacy
Right to health care	Right to education
Freedom from stigma and discrimination	Right to police protection

Slide 3.



PLHIV, MDS and trans women not always sure about the source of their human rights, but also not particularly concerned about this.

People suggest a range of sources

- Human rights conventions and declarations
- PNG Constitution
- HIV/AIDS Management and Prevention Act and other national laws
- Culture and community

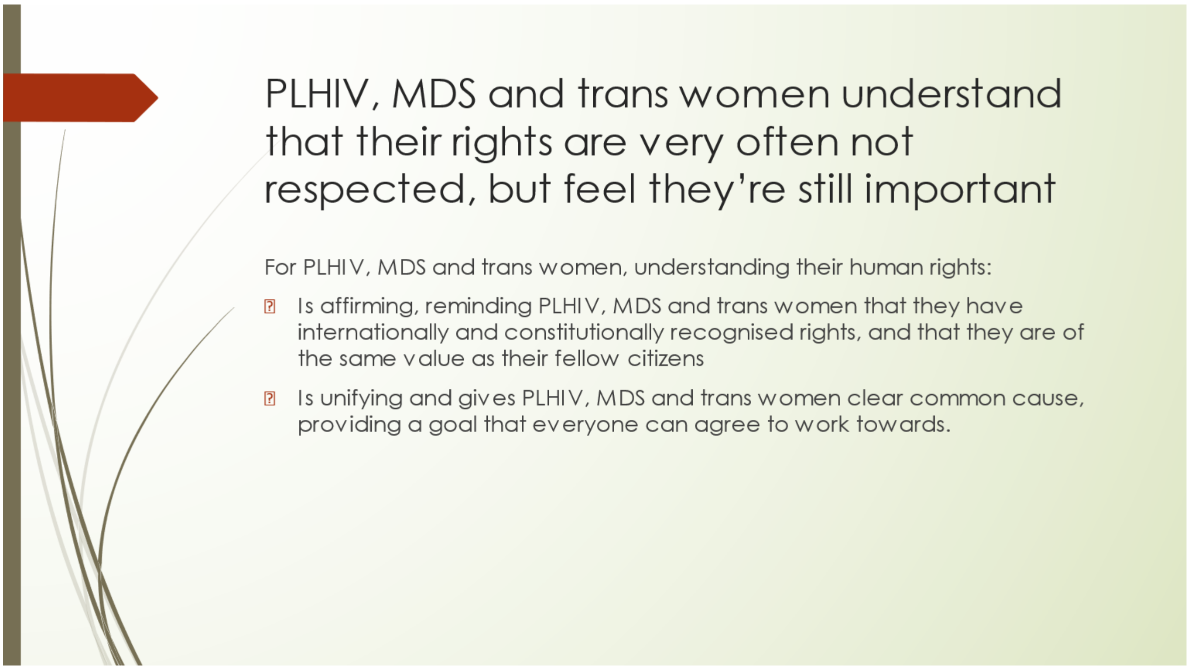
Slide 4.

General community awareness of human rights not high but growing. Awareness higher amongst PLHIV, MDS and trans women. For these groups, human rights have meaning.

- Awareness of human rights is growing across PNG. The work of women's rights advocates is bringing about change, supported by environmental protection movements, anti-violence programs and anti-poverty campaigns. Young people are showing interest.

- 'People are now having broader mindset of what is right and I believe that PNG is a signatory to the Human Declaration of Human Rights. I know that, so it's now [that] people are beginning to see that, OK, within the constitution, in our constitution, we have our right. It is my right to vote as the man and a woman. It is my right of employment etc. it goes down. So people know that the constitution is made out of rights, citizens [and] their rights. How to protect themselves, how to uphold themselves in this beautiful country, PNG' (Transgender Interviewee).

Slide 5.

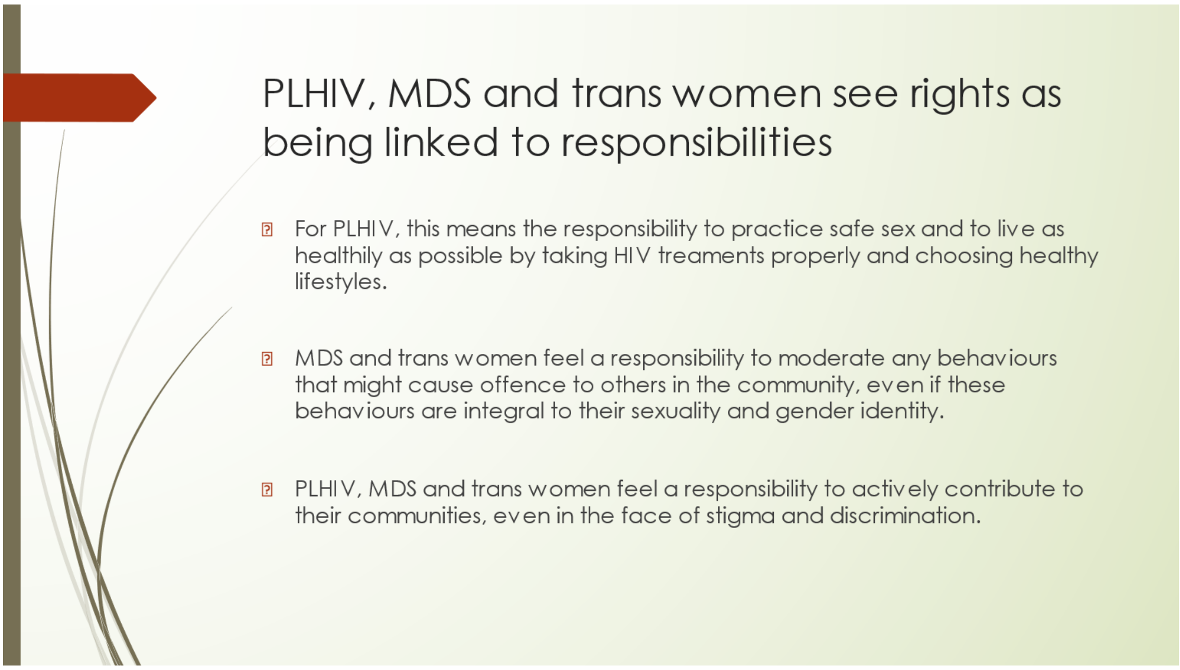


PLHIV, MDS and trans women understand that their rights are very often not respected, but feel they're still important

For PLHIV, MDS and trans women, understanding their human rights:

- Is affirming, reminding PLHIV, MDS and trans women that they have internationally and constitutionally recognised rights, and that they are of the same value as their fellow citizens
- Is unifying and gives PLHIV, MDS and trans women clear common cause, providing a goal that everyone can agree to work towards.

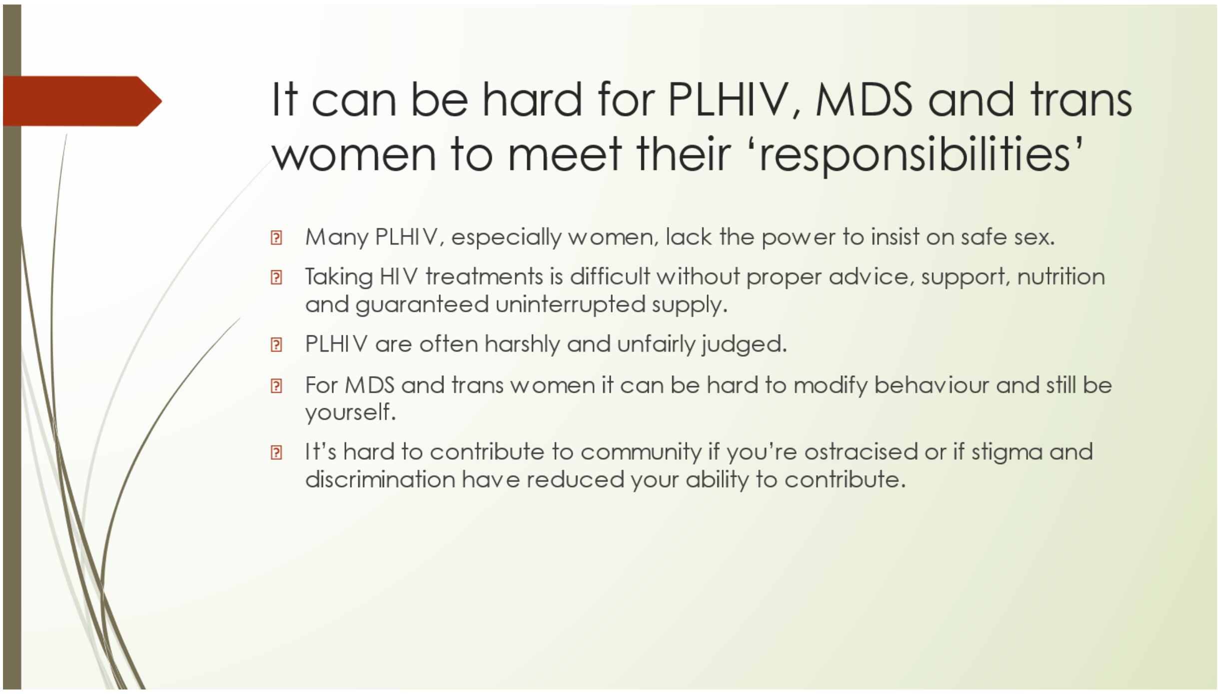
Slide 6.



PLHIV, MDS and trans women see rights as being linked to responsibilities

- For PLHIV, this means the responsibility to practice safe sex and to live as healthily as possible by taking HIV treaments properly and choosing healthy lifestyles.
- MDS and trans women feel a responsibility to moderate any behaviours that might cause offence to others in the community, even if these behaviours are integral to their sexuality and gender identity.
- PLHIV, MDS and trans women feel a responsibility to actively contribute to their communities, even in the face of stigma and discrimination.

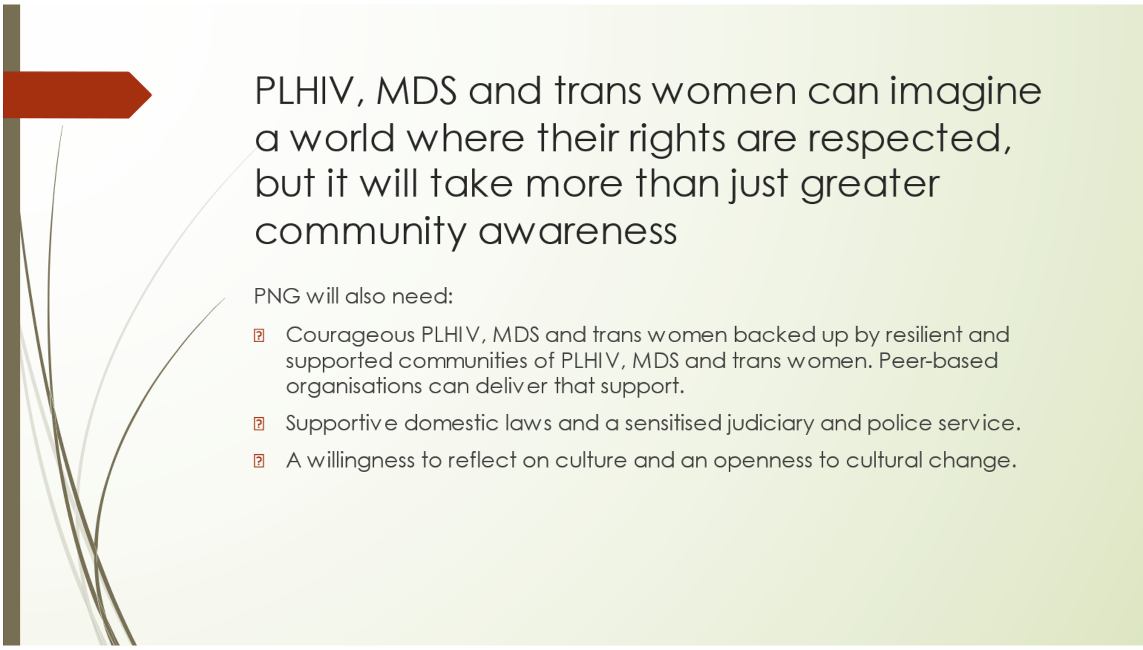
Slide 7.



It can be hard for PLHIV, MDS and trans women to meet their 'responsibilities'

- Many PLHIV, especially women, lack the power to insist on safe sex.
- Taking HIV treatments is difficult without proper advice, support, nutrition and guaranteed uninterrupted supply.
- PLHIV are often harshly and unfairly judged.
- For MDS and trans women it can be hard to modify behaviour and still be yourself.
- It's hard to contribute to community if you're ostracised or if stigma and discrimination have reduced your ability to contribute.

Slide 8.



PLHIV, MDS and trans women can imagine a world where their rights are respected, but it will take more than just greater community awareness

PNG will also need:

- Courageous PLHIV, MDS and trans women backed up by resilient and supported communities of PLHIV, MDS and trans women. Peer-based organisations can deliver that support.
- Supportive domestic laws and a sensitised judiciary and police service.
- A willingness to reflect on culture and an openness to cultural change.

*

Observation Three

Promoting human rights is a good thing. Successful promotion of the human rights of PLHIV, MDS and transwomen will involve grounding them in the PNG experience. That will involve linking human rights to the PNG Constitution.

This conclusion might be captured via a poster or some form of graphic or animation. In summary, Papua New Guineans have human rights by virtue of the United Nations Universal Declaration of Human Rights, but many of these rights are also articulated and guaranteed by the PNG Constitution. Quite a few interviewees knew about one or both of these sources, but many did not.

Interviewees also pointed to other sources of their human rights such as Papua New Guinean culture and tradition, and national laws such as the HIV/AIDS Management and Prevention Act. Interviewees mostly agreed that Papua New Guineans would find the PNG Constitution a more persuasive authority than the Universal Declaration, although they also considered that a focus on the precise source of these rights might be unnecessary. The point about these rights is that they *have* them, and the focus should be on promoting this fact and building support for the protection of these rights. Interviewees warned against promotional strategies that created an ‘us-versus-them’ response from the community. Instead, people should be encouraged to understand that human rights are for everyone and that we all benefit from protecting human rights. The message should be not that the marginalised have special rights, but that EVERYBODY has the same rights.

A key message might be: Our rights = Your rights = Human rights. Images might include the Constitution, the Universal Declaration, and groups of PLHIV, MDS and trans women and other marginalised groups. However, the imagery will need to emphasise that these individuals have membership of the broader community, so while images may depict PLHIV, MDS and trans women, they must be connected to community. The tone should be encouraging rather than censorious. The message needs to be uniting and respectful.

An example of how this might be done is attached, in the form of a simple animation.

*

Observation Four

PLHIV, MDS and trans women communities have quite sophisticated understandings of the reasons their rights are not respected. They have sophisticated solutions that do not reduce rights down to 'us and them'. Their solutions are underpinned by the principles of inclusion and respect for culture. If we want to know how to promote human rights in PNG for PLHIV, MDS and trans women, we have been clearly told how to do so by the experts.

This conclusion is framed as a speech by an elected representative of either Igat Hope or Kapul Champions, to a conference, forum or meeting. It is targeted particularly towards people in authority, such as community and church leaders, who may be concerned that this doctrine of 'human rights' constitutes a threat to social order and PNG culture. I have crafted it by threading together a range of thoughts and arguments shared with me through my research interviews, as well as some of my own thinking.

Thank you for the chance to speak today. I want to talk about human rights, and I want to address this view held by some people that human rights are somehow threatening to other systems we hold dear in PNG — our culture and our Christian faith. I have often been told that human rights are going against culture. When people say this, I ask them some questions. First, I ask: when you say human rights, what do you mean? Because people don't always know what they are talking about; they may have a view of these human rights which can be quite mistaken. I encourage people to read the Universal Declaration, and then to read the PNG Constitution. And then I say, 'Now, now I will talk to you about how human rights interconnect with our culture and our faith.'

At this point people sometimes say, ‘Well, I may not know much about these human rights but neither does anyone else. They are not important to Papua New Guineans so why are we wasting our time talking about them all the time?’ To that I say this: human rights may not be important to you, but they are important to PLHIV, MDS and trans women. They can tell you quite a bit about their human rights. They might not be able to tell you exactly where they come from, they may not know exactly what a declaration or a convention is, and they may never have read the constitution. But they know they have rights. And they know that their rights are not being respected in PNG. They know that their routine exposure to violence and abuse, to rejection and other forms of discrimination is not right. They can imagine a world where this is different, and they want to help bring about that world. You might think it would be depressing to have a whole bunch of rights that you cannot enforce. But these communities see these rights as empowering, affirming, uniting and galvanising.

So, you say that these rights go against culture? We hear this often. But we would encourage you to consider a couple of things. First: there is not one, monolithic culture in PNG. There are many, many different local cultures that interweave to produce a diverse community. Yes, there are lots of commonalities and similarities and unifying elements, but there is also variation. We’d also ask you to allow for the possibility, just the possibility, that traditional, pre-colonial culture, whatever that might be, incorporated or was accommodating of sexual and gender difference. We can show you highly regarded research that suggests this was the case in some parts of PNG, and we have our own stories that are consistent with this. If you have a different view of PNG history, we will respect that, but we would make the point that your history is also a history of our own communities and that our views are valid too.

And then we’d like you to reflect on the possibility that our culture is evolving all the time, as it incorporates new elements with the community’s consent. Culture isn't incompatible with change and we shouldn’t be afraid of it. After all, there was a time when PNG culture was not Christian, and yet now people often talk about culture and Christianity as if they are one and the same thing. You wouldn’t say that culture was destroyed by Christianity, so why would it be destroyed by human rights?

Next, we’d like you to think about the possibility that ‘culture’ is used to mask exploitation of some people by others. People use culture to defend the silencing and abuse of women and children, and all other kinds of injustice. And some of these aren’t traditional at all but represent new power grabs by those with authority acting under the rubric of culture. Courts right across the Pacific are ruling that these ‘cultural practices’ are in fact nothing of the sort, but instead are abuses of power that in many cases undermine the very culture these abusers purport to be defending.

