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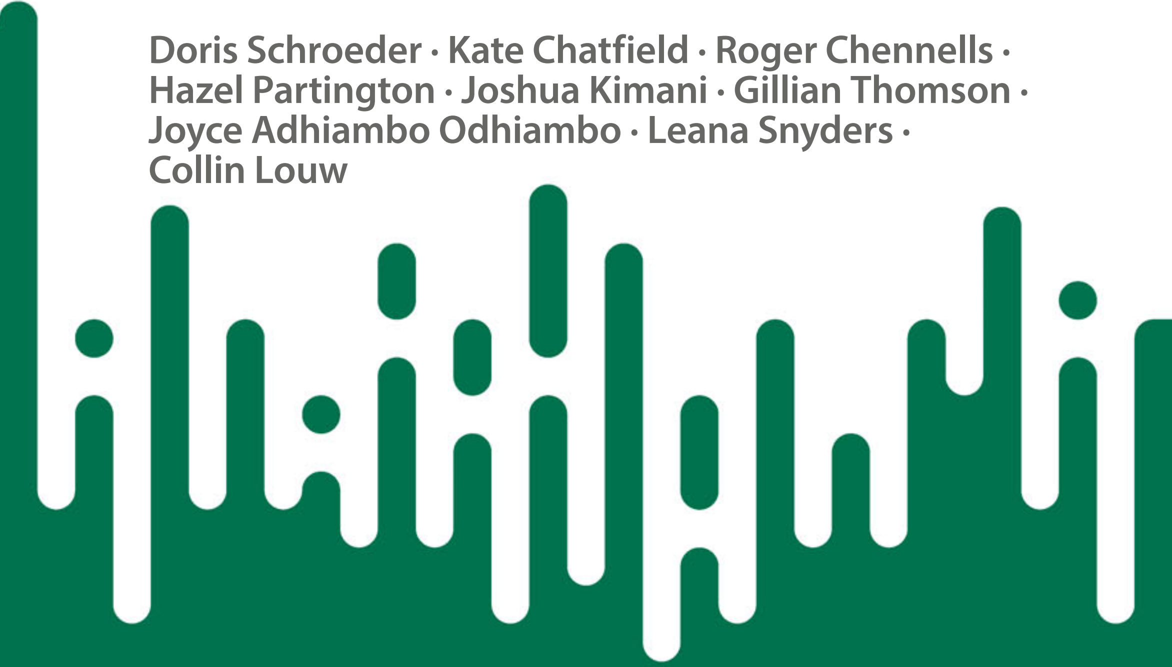

Vulnerability Revisited

Leaving No One Behind in Research

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In memory of
Paul Woodgate (1974–2020)

Foreword

Everybody who takes part in research deserves protection from exploitation and harm. This is particularly true for vulnerable individuals who may have fewer means to protect themselves, for instance if they suffer from severe poverty, high illiteracy or lack of awareness of their rights. Excluding vulnerable groups from research—for their own protection—seemed the most reasonable strategy to avoid the recurrence of exploitation and harm inflicted on them in the past.

Two main developments have led to the questioning of the protection-through-exclusion strategy: the leaving no one behind initiative associated with the UN's 2030 Agenda, and diversity, equity and inclusion policies, which aim to increase representativeness in all fields of life, including in research. As I have shown elsewhere (Castillo 2015), exclusion from research can itself lead to significant harm, especially for women whose medical care often relies on research results based on studying males. Well-intentioned routine exclusion of vulnerable groups can therefore be harmful as well as patronising.

Instead of protection through exclusion, genuinely enabling, democratic and caring processes in every stage of the research—from the development of the research design to the use of the research output—should be mainstreamed. As clearly evidenced in this book, communities like sex workers and Indigenous peoples, who suffer from the intergenerational impact of intersecting factors of discrimination, poverty and exploitation, can be dynamic, effective and crucial partners in research.

Their participation, aside from its benefits to them, can enhance scientific rigour and the ethical vigour of research. This has also been my experience in working with vulnerable populations in the Philippines for many years.