Now, allow for a moment that culture is evolving and that human rights can be gently interwoven with our culture so that our culture is enhanced and the best elements are highlighted through this addition. If you like the sound of this, let me tell you why they can be interwoven. This notion that human rights promote the individual over community isn't true. PLHIV, MDS and trans women value community above everything else, we want rights advancement that respects community and secures our place within it. Sure, in different countries communities of PLHIV, MDS and trans women might choose a different approach. They might choose to be more abrasive, to have less patience with the oppression they experience and to assert a need for radical overhaul of community. But our movement has rejected this approach. We don't see recognition of our human rights as part of a 'zero sum-game'. Yes, there must be some acknowledgement of power imbalances in PNG life and a greater acknowledgement of the rights and entitlements of PLHIV, MDS and trans women, and, while we're at it, of all women, and children, and people with disability, and other Papua New Guineans who suffer from a lack of power. But this national reflection on who has and who lacks power in PNG is already underway, with women leading the charge. Papua New Guineans are already seeing that to share power is not to lose it. We see full recognition of human rights as being accommodated within the evolving PNG culture. These rights, then, don't need to be forced upon Papua New Guineans by some external force, they can simply be acknowledged domestically.

When it comes to religion, we are often seen as sinners, simply by virtue of our membership of PLHIV, MDS or transgender communities. We have seen firsthand the complexity of Christian Church responses to HIV. Many of our members have died because of the churches: some of you have called us sinners and encouraged our families and communities to reject us. That kills people. Some of you have told us to abandon our HIV treatments and instead put all our faith in God, as if you couldn't do the one without the other. And that bad advice has killed people. Some of you have made access to treatment and care conditional upon our 'repentance' or on us agreeing to change and live as you think we should live. That kills people. Some of you have railed against condom use, and that has cost lives as well. And yet, at the same time, you've responded to our suffering with great compassion. You have nursed us when our families wouldn't even be in the same house for fear of infection. Many of you have risked sanction by your own churches for subverting church policy for our sake, or at least interpreting it in ways that benefited us but left you vulnerable to criticism or penalty. So, we get the complexity, and that the church suffers its own internal conflict around how to treat us. We understand that, like us, the church is diverse and full of different views and that there is no one, universally accepted interpretation of God's Word.

But one thing that hasn't helped is this conflation of your interpretation of Christianity with 'culture', and your assertion that by living with HIV, or as an MDS or as a trans woman, we are not only sinning but going against culture. We understand that in a country of over 800 languages, Christianity is a unifying force, and Christianity is an incredibly important component of PNG culture. But it does not define PNG culture, which existed before missionaries. In the same way that PNG culture has become joined with Christianity, this same culture can absorb other new things as well. We can have debates around theology, and debates around culture, but there needs to be acknowledgement that these are not always the same debates.

And finally, we're Christians too. Our movements look to God for support, strength and inspiration. We have found it entirely possible to reconcile our status with our love of God. We are all God's children. There are so many Christian values — of compassion, of caring for the weak and the vulnerable, of leaving to God the business of judging the value of a person's soul, of love for each other, of treating others as we would have them treat us — that demand a different response to PLHIV, MDS and trans women. We appeal to these.

*

Observation Five

PLHIV, MDS and trans women place high value on peer connection. HIV responses that don't recognise this won't work. These communities value their organisations. The organisations have high brand recognition and authority to represent constituents. Now *that's* voice.

Interviewees overwhelmingly support their organisations Igat Hope and Kaul Champions. While many interviewees were able to identify areas where the organisations had in their view underperformed, all interviewees agreed the organisations should continue. There was acknowledgement among interviewees of the very significant challenges the organisations had confronted. This was particularly the case for Igat Hope in having to confront immense challenges very early in the epidemic, with no funding support at all. At least Kapul Champions has had the benefit of a decade of Igat Hope's learnings. There was strong support for the notion that the organisations could learn from their mistakes and could effectively represent their constituents into the future. PLHIV, MDS and trans women all value the peer support they have been able to access via their organisations. This is not just about peer-based programs, although these were highly valued, especially the expert patient trainer and peer-based ART adherence programs delivered by Igat Hope. Interviewees also value the informal, yet critical, peer engagement opportunities attained by dropping into the organisations' offices and attending trainings or meetings or forums. This peer support was considered critical to overcoming isolation, building resilience, combating self-stigma and providing a foil for the stigma and discrimination being experienced in so many parts of their lives.

Peer-based programs to educate PLHIV about ART and to support ART adherence are considered incredibly important by interviewees, who see no viable alternative to these programs. Employment of HIV-positive peer education workers in clinical settings supports PLHIV while building the capacity of clinicians to provide better, more supportive care.

The organisations continue to have authority within their constituent communities. Interviewees valued the way in which these organisations had been established by their peers and not by government or donors. The national consortium that has been established, largely by UNAIDS, and as the only means by which funding for marginalised groups can be obtained, does valuable work. But it is not seen as a peer-based organisation in the same way as Igat Hope and Kapul Champions.

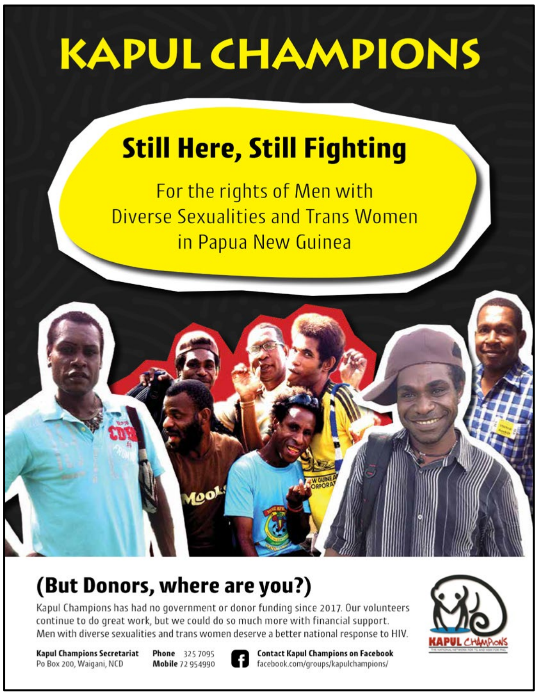
The world has not found a better way of dealing with HIV than by partnership responses that involve governments working with the medical and research sectors and the communities most impacted by the virus. For these responses to work, affected communities must be involved and representatives of these communities must genuinely be connected to and able to speak for their constituencies. Igat Hope and Kapul Champions were built by their constituents, have genuinely peer-based memberships and democratically elected representatives.

For the foreseeable future, the PNG HIV response will need significant focus on men with diverse sexualities and trans women. The epidemiology makes this clear. And *every* HIV response must focus on PLHIV. PNG will need to be able to engage these communities and if Igat Hope and Kapul Champions did not already exist, they would have to be set up. And yet, while they do exist, they are limping along without proper (or any) resourcing. What sense then does it make to starve them of resourcing to the point that their very capacity to function is threatened?

These points need to be repeatedly made to the PNG Department of Health, the National AIDS Council and its Secretariat, the Australian Department of Foreign Affairs and Trade (DFAT) and other donors. It might also be useful to keep reminding NAPWHA and AFAO of their responsibilities here. A simple, ‘light touch’ promotional campaign might help keep these issues and the two organisations on the agenda. A couple of possible (electronic and/or printed) posters have been drafted. They use images sourced via Shutterstock, a library of images which can be licensed for creative use.

Kapul Champions, still here, still fighting for the rights of men with diverse sexualities and trans women in PNG. (But donors, where are you?) (Figure 9).

*Igat Hope, Built **by** people with HIV **for** people with HIV. Celebrating 20 years of struggle and success in our fight against HIV* (Figure 10).



KAPUL CHAMPIONS

Still Here, Still Fighting

For the rights of Men with
Diverse Sexualities and Trans Women
in Papua New Guinea

(But Donors, where are you?)

Kapul Champions has had no government or donor funding since 2017. Our volunteers continue to do great work, but we could do so much more with financial support. Men with diverse sexualities and trans women deserve a better national response to HIV.

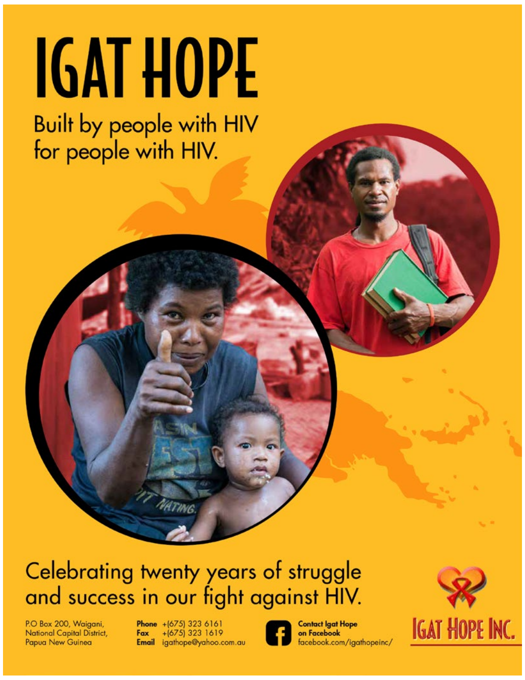
Kapul Champions Secretariat
Po Box 200, Waigani, NCD

Phone 325 7095
Mobile 72 954990

Contact Kapul Champions on Facebook
facebook.com/groups/kapulchampions/

KAPUL CHAMPIONS

Figure 9. ***Kapul Champions: Still Here, Still Fighting … (But donors, where are you?).***
Source. Poster for possible use, created by author. © Tim Leach.



IGAT HOPE

Built by people with HIV
for people with HIV.

Celebrating twenty years of struggle
and success in our fight against HIV.

P.O Box 200, Waigani,
National Capital District,
Papua New Guinea

Phone +(675) 323 6161
Fax +(675) 323 1619
Email igathope@yahoo.com.au

Contact Igat Hope
on Facebook
facebook.com/igathopeinc/

IGAT HOPE INC.

Figure 10. ***Igat Hope, built by people with HIV for people with HIV. Celebrating 20 years of struggle and success in our fight against HIV.***
Source. Poster for possible use, created by author. © Tim Leach.

Observation Six

Community-based organisations can be effective vehicles for service delivery and rights promotion in the PNG context. We know how to tweak the model to make it fit for purpose in PNG.

I have drafted this conclusion as a proposal to be considered by DFAT or other donors, or perhaps even by the Government of PNG. Given DFAT remains still the most likely option, I have imagined the proposal as a kind of briefing for DFAT decision makers that utilises the framing and language of departmental bureaucracy. However, the proposal could be tweaked for other governments or for other donors and could also form the basis of a petition from NAPWHA or AFAO. It draws on my findings regarding the operation of community-based organisations in PNG; specifically it focuses on what we know works and does not work, and on how we need to make sure the successes of these initiatives can be measured and articulated. Igat Hope and Kapul Champions achieved great things, and the model of a community-based organisation can work very effectively in PNG. But we also know that some elements of the CBO model as imported to PNG for use by Igat Hope and Kapul Champions were not entirely fit for purpose and should be modified sensibly. This briefing assures DFAT that the CBO model can deliver, that the learnings of the past 20 years can be easily incorporated into new ways of organisational functioning, and that the most appropriate ways of measuring performance are likely to afford DFAT the opportunity to demonstrate the success of its funding decisions.

While my research has not focused on Friends Frangipani, any DFAT decision to revive support for Igat Hope and Kapul Champions should also provide for the resuscitation of Friends Frangipani. For this reason, Friends Frangipani is included in the brief.

PROPOSAL. A resuscitation of three community-based organisations is proposed. Specifically, it is proposed that funding be provided for Igat Hope, Kapul Champions and Friends Frangipani as a means of enhancing PNG's response to HIV.

Key reasons

- HIV continues to present a significant threat to public health in PNG. The Government of PNG has struggled to adequately respond to the epidemic in the context of a deteriorating economic outlook nationally, multiple health challenges, and demands on the health budget.
- A worsening epidemic in PNG will drain the health funding needed to respond to other health challenges, including several that pose a threat to Australia (notably drug-resistant tuberculosis). Large-scale epidemics impact on the young adult population that

would otherwise be providing the nation's labour force, a labour force that constitutes the bulk of the tax-paying public. This means that epidemics have large impacts on national production and productivity, in PNG's case threatening its fragile economy, which in turn undermine social cohesion and may contribute to violence.

- The epidemic in PNG remains complex and unpredictable. It defies the international trend of falling into one of two categories: either generalised or key populations. It is both, an epidemic that is affecting key communities and it is being experienced as a concentrated epidemic in certain locations. Prevalence rates are high among communities of men who have sex with men, transgender women and sex workers.
- Top-down approaches to managing HIV are insufficient to slow infections or deliver care to those with the virus. The Australian, international and PNG experiences all demonstrate that what is required is a partnership response, with government playing its role and impacted communities also playing a key role. These different roles need to be supported; however, marginalised communities find it difficult to access the government or donor support required to properly undertake the role that they must play.
- Igat Hope was established by people living with HIV in PNG in 2001 and has represented its constituents since that time effectively and with high levels of community support. It continues to operate with employees, an office and with a functional governance comprising people living with HIV. It currently receives modest funding via a consortium with PNG Catholic Health Services and Burnet, along with some funding via the Global Fund.
- Kapul Champions was established in 2011 to represent the communities of men with diverse sexualities and trans women. It had a strong performance record to 2016, the point at which its funding was withdrawn by DFAT.
- Friends Frangipani was established in 2006 to represent sex workers in PNG and has been in existence for around a decade. It was a functional representative body operating in multiple sites across the country until funding was withdrawn by DFAT in 2016.
- The PNG Development Law Association was established in 2011 and provided legal representation to the members of Igat Hope, Kapul Champions and Friends Frangipani, with a focus on test cases that might advance the human rights of these constituent groups. It was funded by DFAT until 2016.
- A review of the work of Igat Hope and Kapul Champions indicates strong records of performance over many years across a series of domains relevant to limiting the epidemic in PNG.
- The organisations have strong human rights records and are particularly conversant with the language and application of human rights frameworks. Support for these organisations would be consistent with the Australian Government's support for the human rights of all people, including those in the Pacific. This offers a useful balance, in the public domain, with Australia's support for the Government of PNG (accused by some of not doing enough to promote the rights of marginalised groups), its association with large-scale mining ventures by Australian companies in PNG (some of which have been accused of rights abuses by local Papua New Guineans), and its operation of a refugee detention facility in Manus Island.
- All three organisations possess a governance and membership infrastructure which continues to be recognised and supported by their constituencies. In this sense they remain the properly constituted representatives of their constituencies with a

governance and institutional infrastructure that remains largely intact and which can be utilised by DFAT without the need for seed funding and establishment expenses, although funds to facilitate meetings of these governance structures and associated operational costs will be required.

- The three organisations remain the best vehicles for engaging with these impacted communities, with strong support from their constituencies and established positions as key players in the national HIV response. There is considerable brand recognition and DFAT support for these organisations will be widely acknowledged by the Government of PNG and other donors as an appropriate strategy for supporting the HIV response in PNG.
- There remains a window of opportunity to build on the past work of DFAT, Igat Hope, Kapul Champions and Friends Frangipani, and to capitalise on the past investment of Australian taxpayers in the community response in PNG. This window will not remain open indefinitely.
- The organisations have a history of conducting themselves as lean operations. The resuscitation of the organisations would involve modest financial outlay and would be likely to provide a significant return on investment. The organisations have collectively demonstrated a capacity to manage finances and there have been no recent significant cases of fraud or misappropriation associated with their operations. By contrast with the National AIDS Council and the NACS Secretariat, other recipients of DFAT support, the national organisations have been remarkably scandal free.

Proposal details

A minimum five-year funding arrangement is proposed with decisions on future funding made consultatively and conveyed to the organisations 12 months before expiration of the initial grant. This is based on:

- An understanding that good development involves investment beyond the short term and organisations need reasonable time frames in order to plan, implement and evaluate interventions.
- DFAT’s fraught history when it comes to the funding of these organisations. Its decision to withdraw funding from 2016 onwards was not well received and, with the benefit of hindsight, it seems clear that this decision has had a negative impact on the HIV response in PNG. DFAT has an opportunity to remedy an error without needing to concede a policy misstep.

Program development

It is proposed that the program be developed through a process of co-design. DFAT can expect the organisations to have quite well-developed views about the most appropriate interventions. The following objectives are proposed:

- To contribute to enhancing the national HIV response by engaging key impacted communities in the design and implementation of the best possible response to HIV in PNG.
- To foster community responses to HIV on the part of PLHIV, MDS, trans women and sex workers, enabling these communities to participate in the design and delivery of

programs that will reduce infection rates and provide better care and support for people living with HIV.

- To support a human rights-based approach to HIV responses in PNG that reduces stigma and discrimination experienced by PLHIV, MDS, trans women and sex workers, and that fosters a national conversation about the value and meaning of human rights in PNG.

Engagement of other key stakeholders will be sought via a process that involves DFAT, the PNG Department of Health, UNAIDS, USAID and other donors. Ideally this process will result in:

- Broadscale support of the program objectives.
- Commitments of support from other stakeholders, including commitments regarding ongoing financial or in-kind support.
- A memorandum of understanding to be signed by stakeholders.

A basic program map will be developed through a meeting of relevant constituent communities, to be held over a minimum of two days and which will be jointly hosted by DFAT and the relevant community organisations. The meeting will:

- Be co-facilitated by DFAT, Igat Hope, Kapul Champions and Friends Frangipani.
- Involve the elected Boards of all three organisations and constituents from around the country.
- Involve NAPWHA, AFAO and Scarlet Alliance, Australian HIV organisations with long histories of support for Igat Hope, Kapul Champions and Friends Frangipani. NAPWHA has had a long history of partnership with Igat Hope; AFAO helped establish and has supported Kapul Champions for almost a decade; Scarlet Alliance supported and mentored Friends Frangipani.
- Provide a safe space for discussion and program development.
- Be informed by the latest research on the epidemic.
- Identify key program goals and activities that will underpin organisational planning for three years.
- Consider the potential for work in the following areas: health promotion, access and adherence to ART, advocacy, human rights, community development, governance.

It is proposed that a detailed activity plan will be collaboratively developed by DFAT, the boards of each organisation and organisational employees.

In recognition of the interconnection between these constituencies and the benefits of collaboration, the program will explore ways of coordinating and collaborating, including options around colocation, resource sharing and coordination of program activities. There should be an early focus on bringing the communities together to shape the work of the organisations, and a structured and rolling program of community meetings. DFAT has already assisted in the establishment of the Key Populations Advocacy Consortium, an umbrella association that can continue to play this coordinating role.

Boards should receive rolling training and mentoring in governance, which is to be properly funded and delivered preferably by local providers.

Each organisation shall undertake a review of its constitution, supported by appropriate technical assistance, that:

- Reflects on documented challenges experienced by Igat Hope, Kapul Champions and Friends Frangipani.
- Provides space for identification of local solutions.
- Considers options for co-opting and appointment of non-peers for a limited period and only provided they are always in the minority.
- Considers providing for board members to be appointed for two-year terms with a maximum of six years, and with half the board being elected every year.
- Explores alternative ways of ensuring boards include people from locations beyond Port Moresby, noting that the approach of having positions attached to regions is only one way of achieving this.

Monitoring and evaluation

A performance framework will be developed that considers:

- Fostering community gatherings: possible measurements include the number of gatherings and attendees, participant experience with reference to peer, voice and space.
- Education: possible measurements include resources developed and distributed (including posters, pamphlets, social media messages, workshops, public commentary); processes of development; feedback and evaluation of resources.
- Advocacy: with measurements including media work and media training, participation in forums and working groups, research and public commentary.
- Organisation functionality: possible measurements including properly conducted elections, board meetings with quorums; board minutes; development and compliance with strategic and annual plans; budget reports and successful annual audits, annual and other reporting.
- Transformation or change: measurements include surveys of constituents or other stakeholders, application of most significant change theory.

Justice system reform: possible measurements including engagement with police and/or justice sector representatives (including law makers and judicial personnel), contributions to discussion of justice reforms (attendance at meetings and forums, submissions and proposals), work to promote legal literacy among constituents through training or development of resources, documenting of injustices, referral of legal issues to legal practitioners.

*

Observation Seven

These organisations can deliver human-rights outcomes

I have drafted this conclusion in the form of a lecture. I studied evaluation and human rights as part of my Master's degree in International Social Development, and I think my fellow-students and I would have enjoyed a lecture like this one.

Welcome to today's lecture and thanks for attending. Today we're exploring the way that two community-based organisations (CBOs) in PNG have successfully championed the human rights of their constituents. The two organisations upon which I am focusing are Igat Hope, the community organisation representing people with HIV in PNG, and Kapul Champions, the community organisation representing men with diverse sexualities and trans women.

Let's begin with some observations on measurement. The question of how best to measure progress in human rights is far from settled. There are different ways of doing it, and different approaches to utilising different indicators. It is not like you can go to a donor website and find its definitive 10-point plan for the measurement of human rights achievements. It's also the case that focus on progress seems to wax and wane and, even where progress might be measured, it often is not. But despite the uncertainty we can work from some sensible guidelines:

- It makes sense to be flexible when developing measurements; adapt for local context and explore indigenous approaches to measurement.
- Accept that not everything can be counted. Numbers are great, but so are real life stories.
- A focus on the marginalised will always be appropriate. A focus on stigma and discrimination experienced by the marginalised will always be appropriate.
- It doesn't always have to be an assessment of failings; we can look for positives as well.
- Experiences of marginalisation need to be understood with reference to the structural factors that cause this marginalisation. Don't just count instances of stigma and discrimination, make sure you explore why communities experience this treatment.

An understanding of a CBO's contribution to promoting human rights outcomes for its constituency will be best understood by considering the following factors:

1. Any role the organisation may have played in facilitating a better understanding of the experience of marginalisation.
2. Any role the organisation may have played in supporting people whose human rights have been infringed to seek redress.
3. Any role the organisations may have played in raising awareness of human rights — whether that be among marginalised communities or more broadly.
4. Any role the organisation may have played in monitoring human rights breaches.

5. Any role the organisation may have played in encouraging regard for the human rights of marginalised groups, including by promoting understanding of the lived experiences of members of these groups and the structural factors oppressing them.

Let's look at some of these achievements by Igat Hope and Kapul Champions in relation to these five factors. Here's an example of Factor 1. In the past two decades, dozens of PLHIV, in many cases trained by, but in all cases supported by, Igat Hope, have shared their stories at public events organised to promote HIV awareness. On many occasions these people have been employees of Igat Hope, and in almost all cases they have been members. They have often been invited to give an HIV-positive perspective, and occasionally this has been off the back of a ghoulish interest in their struggles. But mostly these invitations have been genuine and, by 'bearing witness' and being the 'public face' of PLHIV, understanding of the PLHIV experience has been facilitated. PLHIV have spoken candidly and often quite movingly of their experiences of marginalisation, and many people in many audiences have been influenced by their presentations. Evaluations of these events consistently show the power of the personal perspective.

An example of Factor 2 might be the way in which the organisations, Igat Hope and Kapul Champions, acted as conduits between constituents and legal advocates. For the years it operated, the free legal service for people impacted by HIV, was the PNG Development Law Association (DLA). Both organisations collaborated with DLA to hold joint rights awareness workshops, with knowledge of rights being a critical prerequisite for seeking redress. Both organisations encouraged constituents to seek advice from DLA where constituents' rights had been infringed, often providing the warmest of referrals by literally walking constituents to the DLA office.

An example of Factor 3 might be the *Do you know your rights?* brochure developed by Kapul Champions in 2012. Addressing issues like international human rights, constitutional rights and protections afforded by domestic laws, the brochure was developed for MDS and trans women, widely distributed in English and Tok Pisin and is highly regarded. Perhaps an even better example is the media training conducted by Kapul Champions in 2015, which increased journalists' understanding of the rights of PLHIV, MDS and trans women and resulted in a feature episode of the influential *Olsem Wanem* on EMTV. This episode squarely addressed the experiences of MDS and trans women within a rights-based framework, presenting experiences of marginalisation as examples of rights violations.

An example of Factor 4 might be Kapul Champions's 2015 submission to the UN Periodic Review, an important articulation of the human rights of MDS and trans women and documentation of failings on the part of the Government of PNG to protect and promote these rights. The submission highlighted four key areas of human rights violations for MDS and trans women:

education and employment, access to adequate and appropriate health services, recognition of gender identity and the need for law reform.

An example of Factor 5 might be the way that Igat Hope has highlighted the impact of power imbalances on the experience of people with HIV, particularly in terms of gender-based violence. Through its policy and advocacy work, including its support for the Women Affected By HIV/AIDS (WABHA) network, Igat Hope has sought to build an understanding of how power shapes the experience of HIV-positive women. In fact, both organisations have sought to position their work with reference to structural factors such as the oppression of women, class, homophobia and transphobia.

There are lessons to be learned from all this work

It is possible to pursue human rights outcomes via community HIV organisations. This lesson has been demonstrated in Australia and elsewhere, but Igat Hope and Kapul Champions have provided evidence from PNG. Both Igat Hope and Kapul Champions are HIV organisations, and both have achieved human-rights outcomes. While some might argue that the organisations made less progress in human-rights promotion than might have been hoped, the fact is that significant progress was made. And it was made while the organisations were delivering HIV information and support to their constituents. This is an important lesson: community organisations can do both human-rights work and HIV work, and arguably cannot do the latter without the former.

Second, human rights can be pursued by organisations in ways that do not necessarily alienate governments

While Igat Hope and Kapul Champions have been critics of government and other stakeholders, they have also been sought out as sources of advice and as partners by those same targets. Both organisations have continued to sit on departmental advisory groups. Both have regularly been invited to government HIV events such as World AIDS Day celebrations. This should give comfort to the Australian Government that human rights can be supported without alienating foreign governments, so Australian support for organisations with stated human rights goals need not threaten bilateral relations. They *can* threaten relations, of course, but the point is they need not. The key is possibly the indigenous nature of this advocacy. Igat Hope and Kapul Champions have been governed and staffed by Papua New Guineans, not expatriates, so the criticism may have been easier to take and been devoid of the colonialist and imperialist overtones it might otherwise have had. The organisations also favour advocacy approaches that engage, educate and unite, meaning governments can spend less time defending themselves and more time learning how to do things differently.

Better indicators will help

Both organisations struggled to articulate their human rights achievements because no measurements had ever been agreed with funders, and they had consequently received no training in how to measure these. Indeed, funders seemed oddly disinterested in helping the organisations identify indicators of success in supporting human rights, despite the funding agreements having an emphasis on skills transfer and mentoring, and despite funders knowing that the organisations would receive little support in this area from the Government of PNG or local NGOs.

Organisations can move deftly between human rights advocacy and other strategies that support their communities

Human rights arguments are best considered as part of a toolbox of strategies, and utilised where they are likely to be most effective, giving way to other arguments when appropriate. Igat Hope and Kapul Champions were also able to deploy other strategies: pitches to Christian compassion; education aimed at reminding Papua New Guineans that PLHV, MDS and trans women are part of their own community (to normalise and give a human face to them); direct responses to the needs of individual PLHIV, MDS and trans women for care, support and nurturing; and public health advocacy.

Human rights are probably best promoted when indigenised to an extent

The preference of Papua New Guineans for constitutionally based protections over international human rights involves different factors, including a preference for something familiar, a nationalistic preference for PNG over something international, a reflection of social understanding that rights are somehow communal — to be given, observed and taken away by the community as part of a complex system of reciprocity and interdependence. Whatever the source of this preference, the preference itself is relevant to future human-rights work. Work will be needed to explore how this is best done. It may be that the distinction between the rights afforded under international instruments and the rights guaranteed by the PNG Constitution matters little. Given that enforcement action is unlikely in relation to both/either, does it really matter from whence the rights come? Perhaps it is just enough to know that all Papua New Guineans possess these rights. Or perhaps it is best to conceptualise these different sources as interwoven, with constitutional rights being supported or perhaps underpinned by international law.

Documentation is important

The lived experiences of PLHIV, MDS and trans women are critical to a proper understanding of how human rights are experienced in PNG. They are not the only groups of relevance, of course, but their experiences are illuminating and hint at broader strategies for rights promotion. Every PLHIV, MDS and trans woman has a story of rights violations, although often these will be best pursued via conversations about stigma and discrimination. Through these stories, patterns and themes emerge that give insight into the most critical pressure points, and illuminate the best ways to reduce violations of rights.

Action is needed from other quarters

All PLHIV, MDS and trans women in PNG have stories of rights violations. While PLHIV report improvements in life, they also continue to report serious incidents of rights violations. MDS and trans women report multiple experiences of rights violations with no sign of improvement. Law reform moves slowly, if indeed it is moving at all in PNG. This is the context in which Igat Hope and Kapul Champions are operating, and the scale of the challenge cannot be overstated. While Igat Hope and Kapul Champions can point to human rights achievements, they cannot solve the innumerable human rights challenges alone. Government, donors and development partners, private sector corporations, the business community and other civil society organisations all need to play a role.

*

Observation Eight

The record of donor support for PLHIV, MDS and trans women is very patchy. But understanding what hasn’t worked is the key to better development practice.

This conclusion is written in the form of a blog. It is intentionally direct and constructed as a message to DFAT although it could be tweaked to apply to other donors, indeed any entity that might be open to funding community-based HIV or human-rights work PNG. But in restricting it to DFAT I am adding another story to my list: of DFAT’s 20-year role in community HIV responses in PNG. I think people should remember this story as it holds, in my view, many important lessons in how to do or not do development work. I acknowledge DFAT isn’t here to defend itself, but should it feel motivated to dust off and dive back into its records to mount its defence, I’d be delighted.

OK, listen up DFAT. Your 'management' of donor assistance to the community HIV response in PNG has been a real mess. Here's what can be learned so that mistakes are not repeated.

If you're undertaking to support a community response to HIV, and, let's face it, 30-years of experience tells us that's essential for a proper response, then you have to be in it for the long haul. That means five-year programs, reconsidered and renewed at least 12 months before the expiration of the current term. Five years might sound like a long time, and yes, we know the government's forward estimates only extend for four years, but it's important for you to fully appreciate that community development takes time, often lots of time. You'll need an appreciation of the scale of the challenge and the likelihood that achievements will in many cases take years. Ask your experts in community development and evaluation — they'll confirm this.

Be clearer about your human-rights goals. We know that human-rights gains can be made through programs that don't have human rights in the title. But hiding human rights behind HIV programs or gender equality programs or anti-violence programs isn't always the right call. Better still, show leadership in articulating the importance to development, indeed to *everything*, of protecting and promoting human rights. Acknowledge loudly and repeatedly that an effective HIV response in any developing country necessarily involves the recognition and protection of the human rights of heavily affected, marginalised communities. Talk explicitly about the human rights of people with HIV, gay men, trans men and trans women and sex workers.

You will need high-level goals that are clear and have been developed with an understanding of the complexity of the local environment. They will need to be informed by the best advice of those people you hope your program will assist. Here you will need to invest in processes that secure for you the best possible advice from these communities. This won't always be the easiest advice to follow, but often your best work will come about by following local advice that surprised you or made you uncomfortable or made your job harder. Think about how to secure frank and fearless advice. Think about how to ensure your advice reflects the collective views of communities rather than of individuals who have found a way to get in your ear and may, just may, have a personal agenda.

Whatever goals you come up with, you'll need to feel confident that progress towards these goals can be measured in some way, and this may not always be easy. Indicators of human rights advancements or community development need to be agreed in advance and preferably in consultation, *meaningful* consultation, with the people you're trying to help. There are many different approaches to measurement and not everyone will agree, but the process of seeking agreement will be a benefit in and of itself. Your process will be helped by having an understanding of the basics of measurement and evaluation. We've all moved beyond widget-counting and you'll probably get some useful advice on measurements from the communities you're working with. They'll likely have some locally appropriate strategies for measurement.

Of course, people come and go within any long-term program, and there will be challenges in securing corporate memory and continuity of program implementation. (And if there isn't a fast improvement in the reliability of supply of antiretroviral therapy in PNG, this will be exacerbated by the untimely deaths of prominent advocates.) It is important that there be unifying, binding strands running from year to year to remind people why the work was started in the first place and to help keep the program on track. But here you don't have to do it alone. A partnership with the right NGOs, in Australia and PNG, will help build a formidable brains trust that can act as a shared resource and help improve the program's chances of success. If DFAT is struggling, there are other entities that can help, just as DFAT can sustain the program should these NGOs find themselves in trouble. Hold these NGOs to high standards but pay them properly.

Programs should be reviewed and evaluated, preferably independently, through an open process that builds community confidence, and changes in direction should flow from the findings of such processes. Reviews and evaluations should have regard to the goals of the program. They should provide opportunities for funded NGOs to present their cases. They should document understandings of achievements and of challenges experienced. Programs should not be funded or defunded in the absence of an overarching strategic vision for development. There should be sensible room for mistakes and the opportunity to learn from them.

But DFAT, in case you're feeling beaten down at this point, remember this. At a time when no other donor would step up, DFAT funded and nurtured three extraordinary community movements in PNG: for people with HIV, men with diverse sexualities and trans women, and sex workers. You did this for years and years, in the face of open hostility towards these communities on the part of the PNG Government, and in an environment where many Christian churches, in this most Christian of countries, were denouncing these people as sinners and as the cause of their own troubles. You helped build these organisations into viable community-based entities, in a country where this was very uncommon, and this enabled these organisations to undertake extraordinary work that saved lives. And this helped prevent PNG's epidemic from becoming the national disaster that pretty much everyone was predicting. DFAT was courageous and forward thinking and compassionate. Surely, you'd be up for another crack at that.

Annex 1

Key themes emerging from research interviews with transgenders and men with diverse sexualities in PNG, December 2015

This report is based on interviews conducted in Port Moresby in December 2015. Interviews were conducted with 29 transgenders (TG), seven men identifying as men with diverse sexualities (MDS) and one woman working with TG and MDS. Interviews were conducted in Port Moresby as part of a PhD research program being undertaken by the author.[1] This summary has been produced to reflect key themes and patterns across interviews.

In April 2016, the author held a community meeting in Port Moresby to report back on the December interviews. The meeting was tended by TG, MDS and other interested persons, including most of those who had been interviewed. This report includes feedback from community members present at the April report-back.

This document complements a summary of interviews conducted in April 2016 with people living with HIV and/or working in the HIV sector in PNG.

1. Human rights?

Interviewees were asked about human rights, and specifically what they understood these to mean. There were lots of different descriptions, some of which are set out below:

> Rights concerning every human being and the freedom of expression, freedom of choice and freedom of movement. (TG1)[2]

> You know when you ask I can't quickly see it in my head and you know for someone who has read so much and been involved in some work in Human Rights it is not easy for me to just quickly give you an answer, and I don't see the answer quickly even after having so many experiences — um, that could be the first answer. If I search through my notes in my head, it would be basic rights for everyone … for people to live and just be free, I guess. (MDS1)[3]

> I think rights is who I am, what I am, what I think of to be or to do … Nobody will say 'no it is not good you putting on your makeup, it's not good you are blow-drying your hair'. No one will say that. What I think and what I do it is a right for me for my look and for my beautification. It is me and it is part of

---

[1] Tim Leach, timleach@tpg.com.au.

[2] TG interviewee 1. All TG interviewees were assigned a number T1–T29.

[3] MDS interviewee 1. All MDS interviewees were assigned a number M1–M7.

> rights. You can’t deprive my rights as a TG or MDS of doing anything even to the extreme of having sex with a same-sex partner. It is my right. Right comes from within an individual. (T15)

> Well as a TG I understand rights as one of the important things that all persons do – rights to movement, rights to education, rights to information and all the universal rights that have been used around the world, yeah, so that’s how I understand human rights and basically rights. (T4)

> Human rights is, it’s the feeling that is given to an individual to live a happy, better life. something that is, ah, to be given to them to … have a better life free of any harm or persecution from anybody. (G23)

Interviewees were asked about whether they saw their human rights as being grounded in UN declarations or the PNG constitution or in something else. Some interviewees had a view about the source of their rights but most didn't.

> Yeah I have heard, I have heard of the Geneva Declaration and rights and human rights comes from Geneva or somewhere. (TG2)

Overall interviewees didn’t seem to be overly obsessed about the source of their rights, although interviewees were more likely to cite the constitution than any UN instrument. Interviewees are, it seems, more interested in the best ways to promote their rights. On balance, interviewees see the constitution as offering the best vehicle for promoting rights.

Interviewees who talked about their international human rights mostly saw UN declarations as unpersuasive in the PNG context. They thought Papua New Guineans unlikely to be won over to the cause by reference to things that had been done at the UN level. The constitution was considered far more meaningful for Papua New Guineans.