Naming an entire group as vulnerable and treating them patronisingly is not the correct approach. I salute the team behind this book for involving three community researchers from research inception to co-authorship. And also for involving a further 12 community researchers in carrying out a survey in their home communities in South Africa.

From my own experience, I know that enabling truly equitable partnerships with non-academic partners can be burdensome, but it is also worth it. I hope that this is one of the messages that this book will send out into the world. Inclusive research works.

Researchers who work inclusively have to overcome many hurdles, also potentially imposed by research ethics committees. They have to invest time and they have to be creative, as not many others have been where they are going. In fact, it is possible to avoid time-consuming and costly enabling processes by deciding *not* to involve vulnerable communities in research. Luckily, this group has not taken that easy route.

The book tackles the exclude-to-protect dilemma *knowing* that research can be harmful and burdensome for communities and individuals involved in research, and has tried to reduce risks and burdens in two main ways.

First, the authors reasonably argue that if the risks of research involvement could be reduced significantly, it should be possible to forge ahead with inclusion and overcome the notion of exclude-to-protect in more areas than before. They therefore question mainstream research approaches for their potentially negative impact on the vulnerable populations involved. In the context of the illegality of sex work in Kenya, the obtaining of personal data was a highly delicate matter. I understand that for the research in this book, no personal data was collected from the Indigenous San and the Nairobi sex workers involved in the research. I believe the robust research results speak for themselves. This low-risk approach can work.

Second, the team responsible for this book consistently deployed a *strongly* inclusive way of doing research, especially in the San community. Twelve young San were selected, trained and enabled to conduct conversations in their communities in a spirit of curiosity and humility. They spoke to 239 San from their communities without obtaining personal data, and again I believe the result of this work speaks for itself.

I commend the authors of this book for daring to be creative and for refusing to take the easy path of exclusion, but instead placing their faith in their San and sex worker research partners, who have proven that the dilemma can be overcome.

Manila, Philippines Prof. Fatima Alvarez Castillo

Reference

Castillo FA (2015) Gender and social research. In: Wright JD (ed) International encyclopedia of social and behavioral sciences, 2nd edn. Elsevier, Oxford, pp 715–722. https://doi.org/10.1016/B978-0-08-097086-8.11031-1

Prof. Fatima Alvarez Castillo is a social scientist and professorial lecturer in politics, critical research methods and ethics at the University of the Philippines Manila. She is the author of the first training manual on social research ethics in the Philippines and a former member of the Philippine Health Research Ethics Board, the country's policy-making body on research ethics. She provides expertise on research ethics and gender justice in capability building for NGOs, Indigenous peoples' organisations and faculty researchers in various universities in the Philippines.

Acknowledgements

We are extraordinarily grateful to the Wellcome Trust for their Research Development Award.[1] This one-off scheme rewarded a "compelling and expansive vision", a "creative approach" and "equity in management",[2] and we were privileged to be selected.

Our vision is to leave no one behind in research and to enable participation in the *right* type of research, done in the *right* way, for impoverished and disadvantaged groups. Hopefully you will know what this means once you have read our book.

Thanks to our project officer Sarah Golding at the Wellcome Trust, for flexible, timely, interested and encouraging support. Thanks to the interview committee of Dan O'Connor, Jack Harrington and Sarah Golding for the most difficult question-and-answer session the three main applicants (Joshua Kimani, Roger Chennells and I) have ever experienced *anywhere*, which enabled us to improve the application further for Step 3. Thanks to Dr. Carleigh Krubiner for sharing her very illuminating views on "vulnerability in research".

Finally, in the Wellcome Trust team, very sincere thanks to Paul Woodgate, who tragically died much too early, and to whom this book is dedicated. Paul encouraged me to apply for funding, explaining the multiple advantages Wellcome Trust grants hold over grants from other funders. His belief in working for the best still makes me smile with gratitude.

At Springer, I would like to thank—very sincerely—Jayanthi Krishnamoorthi, our project co-ordinator, for supporting the book from contract to publication stage in a very kind and professional way. Thanks also to Doris Bleier, the academic editor of the series at Springer, for lightning-fast and efficient problem-solving and real interest in our book. And many thanks to Kokila Durairaj for excellent proofs.

Thanks to Paul Wise from Muizenberg in South Africa, my all-time favourite editor. His elegant phrasing, understanding of complex issues, interest in our topics and attention to detail are unsurpassed, and I am surprised every time when he

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[1] Grant number: 222859_Z_21_Z.

[2] https://www.facebook.com/wellcometrust/videos/how-to-apply-for-wellcome-humanities-and-social-science-funding/818996635201300/.

says, “Yes, I can do your book,” as there must be an ever-growing queue of authors outside his house wanting to work with him.

Thanks to Kelly Laas from the Illinois Institute of Technology, the chief librarian of the largest ethics code collection in the world, for undertaking a literature search on “vulnerability” in ethics codes for us.

Thanks to Polly Ngurukiri, a Kenyan social scientist, for supporting community researcher Joyce Adhiambo when she was obtaining views on vulnerability from marginalised sex workers.

Thanks to the group who call themselves “The Chosen Ones”, the twelve San community researchers from the !Khomani, the Khwe and the !Xun, who administered 239 short surveys on vulnerability in their communities. In alphabetical order: Judith Andre, Rickert Beerti, Lannie John, Nadia Koper, Joubert Kumumba, Cohen Louw, Jerelda Mbangu, Sareta Mushavanga, Janika Namiseb, Genevieve Saulse, Dawid Sjambe, and Roderick van Gooi.

Thanks to three anonymous reviewers, as well as Armin Schmidt and François Bompart, for helpful comments that sparked additional ideas.

Thanks to Dave Robinson, an award-winning illustrator (daverobdesign) for producing the figurative diagrams for this book. He had the idea of including real people in diagrams. Please therefore meet Ouma/Una Rooi from the !Khomani San in Fig. 3.2.

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Thanks to Fatima Alvarez Castillo for a very generous foreword. We are honoured, as her credibility in working with vulnerable populations in research is legendary in the Philippines and beyond.

The most heartfelt thanks go to the team. Thanks to the three community researchers, Joyce Adhiambo, Collin Louw and Leana Snyders, for guiding the direction in which we were going and learning fast “on the researcher job”. To Collin for his occasional sudden statesmanlike pronouncements, which had the power to change our angle on a topic. To Leana for inspiring “The Chosen Ones” with personal stories, energy and ideas and also for dealing with the complicated

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[3] https://www.facebook.com/wellcometrust/videos/how-to-apply-for-wellcome-humanities-and-social-science-funding/818996635201300/.

logistics of organising workshops for San representatives, who lived 600 km apart and agreed to travel in minibuses to avoid budget overspends. To Joyce for doing whatever needed to be done, from presenting research to holding conversations with sex workers and co-fronting workshops with her unique style, earning her the nickname “Under 18”, to signify her limitless energy and youthful sense of adventure.

Thanks to the leads of the African teams, Joshua Kimani and Roger Chennells, for constantly keeping an eye on auxiliary benefits for the communities, such as confidence and skills building for “The Chosen Ones” in South Africa and generating bottom-up ideas for reducing HIV infections among the Nairobi sex workers. Thanks to them too for managing a host of unexpected problems with calmness and a can-do attitude, from declined visas to missing Wi-Fi. Thanks to Roger for translating 239 (yes, 239!) community researcher survey scripts into English, a task which he probably regretted having volunteered for. He accomplished it brilliantly, even though the required skill set would not have been a likely match for a barrister and lawyer. And thanks to Joshua for always giving this team the impression that our work was crucial, even though he manages ten clinics for 40,000 members of key populations (i.e. groups who are at a high risk of HIV infection).

Thanks to Kate Chatfield, the lead of the UK team, for her remarkably multiskilled contributions, from providing regular advice to the African teams on community research to conducting interviews on vulnerability with experienced researchers from around the world, to linking intuitions from the team back to cutting-edge participatory social science approaches, and to bringing to bear her invaluable expertise as the editor of a journal focusing on research ethics and a former chair of a health research ethics committee. Thanks to Hazel Partington for undertaking the main analysis of all materials provided by community researchers in the Kalahari and Nairobi. A latecomer to our team, Hazel is now invaluable. Thanks to Gill Thomson for joining this team as a “critical friend” with special expertise in methodologies and community research. She asked incisive questions to ensure that our enthusiasm did not lead us unacceptably far away from standard ways of working in the social sciences. Dropping *all* personal data collection got her approval! And her unusual writing style, analytical *and* uplifting, fitted this group perfectly.