> Personally, it [a UN Declaration] would have no meaning. I mean we have signed up for some of the best and most stringent measures for looking after the environment, all the women’s rights, conventions we have signed up for, nothing gets enforced here and people are not being held accountable for abuse of human rights … maybe if there was some sort of enforcement and people were held accountable, there was some sort of justice, then people would know that all these conventions or where rights were springing up from are really there, so it is still abstract to us because we don’t see the actual thing being implemented, people being punished for abuse of human rights. (MDS1)

> My strength and my rights springs from my family, my roots and my culture. I have a land, I am born to a land, I stand on my land and I have a right. I am someone with a name in my tribe and for me that is the biggest thing. (MDS1)

The general view among interviewees was that most Papua New Guineans are largely uninformed when it comes to rights. Interviewees thought the constitution to have been read by very few Papua New Guineans. Still, most thought the situation was improving and that national discussion of rights was increasing.

Interviewees had learned about their rights through their involvement with Save The Children, Kapul Champions or their attendance at international events.

> I think, um, in the older days Papua New Guineans don't know what is right. What is right you know, but towards this generation where PNG is becoming more westernised, you know, getting informations, accessing new technology coming in, people are now having broader mindset of what is right and I believe that PNG is a signatory to the Human Declaration of Human Rights. I know that, so its now [that] people are beginning to see that OK within the Constitution, in our Constitution, we have our right. It is my right to vote as the man and a woman. It is my right of employment etc. it goes down. So people know that the Constitution is made out of rights, citizens their rights. How to protect themselves, how to uphold themselves in this beautiful country PNG. (TG15)

2. Rights and responsibilities

This issue came up again and again in interviews — that rights are linked with responsibilities. This raised for the interviewer the issue of the *HIV/AIDS Management and Prevention (HAMP) Act*. The *HAMP Act* is the best source of legal rights for MDS and TG in PNG (apart from the Constitution), but the legislation also talks a lot about responsibilities. It is likely that most interviewees would be familiar with the *HAMP Act*.

Some of the conversations around responsibilities left the interviewer wondering whether these 'responsibilities' might include an obligation not to be too gay or transgender.

> We try to be public figure of what we know and how much we can educate and give the people … we can't just consider our rights without, you know, we [must] be equipped with what we know with all relevant information — it's sexuality not just sex sex sex at the end of the day. That's just immature and inhuman. (TG1)

> Why am I disrespected, why haven't I achieved that far, why am I not being employed? Is my approach and my attitude towards the community good? How may I change my attitude so that they may accept me for who I am? OK in terms of employment, why am I not getting this job? Is it because of my identity or is it because I am more feminine? How will I attract this employer to employ me? Maybe next time I can go for a haircut, groom myself, dress as a man, go and sit at the interview and when at the interview let him figure my sexuality, not me expressing him telling him that this is me and this and that … You know sometimes people need to be desensitised about us being different, not us telling them that we are different. We now start looking at this — how we can change ourself when it comes to attitude. How will we behave ourselves so that we get less discriminated and less stigmatised. How can we express ourself or how can we help the community to, you know, like us for who we are. (TG16)

> Our approach should be more empathetical. We should sort of blend in with the community. It is not about forcing the issue like this is what we feel and this is what we deserve. (MDS3)

3. Are rights respected?

> The general perspective in PNG, some people are so bloody mean about this, I mean they are so mean about MDS and TG in PNG because of the way they perceive these people to be, without really understanding them. (M3)

Interviewees were asked whether they felt their rights were respected in PNG. The vast majority said that their rights were routinely violated. A small minority answered something like, 'yes and no'. No interviewee thought that his or her rights were mostly respected, and every interviewee had a story (and most had many stories) of the ways in which that person's rights were not respected.

Many interviewees talked about their right to be themselves.

> OK, as a transgender person in my own point of view is I want to be just me, an ordinary normal person, just like any other person, and to be treated equally amongst the rest of the people that are around me, especially in my community, and in the country as a whole. I just want me to be treated fairly and equally as who I am regardless of my identity and I am proud to be a transgender person. (TG2)

All interviewees talked about safety. Many said that they felt safe within their own community, but that outside of this community they were at serious risk of abuse and violence. All interviewees base decisions about where they go and how they travel with reference to these risks — market places, bus stops and PMVs were considered high risk. The right they believe to be most commonly violated is the right to freedom of movement. It is interesting that this is described in terms of the right to freedom or movement rather than, say, a right to feel safe or to be free from violence. Instead it is commonly described as a violation of their right to move around freely.

> My community accepts me for who I am and if I happen to come into the city and the general population, the attitudes towards the general population is so different where they don't really accept people like us. Some do, but the majority don't, so like in terms of my rights being respect in the general population in PNG, my rights are not respected, I am not respected at all. (TG2)

> OK, for my opinion I would like to say TG are mostly treated in a bad way … They will do all sorts of violence to you, even they going to take out a knife and you know threaten you that's how. They never treat TG properly. But as for me in community, they do understand who we are in the community but if we are to go out into the public they really [treat] us badly. (TG16)

All interviewees talked about having experienced verbal abuse, threats and violence connected with their sexuality or transgender status. Many talked of this experience as commonplace. Many reported sexual violence, and many have been raped.

> Yes it’s an everyday life thing. It’s not on a weekly basis, it’s not on a monthly basis, it happens everyday and I bet you all the TG are going through the same, its not only me. (TG2)
>
> It’s like when they look at me like a TG person just appearing in front of them they are just looking at a monster … and I am just like an object when it’s kind of like … I am kind of like a problem to them. It’s like a TG person is kind of like taking the peace away from them, so they quickly react by saying names, they are already tagging me, labelling me. (TG2)

Interviewees overwhelmingly do not trust the police to protect them. Many have been harassed, assaulted or sexually assaulted by police in connection with their sexuality/transgender status. There was no confidence among interviewees that the police would apply the law to protect them. Some had stories of having tried to get the police to assist them but to no avail. Many said that they wouldn’t bother going to the police for assistance.

> Yeah, well, in fact we all know that there is law there, there is police there, but again if I go to the police, the police won’t really take my case seriously, they will intend to try to, you know, take me to a room and interview me, but not really, you get my statements very seriously but then they will try to, you know, abuse me in the room. So that’s one thing that I get afraid of when I go to the police. I don’t go to the police to report my case when I have been punched by someone else in the street. (TG4)
>
> Ohhhh so many times, even though the both of us you are interviewing here now, we are victims of abuse by police … It is always common for TGs and MDS as well — brutality by police, security guards, any uniform person. (TG15)

At the April community report back, some participants were keen to point out that there has been some progress with the police. The work that Save The Children has done with police was acknowledged, as was the role of some police in championing the rights of MDS and TG. But there was also agreement that much more work needs to be done. The police force was the state service most complained of by interviewees, but there were also complaints about other government services.

Interviewees commonly spoke of their right to education and told stories of how their educational opportunities had been curtailed. Mostly this was because they had been harassed, assaulted and, in some cases, sexually assaulted at school, by both students and teachers. Some said their parents or families had withdrawn them from school when their sexuality or transgender status became apparent or a problem.

> We don’t get better treatment when being seen as TG and MDS, we don’t. Sometimes it will really affect our education even though we are very bright and we know that it is our goal to be a teacher, we want to be a doctor, we want to be a lawyer, but because of, you know, not accepted within the community, being rejected from the family and loved ones, these are some of the factors that make us, you know, we don’t have free access to those things and sometimes a lot of my friends, you know, get scared and being bullied at school at a younger age. That is how most of my friends dropped out from school, it’s because of this. (TG16)

Interviewees also complained of discrimination in health care, although these complaints were less common that complaints about education. Health-care-related complaints included discriminatory attitudes being expressed by nursing staff, discriminatory treatment by other patients that in some cases forced MDS and TG to give up on seeking treatment, and at least one count of being given the wrong medications allegedly because the patient was a TG.

4. Why are rights disrespected?

Interviewees had a range of views on why they were so badly treated by their fellow citizens. A common theme was that the general population did not understand them. Interviewees said that the general population saw them as going against culture:

> We came out in the picture of male, you know, and then we are trapped in the women’s whatever and then, like, why some of the men usually get mad with us, we are spoiling the image of a man. That’s what I’m thinking of, you know, that some of them initially think — sometimes I heard from men calling to me, spoiling this image is not good, you know. (TG15)

Some interviewees saw PNG culture and history as inclusive of MDS and TG. Some interviewees thought that the *hausman* tradition had probably accommodated some homosexual behaviour. Others thought that MDS and TG had always been a part of PNG culture, at least in some parts of the country. Several interviewees cautioned against generalising about the history of homosexuality and transgenderism in PNG, noting that PNG is an incredibly diverse country and what had been acceptable in some parts may have been taboo in others.

> I think for me, looking back, I mean in my time growing up being a TG person I think … most of my community base a problem on culture and customs, that is the most important thing because, not all of PNG, I mean respective provinces, have their own culture, some they accept TG people, some they don’t … Certain culture in the country, for instance the Papuan Region, they do have a lot of respect on TG and MDS people … but as for New Guinea Highlanders it’s a big no and it’s a bit taboo. So, most of my friends TG and MDS they are still in their hidden clothes, if I may say, they don’t really come out. (TG15)

> MDS and TG have always existed in PNG. They have always been included in every aspect of our society. I don't care how many other anthropologists or historians come and done research, I believe we have always existed … people in our villages all over PNG they have always known that there are homosexuals, and they take them on, and they just leave them just like that. (MDS1)

At the April community report back, different people expressed different views on this topic. But there was general agreement that many people in PNG would resist the idea that traditional society in any way accommodated homosexual or transgender behaviour. Participants agreed that these conversations would need to be approached very carefully.

There were different views among interviewees on the role of the Christian Church in shaping attitudes towards MDS and TG. The Christian value of tolerance was said to have encouraged acceptance. The counter view was also expressed — that Christian missionaries had undermined traditional acceptance of TG and MDS and taught communities to think of TG and MDS as sinful.

> We don't accept this, you are a man you get married to a woman, we don't encourage you to have sex with another man. In our Christian belief, you are a man, you are supposed to get married to a woman, you are supposed to have a relationship with a woman, not a man — you are a man. (TG2)

> Broadly let me just say PNG is … known generally as a *Christian* country so when you say, I mean you are trying to look at MDS and TG … when you bring this subject up to any general Papua New Guinean they will think, Oh, what's this, why do we have to recognise them, which way are their rights being abused — I mean — are these really people? (MDS3)

Even though all interviewees agreed that MDS and TG experience high levels of discrimination, some thought there might still be some recognition that TGs are special.

> People begin to see that these people, that are more unique, they are more treasured — why I am saying this is because people begin to see that OK, even though he is different but he can cook, he can do all the chores in the house. (TG15)

> If we are to go to the garden, especially the ladies call us, they usually call us to go and help them go clean their garden and they usually say that these people are much faster than the ladies. They can, you know, finish this garden by two or three hours rather than the women, you know, and also we attract people to come for these Christmas events or whatever or dance or creative dance, especially Pacific Dance. People like us usually pull the crowd to come and enjoy the Christmas Eve. (TG16)

> TGs are flexible in everything, like I said, they are kind of like public figures, you know, they … have this, 'I don't care, I don't care who calls me names,' you know. I am not bothered by your comments, I am who I am. (TG2)

5. Bringing about change

Whatever the reasons behind community rejection, interviewees believed these problems could be overcome over time, provided that certain things were done. A common theme was that MDS and TG (and Kapul Champions) would need to be proactive, otherwise things would not change. Lots of interviewees said that the best way to promote greater acceptance was for MDS and TG to get out and visibly contribute to their communities — through church activities or by other means. This was consistent with the 'rights and responsibilities' theme. To the interviewer, it did feel a bit like having to work a little harder to buy acceptance.

> I had to tell all my fellow TG back in my village, you know, that for us to gain respect we have to engage ourselves in community activities, the church activities, so that is what happened. It took a while for us to gain that respect back from the community, we get pushed away and we kept going in and getting ourselves involved and, like now, the reaction and behaviour of the community has changed totally that they really accept us well as to who we are. (TG2)

Some interviewees were critical of the way that some of their colleagues behaved. This behaviour was described in different ways — talking about sex all the time, inappropriate dressing, being too promiscuous. It was suggested this worked against community acceptance. The interviewer found this very interesting — again the line seems to be that the community can only be expected to tolerate diversity within reason and provided MDS and TG otherwise behave. The interviewer was alert for any hint of the lateral violence so commonly seen in marginalised communities. By and large, however, criticisms of fellow community members tended to be very considered and motivated by a genuine desire for community advancement.

> The difference I see with fellow members of my MDS community is that there is generally a lack of responsibility and respect for people. We push too much our agenda. We don't have to be entirely 100% entirely gay and scream and shout, 'We are women,' and all of that. We can be effeminate in our villages, in our home, but, you know, just tone it down and be respectful. And our sexual exploits also doesn't help. We do it without discretion, it doesn't help, it just gives people the wrong idea … I wouldn't call it hate, it's just disrespect … The strategies we are using are wrong … the strategies should be around talking about the responsibilities and around conforming. Conforming doesn't mean you are losing your identity. (MDS1)

> Our approach should be more connecting with the people down to the grass roots level … because that will give you strong support for you to build your credibility or your advocacy … coming from the top would sort of be creating uneasiness in people's minds. (MDS3)

6. The future and Kapul Champions

Interviewees were very supportive of the work of Kapul Champions. Most were involved in the organisation in some way, or knew people who were, or were at least members. All felt represented by the organisation. On one analysis, perhaps it was predictable that the reviews would be positive, given that interviewees were mostly reached via Kapul Champions staff and board members. Yet it has been the interviewer's experience that marginalised communities are often very critical of their representative bodies, as these structures are often burdened by expectation and riven by competitiveness and infighting. Overall, the interviewer was a little surprised that the feedback was so positive.

> When I first heard about KC I said. 'This is it, this is about time we had an organisation that stands up for all … TG and MDS,' because a lot of us in this country really have a lot of stigma because of shame, lots of violence against the TG. Many of my good friends have been raped and have been the victims of HIV and have passed away. I am very happy because KC has really made this an organisation for all of us to come together and to put our voice as one, we need to speak out and tell the whole world that we are here to stay. (TG4)

> So far KC have now been established as an organisation and becoming a strong foundation and the voice for TG and MDS people in PNG. We have seen that so many of our friends have now come out. We have seen that so many of our friends are really expressing themselves, especially communication-wise and we have KC also created a Facebook page where members go in to give their views or their comments, so if they have problems what are the favourable pathways they can take if KC can help. These are some of the things members posted so we help each other along the way. Now we can see that light. Before I was thinking I am the only feminine one here in PNG, there is no one else, but because of KC I am now saying to myself 'I am proud of who I am because I am not alone'. (TG16)

Interviews were held against a backdrop of massive DFAT funding cuts to Kapul Champions and a relocation of Kapul Champions so that it will now sit 'within' Save The Children. The exact nature of the new relationship remains unclear, but it seems likely that Kapul Champions will lose some independence. Most interviewees had good things to say about Save The Children in PNG, and Save The Children was, of course, the first agency to work in a respectful and supportive way with MDS and TG in PNG. But interviewees still expressed concerns about the new dynamic.

> No, I wouldn't want that. One — Kapul Champions would lose its identity as a — you know, it's a national network for homosexuals, or gay men and MDS in PNG. It will lose that and it will make it difficult for those outside [of Port Moresby] to feel connected to it because they wouldn't want to be connected to Save the Children. (MDS1)

> The difference that I see is, [Save The Children] is a service provider, they help MDS and TG with facilities for HIV testing, STI checks and roll out of ART and they have programs that go out into the community to do outreach, to do peer to peer outreach to give out information on STI and HIV. With Kapul, it is an advocacy organisation and what Kapul does is to advocate at different levels and using different methods to get the message across to everyone, about the rights of a TG person or a male with diverse sexuality. (TG23)

Interviewees want Kapul Champions to continue to advocate around human rights. The overwhelming majority of interviewees hold this view. A minority want Kapul Champions to refocus away from advocacy and rights and towards education. This educative role would see Kapul Champions explaining to the general PNG population that MDS and TG are ‘just like them’. These different views reflect the live debate about the ‘responsibilities’ of MDS and TG to fit in and avoid confronting their fellow citizens.

Interviewees were aware of the risks of corruption within Kapul Champions. They had seen other CBOs and NGOs struggle to manage corruption. The best defence against this was seen to be a large and diverse membership, actively engaged in the scrutiny of the organisation’s performance. Good policies were also cited as important preventative tools.

7. MDS and TG — one community or two different groups?

The interviewer asked about the degree to which MDS and TG were part of a single community. Kapul Champions represents both, but they are also quite different.

Interviewees agreed that the MDS/TG movement is mostly comprised of TG. They agreed that this was because TG had no choice about being openly TG — it was not something they could hide — whereas MDS could and mostly did hide their sexual behaviour.

> When you really come and say, I am gay, you sort of lose that respect of identity quickly in this instant … Compared to TG … They dress like women they talk like women so there is no big deal [but] most of the MDS won’t come out in public because they feel sort of insecure … you sort of lose that power that men have … TG are more open because men sort of accept them — everybody accepts them in a way. (M3)

The interviewer wondered if this left TG feeling a little annoyed that they receive so little support from their MDS brothers, but this seems not to be the case. Mostly interviewees were concerned about how Kapul Champions could attract more MDS members, and a few noted that there are some very prominent and capable MDS whose membership would add significantly to the standing and capacity of Kapul Champions. It still seems to the interviewer that the distinction between TG and MDS remains in many cases blurred, or perhaps it moves backwards and forwards. Some interviewees think the indicator of a TG is that she is the passive partner in anal sex.

The general view among interviewees was clearly that TG and MDS should continue to work together to promote their rights. Interviewees were keen to explore strategies for engaging more MDS in the work of Kapul Champions.

Annex 2

Key themes arising from interviews with PLHIV, April 2016

This report is based on interviews conducted in Port Moresby with 20 Papua New Guineans living with HIV (PLHIV) and three people who work with PLHIV. Interviews were conducted in April 2016 as part of a PhD research program being undertaken by the author.[1] This summary has been produced to reflect key themes and patterns across interviews.

This document complements a summary of interviews conducted in December 2015 with men with diverse sexualities and transgenders.

This report outlines the following key themes:

1. Life has improved for PLHIV;
2. PLHIV still experience stigma and discrimination, and in multiple forms;
3. The improvements reported for PLHIV are relative and not uniform;
4. Adherence is a critical issue, and is intimately connected with stigma and discrimination;
5. There is an issue of class;
6. Igat Hope has definitely helped, but it has also disappointed;
7. There is an understanding of rights amongst PLHIV;
8. Peer connection is very highly valued.

1. Life has improved for PLHIV

The phrase 'stigma and discrimination' has meaning for PLHIV.

Almost every interviewee used the phrase 'stigma and discrimination', mostly to describe adverse experiences linked to being HIV-positive. This is a phrase commonly used in Australian and international HIV discourse, and often by PLHIV organisations. Interviewees often used stigma and discrimination as the measure for determining whether or not their human rights are protected. It was used as the key measure for describing changes in community attitudes.

Interviewees overwhelmingly reported that life for PLHIV in PNG has improved. They generally agreed that stigma and discrimination towards PLHIV has reduced, but there was consensus that these improvements have been limited to urban areas such as Port Moresby.

> 2006 when I was first diagnosed, that was like, how many years ago, more than 10 years ago, it has changed a lot maybe because I am open about my status now and everybody has accepted that I am a person living with HIV. Back then HIV was new in the country so stigma and discrimination was very high but now it's like just another ordinary or common illness or, it's no-one seems to point fingers as

---

[1] Tim Leach, timleach@tpg.com.au.

> much as they do back 10 years ago. I'm just one ordinary woman just walking up and down the streets trying to make ends meet. No one sees me as a woman living with HIV anymore. (A1)

Interviewees generally agreed that there were two main reasons for this improvement in urban areas. First and foremost people said that HIV treatments had contributed to changed attitudes among the general population. The health of PLHIV on treatments had *visibly* improved, so communities no longer feared HIV as a killer disease and instead had begun to see HIV as a manageable illness. PLHIV were no longer seen as posing a risk to the lives of others and fear of PLHIV had subsequently reduced.

The second reason for reduced stigma and discrimination, according to interviewees, was increased understanding around transmission. As people had come to understand that HIV could not be spread via casual contact, fear of contact with PLHIV had reduced, as had related efforts to exclude PLHIV from families and communities.

> Back then we didn't have much information especially our families they didn't know how to take care of us when we were sick and down. They were all scared because they thought that HIV — you could get it just sitting next to a person just eating or whatever, they just didn't have that information and why they were all scared and they didn't want to, so most times like when I was stigma and discriminated, like I was thrown out of the house, put under the house. (A1)

Interviewees considered these improvements in understanding of transmission to be the result of combined efforts on the part of NGOs and CSOs active in Port Moresby and other urban areas. Interviewees thought that advocacy by PLHIV, particularly in being public about their condition and showing the human face of the virus, had been enormously helpful.

> That [improvement] results from people living with HIV having engaged and being involved in public speaking and coming out and running trainings, just speaking publicly on media on what HIV is and what they live with it and living a positive life — that is with treatment. (A19)

2. PLHIV still experience stigma and discrimination, and in multiple forms

In talking about stigma and discrimination, two other points were repeatedly made. Firstly, although things have improved, stigma and discrimination remain realities for PLHIV. And secondly, outside of POM, stigma and discrimination levels remain very high – possibly as high as at any time in the past.

Interviewees consistently described the discrimination they experienced as having the following dimensions: self-stigma, family rejection, village/community discrimination and general-population discrimination.

In terms of self-stigma, many interviewees described this as a phenomena by which people with HIV, often lacking knowledge of the virus, its transmission and treatments options, cut themselves off from family and community to avoid the shaming and rejection they anticipate. This was said to have disastrous results for PLHIV as it caused them to deny themselves access to the life-saving treatments and other supports that they require. It was said to contribute to loneliness, despair and suicidal thoughts. Many PLHV were said to have died as a result of self-stigma.

Many PLHIV described having experienced rejection by family. This was said to result from fear of infection and the shame family members felt by being linked with HIV. The fear was grounded in misunderstanding of transmission risks and a lack of awareness that HIV need no longer be a death sentence. The shame was linked with the sexual nature of transmission, with sex being an uncomfortable topic for public conversation, and transmission being associated with promiscuity, adultery and sex work. Female PLHIV in particular were likely to be pejoratively described as sex workers, whether or not this was actually the case. Family rejection involved refusal by family members to share food, plates or beds with PLHIV. In many cases it involved being ejected from the family home, often with disastrous outcomes for people with no other accommodation or support options.

> Oh, it's happening in the house as well. In their own communities, in the places they live around with people. Name-calling, you know, disowning that person, you know, pushing away from the family, not housing them, thrown out of the house. (A3)

Community discrimination was often described as 'gossiping', but sounded more like exclusion and prejudice expressed towards PLHIV and their families. Refusal to share food, cutting off contact, name calling of PLHIV and their families and talking about PLHIV (spreading information about their status) were commonly reported.

> In churches that you know women try to assist in — you know, we have Melanesian culture, so if there is a big gathering there is food and ladies stand on the table and prepare food and I've seen and noticed and experienced — 'Oh its alright, you don't touch that food,' … its another form of stigma. (A19)

Interviewees also reported stigma and discrimination directed by communities towards their children.

Beyond this, interviewees tended not to report discrimination in other areas of life. It was not generally reported in relation to employment, although two interviewees did report work-related discrimination. It is worth noting that few interviewees were formally employed and, of those who are employed, most work in the HIV sector where HIV-related discrimination would presumably be limited.

Several interviewees reported discrimination in health care settings, although it is perhaps surprising that reports of such discrimination were so few. It is worth noting that many interviewees were in some way or another connected to Igat Hope, so it is reasonable to assume they would be disproportionately likely to be aware of their rights and more capable advocates than the average PLHIV in POM. Perhaps this means they were less easy targets for discrimination.

Discrimination in health care settings does continue, however. Interviewees reported that this discrimination took different forms, including delaying or rushing appointments with PLHIV and judgemental attitudes. Interviewees also reported that PLHIV experience hostile looks and criticisms from other patients, creating yet another barrier to health care.

Several interviewees noted that HIV-positive members of particularly vulnerable populations, including women, MDS and TG, often experience double discrimination.

> The example I gave earlier on — she is a young sex worker and she has got HIV, like there was a kind of a blame given to her — like it's your fault, you were out there partying and bringing in different men so that's what you face. I think it's a level of a different category we come under. If I am a heterosexual and I am HIV positive the discrimination level will be different while an MSM and TG and female sex worker will face a different level of discrimination. (A19)

3. The improvements reported for PLHIV are relative and not uniform

As noted, there was a common view among interviewees that the past had been much harder for PLHIV than the present. Interviewees did not always say when the changes occurred, but the advent of ART was seen as a game changer.

Interviewees also saw distinctions between urban areas like Port Moresby and the rest of PNG.

Many interviewees had stories of people in times past having being murdered because of their HIV status. While these incidents were reported as having occurred in the past, the view that life has not changed for PLHIV outside of urban areas begs the question of what might be happening now for PLHIV in rural areas.

And despite the fact that most people considered life to have improved for PLHIV in urban areas, many interviewees also had recent or current horror stories of gross rights violations. For the interviewer, this seemed a little contradictory and raised the question as to whether, in assessing current levels of stigma and discrimination by reference to past levels, an overly positive contemporary picture might be being presented.

Although stigma and discrimination were said to have reduced, many interviewees said they still carefully controlled information about their status — it is shared with some people and not others (including others within the family). A positive diagnosis was still seen as something about which people would be likely to gossip. Again, this is consistent with a continuing prejudice against PLHIV.

And finally, while the vast majority of interviewees said that stigma and discrimination had reduced, several disputed this proposition. One thought it to be on the rise again, as a result of a combination of factors including reduced funding, declining national media coverage, reduced outputs from Igat Hope and a general failure on the part of the national AIDS Council and its secretariat.

Concerns such as these seem to underscore the fragility of gains for PLHIV. In the absence of a properly funded and supported HIV response in PNG, what might happen for PLHIV? Several interviewees expressed a note of caution that improvements in community attitudes should not be take for granted; progress could be reversed.

4. Adherence is a critical issue, and intimately connected with stigma and discrimination

Interviewees spoke of the challenges involved in encouraging adherence to HIV treatments regimens in PNG. Many reasons were proffered to explain the lack of compliance and many of these related to stigma and discrimination. Self-stigma, family and community rejection were all cited as key reasons that PLHIV don't take their treatments as required.

Other factors, such as being unemployed and poor were also recognised as undermining adherence. Interviewees noted that adherence is facilitated by good nutrition, getting enough sleep, living a healthy lifestyle etc. PLHIV who were without income and living in poverty could not live healthy lifestyles. Several interviewees observed that poverty brings its own set of stigmas and discrimination, further undermining adherence efforts.

> We have free supplement of ART and this is a well-done job by the government but we have not been subsidised in terms of employment and that is one of the need area that I always like to address in a public debate with the government … if I am given my chance I will put my hands up to say create some job opportunities for the PLHIV so that this job opportunity their income to help support them to take medication on time with food and they will be happy, living happy, living positively in happy lifestyle will sustain and expand the lifespan of PLHIV in this country. (A4)

Geography, and its impact on stigma and discrimination, was also a factor.

> Yes, for people living in Port Moresby treatment is very easy to get. Unlike people from other provinces there is still stigma and discrimination which is making and affecting them not bringing them to where they are supposed to get their medicines. (A2)

> Being in Port Moresby it's like a privilege because they have the medication around in Moresby itself. If it's in other provinces there's expenses involved to travel in and out of the districts. Being in

> Moresby is a privilege and we have many people working with different organisations that we can go to and ask for advice. (A3)

Several PLHIV complained of clinics scolding PLHIV regarding adherence, failing to acknowledge the many factors that impact on adherence such as poverty and family/community support.

> I'm involved in the clinics and when the peers come in to be treated or to get treatment, the facial reaction. They are not counselled well … counsellors should be trained not to give their point of view … Some of the counsellors tell us to leave whatever activity we are doing and get on with … life like them [but] they are not there to tell us what to do. (A3)

5. There is an issue of class — poverty and literacy are seen as shaping the experience of being HIV-positive

Many interviewees raised the issue of class. People who were illiterate and people from the settlements were said to have less understanding of HIV and to be more likely to discriminate against PLHIV. This is consistent with a view common among interviewees that knowledge of transmission and treatments is key to reducing discrimination, and a view that illiteracy and poverty are barriers to this knowledge.

> Why I say they have less information is because most of them are actually from the villages coming into the city and they are illiterate so if some of them, most of them don't read and write too. That's if you go into settlements and shanty places you will realise that most of the people are illiterate so if you ask them about HIV they are not really sure but they only know that it's a killer disease, that's what they will tell you. But about information on [how] to protect themselves and how to take care of themselves when they are infected, they are not really sure about there. (A2)

A contrary view was also expressed, that people living in settlements were *less* likely to gossip about PLHIV or discriminate against them, as they were too busy just trying to survive. Gossiping and discriminating were luxuries that could be better afforded by those with employment, it was suggested.

Several interviewees observed that Igat Hope members are disproportionately poorer and without formal employment. The term 'lower class' was used. Such people were said to have less to lose by being associated with HIV (for example, they don't have jobs to lose or positions of authority that might be jeopardised). They were also said to be more in need of supports and assistance so more likely to seek these out from Igat Hope, although such assistance was in fact often not provided.

The old tension between Igat Hope as advocacy organisation and Igat Hope as service provider seems unresolved. This tension has dogged Igat Hope for much of its life with many members wanting it to provide direct supports (money for food, medicines or funerals), while the organisation's constitution and its funders have envisaged an advocacy agency. Many interviewees wanted Igat Hope to provide the very supports its constitution and funding agreements bar it from providing.

6. Igat Hope has definitely helped, but has also disappointed

Interviewees agreed that Igat Hope has achieved a great deal, particularly in terms of reaching out to the provinces and supporting provincial PLHIV responses, treatments advocacy, promoting an understanding of human rights and articulating these rights as relevant to PLHIV, and in being a voice and a face for PLHIV. Igat Hope was said to have succeeded in carving out a place for itself within the national HIV response — a place at the table.

> I think one of the changes is with many of the people who have been involved in [Igat Hope] for a period of time, they are increasingly understanding the hook of Human Rights … I've seen a lot of people shift from just an angry, you know, look after me kind of attitude to a — no wait a minute I have Rights, you need to respect me when I come to the clinic, you need to ensure that I have my medication, you need to … that's not the experience everywhere but it is changing and it's you know, it's something that wasn't there a few years ago. That's now increasingly there so I think [Igat Hope is] understanding the value and power of using Rights, understanding the importance of the law, understanding the importance of ensuring that State actors respects the Rights and the laws and demanding them — insisting on them being provided. (A23)

> IGAT Hope is a leading organisation in PNG which has been the face of people living with HIV, been the voice of people living with HIV and IGAT Hope has very good objectives, vision on how to carry advocacy in PNG in all levels I'll say, and we have done well throughout PNG. (A19)

Igat Hope was observed to have helped individuals. It had helped PLHIV connect with each other and this was seen by many interviewees to have been extremely valuable — the value of peer connection was repeatedly observed. Igat Hope had also helped many PLHIV gain confidence.

> I never came out in telling people about who I was until I joined the organisation and then that gave me confidence in coming out and now I don't feel afraid of talking about HIV and telling people how to look after themselves. (A2)

But there was also general agreement that Igat Hope has failed to deliver in recent years. Interviewees said responsibility for this failure was shared by staff and Boards. There was also a view that funding issues (delays and reductions in funding) had contributed to the organisation's troubles, although most interviewees pinned the organisation's problems on its people rather than external factors.

Importantly, there is strong support for Igat Hope to continue. The model of a representative organisation for PLHIV retains widespread support among interviewees. It was seen as still being a critical part of the national HIV architecture:

> IGAT Hope is from the Government level to the donor level. They are recognised and IGAT Hope is the national PLHIV network in PNG. Without IGAT Hope you can't make any policy, without IGAT Hope you can't make any decision, without IGAT Hope you can't change the HIV infections. (A4)

When talking about failures on the part of Igat Hope, described by some as involving corruption, interviewees nominated a range of strategies for preventing such practices in the future. These included having advisers to the Board and clear criteria for Board eligibility, clear governance rules and ongoing training around governance. Interviewees often talked about the need for Board members and staff to have the right attitude and be motivated by a commitment to PLHIV rights, but there were few specific strategies for ensuring this outcome.

> People are having this mentality of their funds are coming from the donor agencies so its free money, that's what they have in their mind. So we can use it, even if we are doing HIV work or not, we can just use it. (A2)

There was a general agreement among interviewees that interest in HIV nationally is on the wane. Whereas HIV had previously been much covered in national media and funding had been relatively easy to come by, things had changed. Many interviewees expressed concern about reduced funding of HIV and falling levels of public interest in the epidemic. These interviewees observed that while there had been advances in the national response, there remained much work to do, especially outside Port Moresby. They believed that an effective response would require *more* money, not less. There was concern about PLHIV not being seen as a Most-At-Risk-Population (MARP). Several interviewees noted that the national response was being rapidly reoriented to focus on MARPs rather than the general population, but if PLHIV are not seen as a group at risk, they said, then the future of Igat Hope was at risk.

These views indicated to the interviewer a solid grasp of the bigger picture. Many interviewees were able to look beyond what Igat Hope could deliver for them personally; they were able to see the organisation within the context of shifting national priorities.

Interviewees had plenty of suggestions for Igat Hope work, including promoting adherence programs though all ART clinics, working to reduce stigma and discrimination, working on ensuring access to new drug options, and connecting PLHIV to each other.

Igat Hope was seen to have achieved significant success in building provincial-level PLHIV groups, but it had failed to continue this support. Igat Hope was strongly encouraged to rebuild its support for these groups.

7. There is an understanding of rights amongst PLHIV

> My right to go to school. My right to medication. My right to go to hospital. My right to go marketing. My right to hop on the bus. My right to come for a meeting. My right to access office, for seeking application for jobs. My right to report my case to the police station. My rights to, you know, put my contribution in public speaking in a leadership role. (A4)

> Accessibility of services. People have rights despite their status or disabilities or whatever, we all have rights to accessing services, either our rights to be employed, our rights to be served at hospitals. We have rights like every other human beings. (A2)

Interviewees generally expressed a basic awareness that they possessed rights that were supposed to be respected. Most interviewees struggled to suggest the sources of their rights, but this seemed not to be much of an issue for them.

> I wonder if you were asking the same question in Australia or New Zealand if the majority of people would actually give you a good answer as to where their Rights come from. The best hook here … is certainly the Constitution because it is very clear in stating the rights that a Papua New Guinean can expect. Is the average Papua New Guinean aware of what is in the Constitution, no, not likely, but most people in most countries probably aren’t either. (A23)

PLHIV interviewees were more likely than their MDS/TG counterparts to speak of rights in terms of treatments (rights to treatments, to care). Interviewees also mentioned the right to live free from stigma and discrimination, the right to work, to access services despite HIV, to control information about their status, to seek legal redress, to be employed, to get married and to have children, to go to school, to have sex.

As noted, interviewees tended to talk of their human rights violations in terms of their experiences of stigma and discrimination.

The HIV/AIDS Management and Prevention Act was mentioned a few times as a means of protection, but people have had mixed experiences in their efforts to pursue remedies.

As was common with their MDS/TG counterparts, several interviewees saw a link between their rights and their responsibilities. Access to treatments was often described as a right, but several interviewees also said PLHIV had a responsibility to take their treatments. A PLHIV’s legal responsibility to not knowingly pass on the virus was also mentioned.

> A sex worker has the Rights to maybe sell sex — maybe that's what she believes in but it's also the partner's responsibility to use condom. The same as discordant couple. If I am a woman who has a diagnosis negative it's not only my responsibility to talk about condom, it's my responsibility that I have to think about my partner's responsibility to also have condom … there is a law that if now you are here getting HIV status, and getting HIV status you are now responsible, that you are not supposed to pass HIV virus to another person and if you do so, then this law will get you, so. (A6)

8. Peer connection is very highly valued

Interviewees observed that peer supports and connections had been valuable, and that they remained so. Drop-in centres for PLHIV had been important sources of peer connection for many interviewees. Igat Hope has also facilitated connection with peers and its work in doing this for PLHIV in the provinces was considered especially important. There was strong support for Igat Hope continuing to do this work.