If you have read the whole book, I would also like to thank you.

February 2024 Doris Schroeder

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About the Authors

Doris Schroeder is Director of the Centre for Professional Ethics at the University of Central Lancashire UK and Professor of Moral Philosophy at the School of Law, UCLan Cyprus. She is the Lead Author of the TRUST Code and has been working with the San community in South Africa since 2003 and the sex worker community in Nairobi since 2007.

Kate Chatfield is Reader at the Centre for Professional Ethics, UCLan UK and editor of SAGE Research Ethics (2020–2024). She is an empirical ethicist and specialises in research ethics and global justice.

Roger Chennells was legal advisor to the South African San Council and San communities for 30 years. He is a founding partner of the human rights law practice Chennells & Albertyn, founded in 1981. One of his specialist areas of engagement is Indigenous rights. He also holds a Ph.D. in ethics.

Hazel Partington is Senior Research Fellow in Ethics and Health at the Centre for Professional Ethics, UCLan UK. She is a social scientist who recently moved into the field of research ethics from educational research.

Joshua Kimani is an epidemiologist and Director of the Sex Workers Outreach Programme clinics in Nairobi County (SWOP). The ten research clinics provide free HIV prevention and treatment services to over 40,000 female sex workers and men who have sex with men (MSMs), 4700 of whom are living with HIV and are on antiretrovirals (ARVs).

Gillian Thomson is Professor in Perinatal Health at UCLan UK, a social scientist with specialist expertise in a range of qualitative methodologies, in particular hermeneutic phenomenology, and qualitative/narrative based systematic reviews, as well as a keen interest in community research.

Joyce Adhiambo Odhiambo is the community Positive Health, Dignity and Prevention lead at SWOP in Nairobi. She has represented the Nairobi sex worker community on national and international platforms and conferences, winning major awards, for example the Me and My Healthcare Provider award in Mental Health in 2022.

Leana Snyders is the Director of the South African San Council and the Festival Director of the Kalahari Desert Festival. She previously worked as a chief diamond sorter and a senior data compiler for marine and mineral resources, among other activities. She has been involved in advocacy work on behalf of the South African San for almost 15 years.

Collin Louw is the Chair of the Board of the South African San Council, a !Khomani San who is also the Project Manager of the Northern Cape Indigenous Knowledge Systems Documentation Centre and Chairman of the Andries Steenkamp Benefit Sharing Trust. He has been an activist for San development and San rights for the past 30 years.

Abbreviations

BACP	British Association for Counselling and Psychotherapy
CDC	Centers for Disease Control and Prevention
CIOMS	Council for International Organizations of Medical Sciences
ECC	Ethics Codes Collection
ERB	Ethics review boards
EVD	Ebola virus disease
FTE	Full-time equivalent
HICs	High-income countries
ICH	International Council for Harmonisation
IRB	Institutional review board
LMICs	Low- and middle-income countries
MSM	Men who have sex with men
PAR	Participatory action research
PEPFAR	US President's Emergency Plan for AIDS Relief
REC	Research ethics committee
SDGs	Sustainable Development Goals
STI	Sexually transmitted infections
SWOP	Sex Workers Outreach Programme
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization
WMA	World Medical Association

Leaving No One Behind in Research, and the Protection-Inclusion Dilemma for Vulnerable Groups

1

Abstract

Leaving no one behind is the main transformative promise of the UN's 2030 Agenda for Sustainable Development. It encapsulates the 21st-century mission of inclusion. This chapter introduces the main mission of this book: leaving no one behind in research. It provides the context for all the chapters that follow by explaining what it means to leave no one behind in research, how the protection-inclusion dilemma for vulnerable groups and individuals is generated, and how risks and mistrust in research might be reduced. The book was written in collaboration with two groups who are traditionally labelled as highly vulnerable and are therefore often excluded from research: the South African San community and an impoverished sex worker community in Nairobi. Working closely throughout all research stages with the two communities, including co-authorship of this book, we prioritised research-participant needs over researcher needs, aiming for minimally risky and minimally burdensome research, as well as increased trust in researchers. This involved foregoing the collection of personal data and obtaining all research input through community researchers. It led to a potential alternative to exclusion from research, namely research *led by* vulnerable groups *for* vulnerable groups.

Keywords

Research ethics • Inclusion • Leaving no one behind • Vulnerable populations

1.1 Introduction

"Leaving no one behind" encapsulates the 21st-century mission of inclusion. For the UN, it is "the central, transformative promise of the 2030 Agenda for Sustainable Development and its Sustainable Development Goals" (UNSDG n.d.). We

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believe that it should also play a role in refining research ethics for the twenty-first century.

Leaving no one behind *in research* is the vision of this book, and the first chapter will introduce the main ideas and link them to the remainder of the book. The focus will be on how community-led research may have the potential to significantly reduce the risks for certain vulnerable individuals and groups who take part in research.

We use the following definition of vulnerability:

> To be vulnerable means to face a significant probability of incurring an identifiable harm while substantially lacking ability and/or means to protect oneself. (Schroeder and Gefenas 2009)

The definition includes a distinction between those who are unable to protect themselves from harm and exploitation in research because they lack the *ability* to do so, and those who may be unable to protect themselves from harm and exploitation in research because they lack the *means* to do so. The former (lack of ability) applies to all groups who are unable to provide informed consent, because they either are still developing the cognitive abilities required (e.g. children) or have temporarily or permanently lost those abilities (e.g. those in a coma or with severe, advanced Alzheimer's disease). The latter (lack of means) applies to a wide range of groups who are said to be vulnerable, even though they could provide informed consent, prominent examples being pregnant women, persons in dependent situations and impoverished people.

Chapter 2 will present the results of a literature review on which specific groups are considered vulnerable in research today. A simplified preview is given in Table 1.1, which is based on an analysis of 57 ethics guidelines. There is a lot of disagreement in academic debates about which groups should be regarded as vulnerable in research (Hurst 2008; Solomon 2013), and more recently whether *any* groups should be labelled as such, or whether the result is overly patronising (Rogers et al. 2012), leading to additional victimisation (Wrigley and Dawson 2016).

For this reason, the table is built on an analysis of *current* ethics guidance. The groups are split into those who can be said to lack the ability to protect themselves (i.e. who cannot provide informed consent) and those who may lack the means to protect themselves. To accommodate those for whom the distinction cannot be made readily, a heading of "unclear" is added to the table. The order in which the groups are listed corresponds with the frequency with which each group is mentioned as vulnerable in the ethics guidance analysed. Where groups overlap (e.g. refugee *and* minor), only the main grouping has been listed (e.g. refugee).

By far the majority of the groups listed in Table 1.1 are *able* to provide informed consent and could theoretically protect themselves from exploitation and harm by saying "no" to involvement in research. However, saying "no" can be difficult for

Table 1.1 Vulnerable groups in research

Vulnerable group according to ethics guidance	Lacking *ability* to protect themselves	Lacking *means* to protect themselves	Unclear
People who lack the capacity to provide consent	X		
Minors	X		
Refugees		X	
Members of minoritised ethnic groups		X	
Pregnant women			X
Patients with incurable diseases			X
Students		X	
Prisoners		X	
Impoverished people		X	
People with mental health issues		X	
Patients in emergency settings		X	
Homeless people		X	
Unemployed people		X	
People in the armed forces		X	
Subordinate personnel		X	
Employees of the pharmaceutical industry		X	
Nomads		X	

many of those groups. For instance, people in the armed forces, prisoners, students and subordinate personnel might be subject to undue influence, as Table 1.2 summarises.