Igat Hope's program of providing expert patient trainers (peer workers) in ART clinics was spoken of very favourably and there was support for an expansion of this work. Peer knowledge and understanding were seen as critical to supporting PLHIV adherence. Peer connection was described as having built the capacity of individual PLHIV to face the challenges of being HIV-positive in PNG. In this sense it was seen as helping PLHIV to assert their rights and to better cope with situations in which their rights were not respected.

There was also support for ensuring that peer knowledge was a factor in informing Igat Hope's decisions about who should be employed and from whom to obtain technical advice and support.

May 2016

Acronyms

ACON	A Community-Based HIV Organisation in Sydney, formerly the AIDS Council of New South Wales
AFAO	Australian Federation of AIDS Organisations, the national peak organisation representing the community HIV response
AHAPI	AusAID HIV/AIDS Partnership Initiative
ARV/ART	Antiretroviral Therapy/ies, being drugs that prevent disease progression in people with HIV by reducing the amount of virus in the body
AIDS	Aquire Immunodefficiency Syndrome, a chronic, potentially life-threatening illness caused by HIV
APN+	Asia Pacific Newtork of People Living With HIV, a regional association of national PLHIV organisations
AusAID	Australian Agency for International Development, absorbed into the Australian Department of Foreign Affairs and Trade in 2013
CBO	Community-Based Organisation
CEDAW	Convention on the Elimination of all Forms of Discrimination Against Women
CHPNG	Collaboration for Health in Papua New Guinea
DFAT	Department of Foreign Affairs and Trade
DLA	Australian Development Law Association, an organisation that for a while provided free legal services to people in Port Moresby impacted by HIV
FHI360	A not-for-profit development organisation, formerly known as Family Health International
FIFO	Fly In/Fly Out – the practice of development (or other) workers flying in and out of a community to undertake work or deliver services, but living elsewhere. In the context of this thesis, FIFO development workers may fly in and out of Papua New Guinea but live elsewhere, most commonly in Australia or New Zealand
HIV	Human Immunodeficiency Virus, the virus that causes AIDS
GIPA	Greater Involvement of People Living With HIV/AIDS, a principle recognising the right of people living with HIV to be involved in decisions that affect their lives
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICPD	International Conference on Population and Development
IDS	Institute of Development Studies, an independent research institute and think tank associated with the University of Sussex
IDLO	International Development Law Organization, the parent body of PNG Development Law Association
IPA	Investment Promotion Authority
KAP	Key Affected Population
KC	Kapul Champions

LDG	Leadership Development Group, the group that evolved into Kapul Champions
MARP	Most-At-Risk Population
MDS	Man or Men with Diverse Sexuality/ies
MoH	PNG Ministry of Health
MSM	Man/Men who have Sex with Men
NAC	National AIDS Council (of PNG)
NACS	National AIDS Council Secretariat (secretariat to the National AIDS Council)
NAPWHA	National Association of People With HIV Australia
NCD	National Capital District, the area around Port Moresby
NGO	Non-Government Organisation
PLHA	Person or People Living with AIDS (now mostly superseded by PLHIV)
PLHIV	Person or People Living with HIV
PMV	Public Motor Vehicle, privately owned minivans providing transport around Papau New Guinea on a fee-for-service basis
PNG	Papua New Guinea
POM	Port Moresby
PPF	PNG partnership Fund
PrEP	Pre-exposure Prophylaxis
PSP	Poro Sapot Project, a project of Save The Children in PNG targeting men with diverse sexualities and sex workers
SARV	Sorcery Accusation Related Violence
STI	Sexually Transmissible Infection
Trans/TG	Transgender person, being a person born with the physical characteristics of one sex but living/identifying as a member of the other
UDHR	Universal Declaration of Human Rights
UN	United Nations
UNGASS	United Nations General Assembly Special Session
WABHA	Women Affected By HIV/AIDS, a Port Morseby-based group for women living with HIV
WHO	World Health Organization

Glossary

Pidgin English/Papua New Guinean languages

askan	arse cunt, derogatory term for.
disko meri	generally derogative term used to describe women alleged to be engaged in sex work or sex for favours.
geligeli/girly girl	girl-like, often used derogatorily to describe transgender women
kekeni	local language term for girl/woman, used to describe trans women or mem with diverse sexualities engaging in sex with men.
man stret	heterosexual man.
manmeri	man-woman, term used to describe transgender women, and sometimes men with diverse sexuality.
meri stret	heterosexual woman.
palo/palopa	colloquial term for transgender women, and sometimes men with diverse sexuality.
poro/poroman	companion or friend
sapot	support
vavine	local language term for girl/woman, used to describe trans women or mem with diverse sexualities engaging in sex with men.
wantok/s	literally 'one language', term used to describe members of the same family or clan or community.

Other

hizra	term used across the Indian sub-continent to refer to eunuchs, intersex people and transgender people.
kothis	term used across the Indian sub-continent to describe young men who sell sex, generally to other men; kothis may present as effeminate men, often taking on receptive sexual role in a same sex relationship.

Bibliography

Adler, Patricia A, and Peter Adler. 1987. *Membership Roles in Field Research*. Newbury Park, CA: Sage, doi: 10.4135/9781412984973.

Alexeyeff, Kalissa and Niko Besnier. 2014. 'Gender on the edge: Identities, politics, transformations.' In Niko Besnier and Kalissa Alexeyeff (eds). *Gender on the Edge: Transgender, Gay, and Other Pacific Islanders*. Honolulu: University of Hawai'i Press: 1–26, doi: 10.21313/hawaii/9780824838829.003.0001.

Altman, Denis, and Jonathan Symons. 2016. *Queer Wars.* Cambridge: Polity Press.

Amon, Joseph J., and Nina Sun. 2019. 'HIV, human rights and the last mile.' *Journal of the International AIDS Society* 22(12): e25434, doi: 10.1002/jia2.25434.

Australian Human Rights Commission. N.d. 'Human rights and people with disability.' Viewed on 2 Jan. 2021 at: humanrights.gov.au/sites/default/files/content/letstalkaboutrights/downloads/HRA_disability.pdf.

Beijing Declaration and Platform for Action. 1995. UN Women. Fourth World Conference on Women. Viewed on 2 Jan. 2021 at: www.un.org/womenwatch/daw/beijing/pdf/BDPfA%20E.pdf.

Biehl, João. 2009. *Will to Live: AIDS Therapies and the Politics of Survival.* Princeton, NJ: Princeton University Press.

Biersack, Aletta. 2016. 'Human rights work in Papua New Guineas, Fiji and Vanuatu.' In Aletta Biersack, Margaret Jolly and Martha Macintyre (eds). *Gender Violence & Human Rights: Seeking Justice in Fiji, Papua New Guinea & Vanuatu.* Canberra: ANU Press, 271–339, doi: 10.22459/GVHR.12.2016.07.

Bishop, Julie, MP. The Hon. 2013. Address to ACFID Chairs and CEOs, speech 30 October 2013. View on 25 Jan. 2021 at: www.foreignminister.gov.au/minister/julie-bishop/speech/address-acfid-chairs-and-ceos-dinner.

Boellstorff, Tom. 2011. 'But do not identify as gay: A proleptic genealogy of the MSM category.' *Cultural Anthropology* 26(2): 287–312, doi: 10.1111/j.1548-1360.2011.01100.x.

Bonner, Ann, and Gerda Tolhurst. 2002. 'Insider-outsider perspectives of participant observation.' *Nurse Researcher* 9(4): 7–19, doi: 10.7748/nr2002.07.9.4.7.c6194.

Boyce, Paul, and akshay khanna. 2011. 'Rights and representations: Querying the male-to-male sexual subject in India.' *Culture, Health and Sexuality* 13(1): 89–100, doi: 10.1080/13691058.2010.515317.

Breen, Lauren J. 2007. 'The researcher "in the middle": Negotiating the insider/outsider dichotomy.' *The Australian Community Psychologist* 19(1): 163–74.

Brown, Julia. 2018. 'Invisible lines, sacrificial children and touchy subjects: Ethics in psychiatric anthropology.' *The Familiar Strange,* 8 February. Viewed on 24 Jan. 2021 at: thefamiliarstrange.com/2018/02/08/ethics-in-psychiatric-anthropology/.

Brunton, Brian D. 2001. 'Human Rights 1996.' In Anthony J. Regan, Owen Jessep and Eric L. Kwa (eds). *Twenty Years of the Papua New Guinea Constitution.* Sydney: Lawbook Company, 305–13.

Butt, Leslie, and Richard Eves (eds). 2008. *Making Sense of AIDS. Culture, Sexuality, and Power in Melanesia*. Honolulu: University of Hawai'i Press, doi: 10.21313/hawaii/9780824831936.001.0001.

Cameron, Sally, and John Rule (eds). 2009. *The Criminalisation of HIV Transmission in Australia: Legality, Morality and Reality.* Sydney: National Association of People Living With HIV/AIDS Australia (NAPWHA).

Cameron, Sally, Edwin J. Bernard, Lisa Power and Yusuf Azad. 2009. 'International trends towards the criminalisation of HIV transmission UK, New Zealand and Canada: Laws, cases and response'. In Sally Cameron and John Rule (eds), *The Criminalisation of HIV Transmission in Australia: Legality, Morality and Reality,* Sydney: National Association of People Living With HIV/AIDS Australia (NAPWHA), 32–46.

Cancian, Francesca M. 1993. 'Conflicts between activist research and academic success: participatory research and alternative strategies.' *The American Sociologist* 24(1): 92–160, doi: 10.1007/BF02691947.

Carlson, Cindy, Emily Claire Rudland, Katherine Lepani and Marjorie Andrew. 2012. *Responding to Crisis: Evaluation of the Australian AID Program's Contribution to the National HIV Response in Papua New Guinea, 2006–2010.* AusAID Office of Development Effectiveness. Canberra: Commonwealth of Australia. Plus Annex 12, Historical Analysis.

Castro-Peraza, Maria Eliza, Jesús Manuel García-Acosta et al. 2019. 'Gender identity: The human right of depathologization.' *International Journal of Environmental Research and Public Health* 16(6): 978, doi: 10.3390/ijerph16060978.

Chapeau, Serah (for the Australian Federation of AIDS Organisations). 2015. 'Health Campaign Evaluation: "Walk with me – Together We Are PNG" and "Live Your Life",' December 2015.

Clarke, Matthew. 2015. 'Innovative delivery mechanisms: Australian aid partnership with churches in Papua New Guinea.' *Journal of International Development* 27: 1462–78, doi: 10.1002/jid.3185.

Corbin Dwyer, Sonya, and Jennifer L. Buckle. 2009. 'The space between: On being an insider-outsider in qualitative research,' *International Journal of Qualitative Methods* 8(1): 54–63, doi: 10.1177/160940690900800105.

Costello, M., and N. Fazulla. 2015. 'Remembering, recognising, responding: 21 years of the Anwernekenhe Aboriginal and Torres Strait Islander response to HIV.' *HIV Australia* 13(3). Viewed on 2 Jan. 2021 at: www.afao.org.au/article/remembering-recognising-responding-21-years-anwernekenhe-aboriginal-torres-strait-islander-response-hiv/.

Cowan, Jane K. 2006. 'Culture and rights after "culture and rights".' *American Anthropologist* 108(1): 9–24, doi: 10.1525/aa.2006.108.1.9.

Cox, John. 2014. 'Grassroots, elites and the new "working class" of Papua New Guinea.' In Brief 2014/6. State, Society and Governance in Melanesia Program. The Australian National University. Viewed on 18 Nov. 2020 at: researchers.anu.edu.au/publications/94175.

CREA (Creating Resources for Empowerment in Action). 2006. *Sexual Rights and Social Movements.* New Delhi: CREA.

Crenshaw, Kimberlé Williams. 2008. 'Mapping the margins: Intersectionality, identity politics and violence against women of color.' In Alison Bailey and Chris Cuomo (eds), *The Feminist Philosophy Reader.* New York: McGraw-Hill, 279–309.

de Beco, Gauthier. 2013. 'Human rights indicators: From theoretical debate to practical application,' *Journal of Human Rights Practice* 5(2): 380–97, doi: 10.1093/jhuman/hut003.

Department of Education of PNG. N.d. *Teachers in School Electronic Resources (TiseR).* Viewed on 15 Nov. 2020 at: www.education.gov.pg/TISER/index.html.

Department of Foreign Affairs and Trade. 2014. *Strategic Priorities for Australia's International Response to HIV*. Viewed on 15 Nov. 2020 at: ww.dfat.gov.au/sites/default/files/strat-priorities-aus-response-hiv.pdf.

Dinnen, Sinclair. 2000. *Law and Order in a Weak State: Crime and Politics in Papua New Guinea.* Honolulu, HI: University of Hawaii Press, doi: 10.1515/9780824863296.

Dobrin, Lisa M., and Alex Golub. 2020. 'The legacy of Bernard Narokobi and the Melanesian way.' *Journal of Pacific History* 55(2): 149–64, doi: 10.1080/00223344.2020.1759406.

Dowsett, Gary. 2003. 'HIV/AIDS and homophobia: Subtle hatreds, severe consequences and the question of origin.' *Culture, Health and Sexuality: An International Journal for Research, Intervention and Care* 5(2): 121–36.

Earl, Cassie. 2017. 'The researcher as cognitive activist and the mutually useful conversation.' *Power and Education* 9(2): 129–44, doi: 10.1177/1757743817714281.

EMTV. 2016. *Olsem Wanam Episode 24.* Viewed on 20 Dec. 2020 at: emtv.com.pg/olsem-wanem-episode-24-2016-2/.

Ergun, Ayça, and Aykan Erdemir. 2010. 'Negotiating insider and outsider identities in the field: "Insider" in a foreign land; "outsider" in one's own land.' *Field Methods* 22(1): 16–38, doi: 10.1177/1525822X09349919.

Ernst, Thomas M. 1991. 'Onabasulu male homosexuality: Cosmology, affect and precribed male homosexual activity among the Onabasulu of the Great Papuan Plateau.' *Oceania* 62(1) 1–11, doi: 10.1002/j.1834-4461.1991.tb02365.x.

Eves, Richard. 2003. 'AIDS and apocalypticism: Interpretations of the epidemic from Papua New Guinea.' *Culture, Health and Sexuality* 5(3): 249–64, doi: 10.1080/136910501171706.

________. 2008. 'Moral reform and miraculous cures. Christian healing and AIDS In New Ireland, Papua New Guinea.' In Leslie Butt and Richard Eves, *Making Sense of AIDS: Culture, Sexuality, and Power in Melanesia*. Honolulu, HI: University of Hawai'i Press, pp. 206–23, doi: 10.21313/hawaii/9780824831936.003.0012.

Farmer, Paul. 2003. *Pathologies of Power: Health, Human Rights and the New War on the Poor*. Berkeley, CA: University of California Press, doi: 10.1525/9780520931473.

Farrell, P. 2014. 'Julie Bishop calls for aid rethink as PNG slips down UN rankings.' *Guardian,* 20 May. Viewed on 5 Jan. 2021 at: www.theguardian.com/world/2014/may/20/julie-bishop-calls-for-aid-rethink-as-png-slips-down-the-rankings/.

Fay, Brian. 1966. *Contemporary Philosophy of Social Science: A Multicultural Approach.* Cambridge: Blackwell.

Finlay, Linda. 2002. '"Outing" the researcher: The provenance, process, and practice of reflexivity.' *PubMed* 12(4): 531–45, doi: 10.1177/104973202129120052.

Forsyth, Margaret, and Richard Eves (eds). 2015. *Talking it Through: Responses to Sorcery and Witchcraft Beliefs and Practices in Melanesia*. Canberra: ANU Press, doi: 10.26530/OAPEN_569113.

Foucault, Michel. 1991. 'Governmentality.' In Graham Burchell, Colin Gordon and Peter Miller (eds.), *The Foucault Effect: Studies in Governmentality.* Hemel Hempstead: Harvester Wheatsheaf, 87–104.

Franklin, Karl J. 2007. 'Framework for a Melanesian worldview.' *Catalyst* 37(1): 25–52.

Freire, Paulo. 1996 [1968]. *Pedagogy of the Oppressed.* Translated by Myra Bergman Ramos. London: Penguin

________. 1998. *Pedagogy of Freedom: Ethics, Democracy and Civic Courage.* Translated by Patrick Clark. Lanham, MD: Rowman and Littlefield.

'Gay PNG Citizens Face Discrimination.' 2012. *SBS World News,* 16 September. Viewed on 10 Oct. 2020 at: www.youtube.com/watch?v=4kVl8U5cTMarta.

Gerawa, M., and A. Rheeney. 2004. 'Sir Peter urges MPs to fight HIV.' *The Post-Courier,* 13 May 2004.

Gewertz, Deborah, and Frederick Errington. 1992. *Twisted Histories, Altered Contexts: Representing the Chambri in a World System.* Cambridge: Cambridge University Press.

________. 1998. 'Sleights of hand and the construction of desire in a Papua New Guinea modernity.' *The Contemporary Pacific* 10(2): (Fall 1998): 345–68.

Gibbs, Philip. 2005. 'Political discourse and religious narratives of church and state in Papua New Guinea.' Working Paper 2005/1. State, Society and Governance in Melanesia Project, The Australian National Universtity, 1–30. Viewed 2 Jan. 2021 at: dpa.bellschool.anu.edu.au/sites/default/files/publications/attachments/2015-12/05_01wp_Gibbs_0.pdf.

________ 2016. 'Men's matters: Changing masculine identities in Papua New Guinea.' In Aletta Biersack, Margaret Jolly and Martha Macintyre (eds). *Gender Violence & Human Rights: Seeking Justice in Fiji, Papua New Guinea & Vanuatu.* Canberra: ANU Press, 127–58, doi: 10.22459/GVHR.12.2016.

Godelier, Maurice. 1986. *The Making of Great Men: Male Domination and Power Among the New Guinea Baruya.* Translated by Rupert Swyer. New York: Cambridge University Press, doi: 10.1177/030981688703100116.

Gruskin, Sofia, Edward J. Mills and Daniel Tarantola. 2007. 'History, principles, and practice of health and human rights.' *The Lancet,* 4–10 August: 449–55.

Hakim, Avi J., Kelsey Coy, Steven G. Badman et al. 2019. 'One size does not fit all: HIV prevalence and correlates of risk for men who have sex with men, transgender women in multiple cities in Papua New Guinea.' *BMC Public Health* 19(623), doi: 10.1186/s12889-019-6942-7.

Haley, Nicole. 2010. 'Witchcraft, torture and HIV.' In Vicki Luker and Sinclair Dinnen (eds). *Civic Insecurity: Law, Order and HIV in Papua New Guinea.* Canberra: ANU E Press, 219–36, doi: 10.22459/CI.12.2010.

Hallgarth, Lauren, and Daniel Tarantola. 2008. 'A rights-based approach to the assessment of global health initiatives.' *Australian Journal of Human Rights* 13(2):157–80, doi: 10.1080/1323238X.2008.11910838.

Hammar, Lawrence J. 2008. 'Fear and loathing in Papua New Guinea: Sexual health a nation under siege.' In Leslie Butt and Richard Eves (eds). *Making Sense of AIDS: Culture, Sexuality and Power in Melanesia.* Honolulu, HI: University of Hawai'i Press, 60–79, doi: 10.21313/hawaii/9780824831936.003.0004.

________. 2010. *Sin, Sex and Stigma: A Pacific Response to HIV and AIDS.* Canon Pyon, Herefordshire: Sean Kingston Publishing.

Hammarberg, Thomas. 2001. 'Searching the truth: The need to monitor human rights with relevant and reliable means.' *Statistical Journal of the United Nations Economic Commission for Europe* 18(2/3): 31–140. (Paper presented to the Statistics, Development, and Human Rights Conference of the International Association for Official Statistics, Montreux, Switzerland, 4–8 September 2000.)

Hardon, Anita. 2012. 'Biomedical hype and hopes: AIDS medicines for Africa.' In Paul Wenzel Geissler, Richard Rottenberg and Julia Zenker (eds). *Rethinking Biomedicine and Governance in Africa: Contributions from Anthropology.* Verlag: Transcript: 77–96.

Hauck, Volker, Angela Mandie-Filer and Joe Bolger. 2005. 'Ringing the church bell: The role of churches in governance and public performance in Papua New Guinea,' January. Discussion Paper 57E: Maastricht: European Centre for Development Policy Management.

Herdt, Gilbert H. 1984. *Ritualised Homosexuality in Melandesia.* Berkeley, CA: University of California Press.

________. 2003. *Secrecy and Cultural Reality.* Ann Arbor, MI: University of Michigan Press.

________. 2009. 'Introduction.' In Gilbert H. Herdt (ed.). *Moral Panics: Fear and the Fight Over Sexual Rights.* New York: New York University Press, 1–46.

________. 2011. 'Talking about Sex: On the relationship between discourse, secrecy and sexual subjectivity in Melanesia.' In David Lipset and Paul Roscoe (eds). *Echoes of the Tambaran: Masculinity, History and the Subject in the Work of Donald F. Tuzin.* Canberra: ANU Press, doi: 10.22459/ET.10.2011.

Hermkens, Anna-Karina. 2012. 'Becoming Mary: Marian devotion as a solution to gender-based violence in urban PNG.' In Margaret Jolly, Christine Stewart and Carolyn Brewer (eds). *Engendering Violence in Papua New Guinea.* Canberra: ANU Press, doi: 10.22459/EVPNG.07.2012.

'HIV in PNG is now estimated to be about 70,000: Igat Hope.' 2018. *Post Courier Newspaper,* 21 June.

Igat Hope. 2010. *Waigani Statement on HIV Treatment Action 2010.* Viewed on 1 Oct. 2020 at: www.igathope.org.

'Igat Hope launches new website for PLHIV members.' 2018. *Post Courier Newspaper,* 8 June.

Inda, Jonathan X., and Renato Rosaldo. 2008. 'Tracking global flows.' In Jonathan Xavier Inda and Renato Rosaldo (eds.), *The Anthropology of Globalization: A Reader* (2nd edition). Malden, MA and Oxford: Wiley-Blackwell, 3–46.

'Inspirational women providing HIV care in Mt Hagen.' 2018. *Post Courier,* 30 November.

Institute of Development Studies. 2010. *An Upside-Down View of Governance.* Brighton: University of Sussex. Viewed on 15 Nov. 2020 at: www2.ids.ac.uk/gdr/cfs/pdfs/AnUpside-downViewofGovernance.pdf.

International Development Law Organization, Rome. 2013. *Addressing HIV-Related Discrimination in Papua New Guinea.* This video was funded by the OPEC Fund for International Development and DFAT. Viewed on 31 Aug. 2020 at: www.youtube.com/watch?v=hmPtLLcdBvI.

Jenkins, Carol, and S. Sakar. 2004. 'Creating Environments that Care: Interventions for HIV Prevention and Support for Vulnerable Populations' (draft). Policy Project (USAID) and UNAIDS.

Jenkins, Carol. 1994. *Situational Assessment of Commercial Sex Workers in Urban Papua New Guinea.* Goroka: Papua New Guinea Institute of Medical Research.

________. 1996. 'The homosexual context of heterosexual practice in Papua New Guinea.' In Peter Aggleton (ed.). *Bisexualities and AIDS: International Perspectives,* Social Aspects of AIDS Series. London, Taylor and Francis, 191–206.

Jessep, Owen. 2001, 'Integrating custom and common law.' In Anthony J. Regan, Owen Jessep and Eric L. Kwa (eds). *Twenty Years of the Papua New Guinea Constitution.* Sydney: Lawbook Company, 114–58.

Jolly, Margaret. 1996. 'Women ikat raet long human raet o no? Women's rights, human rights and domestic violence in Vanuatu.' *Feminist Review* 52 (Spring): 169–90.

________. 2012. 'Prologue: The place of Papua New Guinea in contours of gender violence.' In Margaret Jolly, Christine Stewart and Carolyn Brewer (eds). *Engendering Violence in Papua New Guinea.* Canberra: ANU E Press, xvii–xxvii, doi: 10.22459/EVPNG.07.2012.

________. 2016. 'When she cries oceans: Navigating Gender Violence in the Western Pacific.' In Aletta Biersack, Margaret Jolly and Martha Macintyre (eds). *Gender Violence & Human Rights: Seeking Justice in Fiji, Papua New Guinea & Vanuatu.* Canberra: ANU Press, 341–380, doi: 10.22459/GVHR.12.2016.08.

Kanuha, Valli Kalei. 2000. '"Being" native versus "going native": Conducting social work research as an insider.' *Social Work* 45(5) (October): 439–47.

Kapul Champions and Australian Federation of AIDS Organisations. 2015. Joint application to Australian Department of Foreign Affairs and Trade for funding 2016.

Kelly, Angela. 2009. 'The body of Christ has AIDS: The Catholic Church responding faithfully to HIV and AIDS in Papua New Guinea.' *Journal of Religion and Health* 48(1):16–28, doi: 10.1007/s10943-008-9220-z.

Kelly, Angela, M. Kupul, W.Y.N. Man et al. 2011. *Askim na Save (Ask and Understand): People who Sell and/or Exchange Sex in Port Moresby. Key Quantitative Findings.* Goraka and Sydney: Papua New Guinea Institute of Medical Research and the University of New South Wales.

Kelly-Hanku, A., B. Willie, D.A. Weikum et al. 2018. *Kauntim mi tu: Multi-Site Summary Report from the Key Population Integrated Bio-Behavioural Survey, Papua New Guinea.* Goroka and Sydney: Papua New Guinea Institute of Medical Research and Kirby Institute, the University of New South Wales.

Kelly-Hanku, Angela, A. Amos-Kuma, S.G. Badman et al. 2017. *Kauntim mi tu – Port Moresby: Key findings from the Key Population Integrated Bio-Behavioural Survey, Port Moresby, Papua New Guinea.* Goroka and Sydney: Papua New Guinea Institute of Medical Research and Kirby Institute, University of New South Wales Sydney.

Kelly-Hanku, Angela, Peter Aggleton and Patti Shih. 2014. '"We call it a virus but I want to say it's the devil inside": Redemption, moral reform and relationships with God among people living with HIV in Papua New Guinea.' *Social Science and Medicine* 119 (October): 106–13, doi: 10.1016/j.socscimed.2014.08.020.

Kelly-Hanku, Angela, Thomas Kawage, Andrew Vallely, Agnes Mek and Bradley Mathers. 2015. 'Sex, violence and HIV on the inside: Cultures of violence, denial, gender inequality and homophobia negatively influence the health outcomes of those in closed settings.' *Culture, Health and Sexuality* 17(8): 990–1003.

Klitgaard, Robert. 1991.*Controlling Corruption.* Berkeley, CA: University of California Press.

Knauft, Bruce M. 2003. 'Whatever happened to ritualized homosexuality? Modern sexual subjects in Melanesia and elsewhere.' *Annual Review of Sex Research* 14(1): 137–59, doi: 10.1080/10532528.2003.10559814.

Knauft, Bruce. 1993. 'Sexuality in the regional analysis of South New Guinea.' In Bruce Knauft (ed.). *South Coast New Guinea Cultures: History, Comparison, Dialectic.* Cambridge: Cambridge University Press, 45–59.

Larmour, Peter. 2009. 'How much corruption is there in the Pacific Islands? A review of different approaches to measurement.' *Pacific Economic Bulletin* 24(1): 144–60.

Lather, Patti. 1986. 'Issues of validity in openly ideological research: Between a rock and a soft place.' *Interchange* 17(4): 63–84.

Lau, Holning. 2004. 'Sexual orientation: Testing the universality of International Human Rights Law.' *The University of Chicago Law Review* 71(4): 1689–720.

Leach, Tim. 2020. *Widespread Discrimination Based on HIV-Status, Sexuality and Gender Identity.* Viewed on 26 Jan. 2021 at: www.timleachphd.com/.

Leach, Tim, and John Rule. 2013. *Reflections on the Practice of Partnerships: A decade of collaboration between the National Association of People with HIV Australia and Igat Hope, the National Association of People with HIV in PNG.* National Association of People with HIV Australia, doi: 10.13140/RG.2.2.30982.88648.

________. 2014. 'Australian support for community HIV responses in PNG: What works, how do we show it, and who will fund it anyway?.' *Australian Federation of AIDS Organisations (AFAO)* 12(2) (July). Viewed on 4 Jan. 2021 at: www.afao.org.au/article/australian-support-community-hiv-responses-png-works-show-will-fund-anyway/.

Lepani, Katherine. 2008. 'Mobility, violence, and the gendering of HIV in Papua New Guinea.' In Paul Taylor (ed.), *Changing Pacific Masculinities,* special issue of *The Australian Journal of Anthropology* 19(2): 150–64, doi: 10.1111/j.1835-9310.2008.tb00119.x.

________. 2010. 'Moving towards sexual citizenship in the response to HIV.' *HIV Australia* 8(2): 21–23.

________. 2012. *Islands of Love, Islands of Risk: Culture and HIV in the Trobriands.* Nashville, TN: Vanderbilt University Press.

________. 2015. '"I am still a young girl if i want": Relational personhood and individual autonomy in the Trobriand Islands.*' Gender and Person in Oceania,* special issue of *Oceania* 85(1): 51–62, doi: 10.1002/ocea.5073.

________. 2016. 'Proclivity and prevalence: Accounting for the dynamics of sexual violence in the response to HIV in Papua New Guinea.' In Aletta Biersack, Margaret Jolly and MarthaMacintyre (eds). *Gender Violence & Human Rights: Seeking Justice in Fiji, Papua New Guinea & Vanuatu.* Canberra: ANU Press, 159–196, doi: 10.22459/GVHR.12.2016.04.

'LGBTI community wants to be heard.' 2017. *Post Courier Newspaper,* 23 June.

Luker, Vicki. 2004. 'Civil society, social capital and the churches: HIV/AIDS in Papua New Guinea.' Working Paper 2004/1. State, Society and Governance in Melanesia Project, The Australian National University.

Luker, Vicki, and Sinclair Dinnen (eds). 2010. *Civic Insecurity: Law, Order and HIV in Papua New Guinea.* Canberra: ANU E Press, doi: 10.26530/OAPEN_458878.

MacDonald, Ewen. 2014. 'Australia's domestic and regional response to HIV: Shaping the future, learning from the past.' Speech to 'AIDS 2014. 20th Annual AIDS Conference,' Melbourne, 22 July. Viewed on 4 Jan. 2021 at: www.dfat.gov.au/news/speeches/Pages/140722_aids2014.

Macintyre, Martha. 2000. '"Hear us, women of Papua New Guinea!": Melanesian women and human rights.' In Anne-Marie Hilsdon, Martha Macintyre, Vera Mackie and Maila Stivans (eds). *Human Rights and Gender Politics: Asia-Pacific Perspectives.* London : Routledge, 147–71.

Maguire, Patricia. 1987. *Doing Participatory Research: A Feminist Approach*. Amherst, MA: The Centre for International Education, School of Education, University of Massachusetts.

Maibani-Michie, G., and W. Yeka. 2005. *A Baseline Research for Poro Sapot Project: A Program for Prevention of HIV/AIDS among MSM in Port Moresby and FSW in Goroka and Port Moresby Papua New Guinea.* PNG IMR/FHI Research Report to USAID.

Mann, Jonathan, and Daniel Tarantola. 1998. 'Responding to HIV/AIDS: A historical perspective.' *Health and Human Rights* 2(4): 5–8, doi: 10.2307/4065182.

Mann, Jonathan, Lawrence Gostin, Sofia Gruskin et al. 1994. 'Health and human rights.' *Health and Human Rights* 1(1): 6–23, doi: 10.2307/4065260.

Mattes, Dominic. 2011. '"We are just supposed to be quiet": The production of adherence to antiretroviral treatment in urban Tanzania.' *Medical Anthropology* 30(2): 158–82.

Mcinnes, David, Liz Mcdonnell and Gary Dowsett. 2004. 'Accumulating reflexivity in collaborative HIV educational research: a model in theory and practice.' *Reflexive Practice* 5(2): 209–24, doi: 10.1080/14623940410001690983.

McPherson, Naomi. 2008. 'Sik AIDS: Deconstructing the awareness campaign in rural West New Britain, Papua New Guinea.' In Leslie Butt and Richard Eves (eds). 2008. *Making Sense of AIDS. Culture, Sexuality and Power in Melanesia.* Honolulu, HI: University of Hawai'i Press, 47–72.

________. 2012. 'Black and blue: Shades of violence in West New Britain, PNG.' In Margaret Jolly, Christine Stewart and Carolyn Brewer (eds). *Engendering Violence in Papua New Guinea.* Canberra: ANU Press, 47–72, doi: 10.22459/EVPNG.07.2012.01.

Merry, Sally Engle. 2006a. *Human Rights and Gender Violence: Translating International Law into Local Justice.* Chicago, IL: University of Chicago Press

________. 2006b. 'Transnational human rights and local activism: Mapping the middle.' In *Anthropology and Human Rights in a New Key,* special issue of *American Anthropologist* 108(1): 38–51.

________. 2011. 'Measuring the World: Indicators, human rights and global governance.' *Current Anthropology* 52(S3): 83–95.

Ministry of Health (MOH), National AIDS Council Secretariat (NACS) and World Health Organization (WHO). 2000. *Consensus Workshop on the Epidemiology of Sexually Transmitted Infections and HIV/AIDS in Papua New Guinea.* Port Moresby: MOH, NACS and WHO.

Mosko, Mark. 2010. 'Partible penitents: Dividual personhood and Christian practice in Melanesia and the West.' *Journal of the Royal Anthropological Institute* 16(2): 215–40.

Narokobi, B. [Bernard]. 1983. *The Melanesian Way.* Boroko and Suva: Institute of Papua New Guinea Studies and Institute of Pacific Studies, University of the South Pacific.

National AIDS Council of Papua New Guinea. 2007. *2007 Estimation Report on the HIV Epidemic in Papua New Guinea*, Port Moresby.

________. 2018. *National STI and HIV Strategy 2018–2011.* Viewed on 5 Dec. 2020 at: www.aidsdatahub.org/resource/papua-new-guinea-national-sti-and-hiv-strategy-2018-2022.

National Violence Against Women Prevention Research Centre. 2001. *Fostering Collaborations to Prevent Violence Against Women: Integrating Findings from Practitioner and Researcher Focus Groups*. Charleston: Medical University of South Carolina.

Nguyen, Vinh-Kim. 2010. The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS. Durham, NC: Duke University Press.

________. 2013. 'Counselling against HIV in Africa: A genealogy of confessional technologies.' *Culture, Health and Sexuality* 15(sup4): S440–S452, doi: 10.1080/13691058.2013.809146.

Office of the United Nations High Commissioner for Human Rights. United Nations Free and Equal Campaign: 'LGBTI equality: Frequently asked questions'. Viewed on 15 Feb. 2021 at: www.unfe.org/wp-content/uploads/2018/10/FAQs-English.pdf.

Ortner, Sherry. 2016. 'Dark anthropology and its others: Theory since the eighties.' *HAU: Journal of Ethnographic Theory* 6(1): 47–73.

Ottley, Bruce L., and Jean G. Zorn. 1983. 'Criminal law in Papua New Guinea: Code, custom and the courts in conflict.' *The American Journal of Comparative Law* 31 (Spring) 251–300.

Parker, Richard Guy. 2010. 'Reinventing sexual scripts: Sexuality and social change in the twenty-first century.' *Sexuality Research and Social Policy* 7(1): 58–66, doi: 10.1007/s13178-010-0004-3.

Parkinson, R. 1907. *Dreisig Jahre in der Sudsee: Land und Leute, Sitten und Gebrauche im Bismarck Archipel und auf den duetschen Salmoninseln.* Stuttgart: Strecker und Schroeder.

Partnership Network Coalition and UNAIDS. 2018. *A New Way to Work with Key Populations in Papua New Guinea.*

Rapporteur Report, 'Legal/Legislative Consultation to Explore a Rights-Based Approach to Public Health and HIV in PNG – 26–27 May 2015' (obtained from UNAIDS PNG).

Regan, Anthony J. 2001. ‘Introduction.’ In Anthony J. Regan, Owen Jessep and Eric L. Kwa (eds). *Twenty Years of the Papua New Guinea Constitution.* Sydney: Lawbook Company, 1–11.

Reid, Elizabeth. 2010a. ‘Re-thinking human rights and the HIV epidemic: A reflection on power and goodness.’ In Vicki Luker, Sinclair and Dinnen (eds). *Civic Insecurity: Law, Order and HIV in Papua New Guinea.* Canberra: ANU E Press, 265–74, doi: 10.22459/CI.12.2010.13.

________. 2010b. ‘Putting values into practice in PNG – The Poro Sapot Project and aid effectiveness.’ *The eJournal of the Australian Association for the Advancement of Pacific Studies* 1.2–2.1 (April).

Richardson, Diane. 2000. ‘Constructing sexual citizenship: theorizing sexual rights.’ *Critical Social Policy* 20(1): 105–35, doi: 10.1177/026101830002000105.

Rispel, Laeticia C., Allanise Cloete and Carol A. Metcalf. 2015. ‘“We keep her status to ourselves”: Experiences of stigma and discrimination among HIV-discordant couples in South Africa, Tanzania and Ukraine.’ *Journal of Social Aspects of HIV/AIDS Research Alliance (SAHARA J)* 12(1): 10–17, doi: 10.1080/17290376.2015.1014403.

Ritchie, Jonathan. 2020. ‘From the grassroots: Bernard Narokobi and the making of Papua New Guinea’s Constitution.’ *The Journal of Pacific History* 55(2): 235–54, doi: 10.1080/00223344.2020.1759408.

Rose, Nikolas. 2000. ‘Government and control.’ *Criminology and Social Theory*, special issue of *The British Journal of Criminology* 40(2) (Spring): 321–39.

Rose-Ackerman, Susan. 1999. *Corruption and Government: Causes, Consequences and Reform.* New York, NY: Cambridge University Press.

Rule, John, and Don Liriope. 2016. *HIV-Related Stigma and Discrimination and Human Rights in Papua New Guinea: A Report on the Application of the HIV Stigma Index in the Western Highlands and Chimbu Provinces.* Port Moresby: Igat Hope.

Save the Children. 2017. *Stori bilong Mi: 15 Years of Poro Sapot, Stories of Change from the Poro Sapot Project.* Viewed on 15 Dec. 2020 at: resourcecentre.savethechildren.net/node/12638/pdf/poro-sapot-booklet.pdf.

Scheper-Hughes, Nancy. 1979. *Saints, Scholars, and Schizophrenics: Mental Illness in Rural Ireland.* Berkeley, CA: University of California Press.

________. 1996. ‘Small wars and invisible genocides.’ *Social Science and Medicine* 43(5): 889–900.

________. 2000. ‘Ire in Ireland.’ *Ethnography* 1(1): 117–40.

Shanahan, D. 2013. ‘“Jakarta relations beyond boats,” says Tony Abbott,’ *Australian,* 21 September.

Sharma, Jaya. 2008. ‘The language of rights.’ In Andrea Cornwall, Sonia Correa and Susie Jolly (eds). *Development with a Body: Sexuality, Human Rights and Development.* London: Zed Books, 67–76.

Sheill, Kate. 2008. ‘Sexual rights are human rights.’ In Andrea Cornwall, Sonia Correa and Susie Jolly (eds). *Development with a Body: Sexuality, Human Rights and Development.* London: Zed Books, 45–53.

Shutterstock, Library of images which can be licensed for creative use. Viewed on 26 Jan. 2021 at: www.shutterstock.com.

SOGI Campaigns. 2014. ‘Strike a pose … with a poster!’ Viewed on 10 Jul. 2020 at: sogicampaigns.org/portfolio/strike-a-pose-with-a-poster/.

Sokhin, Vlad, and Roman Kalyakin. 2014. *Guava and Bananas: Living Gay in Papua New Guinea.* Documentary screened at the 5th PNG Human Rights Film Festival in Port Moresby. Viewed on 15 Dec. 2020 at: vimeo.com/87629545.

Stahl, Roland, and Corey Shdaimah. 2008. ‘Collaboration between community advocates and academic researchers: Scientific advocacy or political research?’ *British Journal of Social Work* 38(8): 1610–29, doi: 10.1093/bjsw/bcm069.

Stewart, Christine. 2010. ‘Enabling environments: The role of the law.’ In Vicki Luker and Sinclair Dinnen (eds). *Civic Insecurity: Law, Order and HIV in Papua New Guinea.* Canberra: ANU E Press, 275–285, doi: 10.22459/CI.12.2010.14.

________. 2014. *Name, Shame and Blame: Criminalising Consensual Sex in Papua New Guinea.* Canberra: ANU Press, doi: 10.22459/NSB.12.2014.

Strathern, Marilyn. 1988. *Gender of the Gift: Problems with Women and Problems with Society in Melanesia.* Berkeley, CA: University of California Press.

Tan, Sherman. 2015. 'Gay Asia should resist liberal assimilation.' *East Asia Forum,* 28 August. Viewed on 4 Jan. 2021 at: www.eastasiaforum.org/2015/08/28/gay-asia-should-resist-liveral0assimilation-2/.

Teaiwa, Teresa. 2014. 'Same sex, different armies: Sexual minority invisibility among Fijians in the Fiji Military Forces and British Army.' In Niko Besnier and Kalissa Alexeyeff (eds). *Gender on the Edge.* Honolulu, HI: University of Hawai'i Press.

Tencic, Natalie. 2014. 'Papua New Guinea's gay and transgender community finds safety in Hanuabada village,' *ABC News,* 8 October. Viewed on 15 Dec. 2020 at: www.abc.net.au/news/2014-10-08/living-gay-in-papua-new-guinea/5796236; referencing *Guava and Bananas: Living Gay in Papua New Guinea*, a 2014 documentary by Vlad Sokhin and Roman Kalyakin screened at the 5th PNG Human Rights Film Festival in Port Moresby. Viewed on 15 Dec. 2020 at: vimeo.com/87629545.

'The gay divide.' 2014. *Economist,* 11 October.

Thèry, Irène. 2009. 'Gender: A question of personal identity or a mode of social relations?' Translated by Stephanie Anderson-Moreton in collaboration with SergeTcherkezoff. Berlin: Centre M. Bloch, School for Advanced Studies in the Social Sciences (EHESS). Viewed on 4 Jan. 2021 at: www.pacific-dialogues.fr/pdf/4-IT_ConfBerlin_2009_def.pdf.

'Transgender Human Rights Affirmed.' 2011. *Polare Magazine* 55 (July) (updated October 2013). Viewed on 4 Jan. 2021 at: webcache.googleusercontent.com/search?q=cache:llfR_9yg-r0J:https://gendercentre.org.au/polare-magazines/download-polare-archives%3Fdownload%3D162:polare-55%26start%3D60+andcd=1andhl=enandct=clnkandgl=auandclient=firefox-b-d.

Transparency International: The Global Coalition against Corruption. Viewed on 4 Jan. 2021 at: www.transparency.org/en.

Tuhiwai Smith, Linda. 2013. *Decolonizing Methodologies: Research and Indigenous Peoples.* London: Zed Books.

UNHCR/UNAIDS. 1996. *HIV/AIDS and Human Rights: International Guidelines*. New York and Geneva: United Nations Commmissioner for Human Rights and Joint United Nations Programme on HIV/AIDS. This is now published as a consolidated and updated 2006 version.

United Nations Human Rights Office. N.d. *HIV/AIDS and Human Rights.* Viewed on 11 Nov. 2020 at: www.ohchr.org/en/issues/hiv/pages/hivindex.aspx.

________. N.d. *International Human Rights Law and Sexual Orientation and Gender Identity.* Viewed on 4 Jun. 2020 at: www.unfe.org/wp-content/uploads/2018/10/International-Human-Rights-Law-English.pdf.

________. N.d. *LGBTI Equality: Frequently Asked Questions.* Viewed on 4 Jun. 2020 at: www.unfe.org/wp-content/uploads/2018/10/FAQs-English.pdf.

United Nations Office of the High Commissioner for Human Rights Regional Office of the Pacific and the Pacific Islands Forum Secretariat. 2009. *Ratification of International Human Rights Treaties: Added Value for the Pacific Region.* Viewed on 5 Oct. 2020 at: pacific.ohchr.org/docs/RatificationBook.pdf.

United Nations General Assembly Special Session on HIV/AIDS (UNGASS). 2010. *2010 Country Progress Report: Papua New Guinea.* National AIDS Council of Papua New Guinea and Partners.

Vallance, Roger. 2007. 'Is there a Melanesian research methodology?' *Contemporary PNG Studies: Divine Word University Research Journal* 7 (November): 1–15.

Van Reyk, Paul (for Australian Federation of AIDS Organisations). 2012. *Evaluation of the PNG MSM and TG Leadership Development Group August 2012*.

Walff, Tim (director). 2019. *I'm Moshanti. Do You Love Me?* Documentary starring Moses Tau. 59 minutes.

Waling, Andrea. 2018. ‘I can’t/can I touch him? Erotic subjectivity, sexual attraction, and research in the field.’ *Qualitative Inquiry* 24(9): 720–27, doi: 10.1177/1077800417734561.

Walton, Grant W. 2013. ‘An argument for reframing debates about corruption: Insights from Papua New Guinea.’ *Asia Pacific Viewpoint* 54(1): 61–76, doi: 10.1111/apv.12002.

Wardlow, Holly. 2001. ‘Anger, economy, and female agency: Problematizing “prostitution” and “sex work” among the Huli of Papua New Guinea.’ *Signs* 29(4): 1017–40, doi: 10.1086/382628.

________. 2006. *Wayward Women – Sexuality and Agency in a New Guinea Society.* Berkeley, CA: University of California Press.

________. 2008. ‘“You have to understand: Some of US are glad AIDS has arrived.”’ In Leslie Butt and Richard Eves (eds). 2008. *Making Sense of AIDS: Culture, Sexuality and Power in Melanesia.* Honolulu, HI: University of Hawai’i Press, 187–205, doi: 10.21313/hawaii/9780824831936.003.0011.

________. 2017. ‘The (extra)ordinary ethics of being HIV-positive in rural Papua New Guinea.’ *Journal of the Royal Anthropological Institute* 23(1): 103–19, doi: 10.1111/1467-9655.12546.

________. 2019. ‘“With AIDS I am happier than I have ever been before.”’ *The Australian Journal of Anthropology* 30(1): 53–67, doi: 10.1111/taja.12304.

Wesley, Michael. 2013. ‘Asia forum less about Geneva, more about Jakarta.’ *East Asia Forum,* 10 September. Viewed on 20 Dec. 2020 at: www.eastasiaforum.org/2013/09/10/in-australia-its-now-less-about-geneva-more-about-jakarta.

Wetterberg, Anna, Derick Brinkerhoff and Jana Hertz. 2015. ‘From compliant to capable: Balanced capacity development for local organisations.’ *Development in Practice* 25(7): 966–85, doi: 10.1080/09614524.2015.1073224.

Williams, Linda M. 2004. ‘Researcher-advocate collaborations to end violence against women: Towards liberating methodologies for action research. *Journal of Interpersonal Violence* 19(11) (November): 1350–57.

World Health Organization. 2006. *Defining Sexual Health: Report of a Technical Consultation on Sexual Health 28–31 January 2002*, Geneva. Viewed on 27 Jul. 2021 at: https://www.who.int/reproductivehealth/publications/sexual_health/defining_sexual_health.pdf.

World Health Organization. 2015. *Sexual Health, Human Rights and the Law.* Viewed on 27 July at: https://www.who.int/reproductivehealth/publications/sexual_health/sexual-health-human-rights-law/en/.

World Health Organization. 2017. *PNG Making Significant Strides in its Battle against PNG.* Viewed on 30 Sep. 2020 at: www.who.int/westernpacific/news/feature-stories/detail/papua-new-guinea-making-significant-strides-in-its-battle-against-hiv.

Yogyakarta Principles, published as the outcome of an international meeting of human rights groups. November 2006, and supplemented in 2017. Viewed on 1 Dec. 2020 at: yogyakartaprinciples.org.

Zorn, Jean. 2016. ‘Translating and internalising International Human Rights Law: The courts of Melanesia confront gendered violence.’ In Aletta Biersack, Margaret Jolly and Martha Macintyre (eds). 2016. *Gender Violence & Human Rights: Seeking Justice in Fiji, Papua New Guinea & Vanuatu*. Canberra: ANU Press 229–69, doi: 10.22459/GVHR.12.2016.06.

Documents in personal possession of author

Leach, Tim. 2013. *Evaluation of Kapul Champions 2013* (for Australian Federation of AIDS Organisations).

Muwadda, W. [Wilo]. 2012. *Leadership Development Group Gender Mapping Report* (to Australian Federation of AIDS Organisations) and *Notes on Technical Support Visit to PNG* (2011) (prepared for National Association of People Living With HIV Australia).

Partnership Network Coalition and UNAIDS. 2018. *A New Way to Work with Key Populations in Papua New Guinea.*

Speaking Notes for Parliament March 2016, drafted to support a Bill to amend the Criminal Code and Summary Offences Act, funded by UNAIDS PNG.

Stewart, Christine. 2005. 'Prostitution and homosexuality in Papua New Guinea: Legal, ethical and human rights issues –a background paper prepared for Poro Sapot Project Save the Children in Papua New Guinea, June 2005.' Port Moresby: Save the Children in PNG.

Igat Hope

AusAID/Igat Hope Funding Agreement 2009.

Department of Health HIV/AIDS Prevention and Control in Rural Development Enclaves Project and Igat Hope Report, 6 October 2010.

Good Governance Training Report, 23–26 March 2009, Melanesian NGO Centre for Leadership.

Grant Agreement Deed between AusAID and Igat Hope 2012.

Igat Hope Annual Implementation Plan 2010.

Igat Hope Annual Implementation Plan and Budget 2010 (for submission to AusAID).

Igat Hope Annual Implementation Plan and Budget 2011.

Igat Hope Annual Plan 2008.

Igat Hope Annual Plan 2010.

Igat Hope Funding Proposal to Asian Development Bank, October 2009.

Igat Hope Governance Kit 2008.

Igat Hope Multi-Year Plan 2010–12.

Igat Hope National Conference Report November 2008.

Igat Hope, Quality at Implementation Report December 2011.

Igat Hope, Quality at Implementation Report December 2012.

Igat Hope, Quality at Implementation Report June 2011.

Igat Hope, Quality at Implementation Report June 2012.

Igat Hope, Quality at Implementation Report November 2010.

Igat Hope Strategic Plan 2009–2011.

Igat Hope/NAPWHA Funding Proposal to AusAID (Sanap Wantaim) 2008.

Igat Hope/NAPWHA Funding Proposal to Collaboration for Health in PNG 2016.

NAPWHA Progress Report to AusAID December 2010.

NAPWHA Proposal to AusAID 2009–2010.

NAPWHA Proposal to AusAID 2010.

Notes from Project, 'Hungry for Learning – Diba Bona Goada Abia Workshop.' Igat Hope, 26–27 March 2007, Shady Rest Motel, Port Moresby, PNG.

Kapul Champions

Evaluation of Media Workshop 2015.

Evera, Nick (for Kapul Champions). 2015. 'Test and Treat – Know your HIV status – Plan your future, Kapul Champions 2015.'

HIV/AIDS Management and Prevention Act - A User's Guide 2014.

Kapul Champions Annual Activity Plan 2012.

Kapul Champions Annual Activity Plan 2013.

Kapul Champions Annual Activity Plan 2014.

Kapul Champions Annual Activity Plan 2015.

Kapul Champions Annual Activity Plan 2016.

Kapul Champions Code of Conduct for Staff and Volunteers 2013.

Kapul Champions Constitution 2014.

Kapul Champions Memorandum of Understanding 2015.

Kapul Champions Report of Senior Project Officer trip to Simbu April 2015.

Kapul Champions Report on Closed Meeting for MDS+ in Lae 2015.

Kapul Champions Report on Social Marketing 2015.

Kapul Champions Rules 2012.

Kapul Champions Strategic Plan 2013.

Kapul Champions Submission to Universal Periodic Review, 2015.

Kapul Champions. 2015. Single Submission to the United Nations Universal Periodic Review, 21 September.

Kapul Champions: Positive MDS/TG ‘Closed’ Meeting, Lae, 16th April 2015 — Meeting Report.

Do you know your rights? 2014.

Treataware HIV Antiretroviral Therapy and Adherence Brochure 2014.

Workshop on Rights and Laws for Men of Diverse Sexualities and Transgenders in PNG – Workshop Manual 2014.

Legal cases

Dudgeon v United Kingdom (Article 50) (1983) ECHR Application 7525/76 24 February 1983.

Lustig-Prean & Beckett v United Kingdom (2000) 29 Eur Ct HR 548.

Toonen v Australia (1994) UN GAOR Hum Rts Comm, 49th Sess, Supp No 40, vol 2, at 226, UN Doc a/49/40.

Young v Australia (2000) UN GAOR Hum Rts Comm, 78th Sess, UN Doc CCPR/C/78/D/941/2000.

Statutes and other legal documents

Criminal Code 1889 (Qld).

Criminal Code 1975 (Papua New Guinea).

Disability Discrimination Act 1993 (Cth).

HIV/AIDS Management and Prevention Act 2003 (Papua New Guinea).

Igat Hope Constitution.

Kapul Champions Constitution.

International declarations and covenants and other United Nations documents

Beijing Declaration and Platform for Action, adopted 15 September 1995.

Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, opened for signature 10 December 1984 (entry into force 16 June 1987).

Convention on the Elimination of all Forms of Discrimination Against Women, opened for signature 1 March 1980 (entry into force 3 September 1981).

Convention on the Rights of Persons with Disabilities, opened for signature 30 March 2007 (entry into force 3 May 2008).

Convention on the Rights of the Child, opened for signature 1989 (entered into force 2 September 1990).

International Covenant on Civil and Political Rights, opened for signature 16 December 1966 (entered into force 23 March 1976.

International Covenant on Economic and Social Rights opened for signature 19 December 1966 (entered into force 3 January 1976).

International Guidelines on HIV/AIDS and Human Rights 2006 (consolidating Guidelines first published in 1998 and revision of Guideline 6 in 2002).

Optional Protocol to the International Covenant on Civil and Political Rights, opened for signature 16 December 1966 (entered into force 23 March 1976).

Universal Declaration of Human Rights (10 December 1948).

Websites

Igat Hope www.igathope.org.

United Nations Office of the High Commissioner for Human Rights www.ohchr.org.