This book was written in collaboration with representatives from the South African San community, an Indigenous group which has historically suffered severe trauma at the hands of outsiders (e.g. genocide by colonists), and representatives from an impoverished sex worker community in Nairobi whose contributions to research have been invaluable, for instance in HIV/Aids research. One of our methodologies (for the surveys described in Chap. 3) additionally involved 12 San community researchers who had no prior experience of being involved in research teams before our work began.

The book is *not* about individuals who are *unable* to provide consent. They are outside the scope of our work. Instead, our main focus is on two groups that are a subset of the groups listed in italics in Table 1.1: minoritised ethnic groups (who include Indigenous peoples) and impoverished people (who include most sex workers in low-income settings). The reason for limiting the focus to two specific groups is that the research for this book was fully inclusive, in that it was not *about* these groups but *with* and *for* these groups. We could not have completed

Table 1.2 Vulnerability based on the potential of undue influence

Groups	Why classified as "vulnerable group" in research
Armed forces	"Human subjects research should identify military personnel as a vulnerable population. Such a classification … would acknowledge that service members are a class of individuals that is subject to coercion or undue influence." (Parasidis 2014)
Prisoners	"It is clear that prisoners are still an extremely vulnerable population, with severely restricted autonomy; thus, this issue requires special attention. Prisoners still need to be protected from the risk of coercion, undue inducement, and exploitation." (Pope et al. 2007: 117)
Students	"Students are often in potentially coercive situations, especially when the research in question is being conducted by an educator-researcher who will later assess them." (Sykes and Dullabh 2012: 224)
Subordinate personnel	"Employees who participate in employer-based research are vulnerable participants due to their susceptibility to coercion or undue influence in the work environment." (Resnik 2016: 15)

this research in the time available without confining ourselves to two groups. We do hope, however, that our findings and recommendations apply to other groups too, and will offer evidence for broader application wherever we can.

This chapter is structured as follows. The first section briefly introduces the concept of leaving no one behind, as popularised by the 2030 Agenda (UNSDG n.d.). The second section links that concept to research. All the main possibilities for leaving no one behind in research will be identified, in order to situate and pinpoint the origin of the protection-inclusion dilemma. The third section applies the distinctions made in the first section to the dilemma identified in the second, that is, the protection-inclusion dilemma (Friesen et al. 2023).

What will become clear is that prioritising research participant needs over researcher needs can significantly reduce the risks to Indigenous peoples and sex workers involved in research and simultaneously increase their trust in researchers. Our experiments involved sacrificing the collection of personal data and obtaining all research input through community researchers. We carried out non-clinical health and ethics research, and leave it to other researchers and/or future studies to determine whether our findings may also be relevant to clinical research.

How the remaining chapters contribute to ameliorating the protection-inclusion dilemma is set out in Sect. 1.3. As we will be moving from a big topic—leaving no one behind—to increasingly specific topics, we present an overview of the main topics of the book in Fig. 1.1.

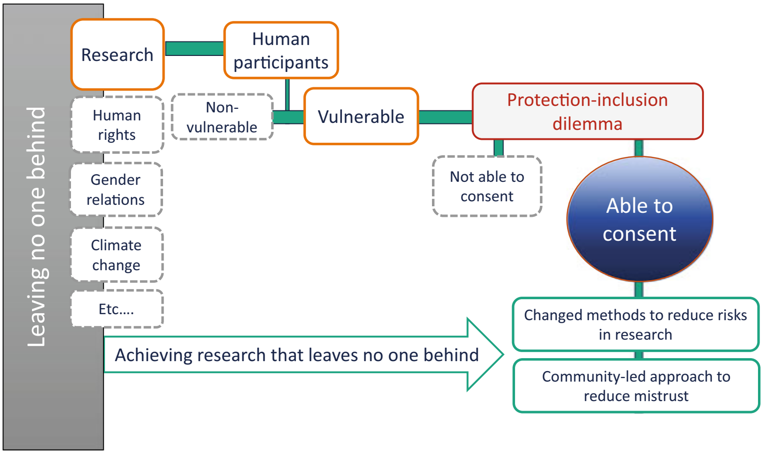

Fig. 1.1 Main topics of book

1.2 Leaving No One Behind

The concept of leaving no one behind became widespread in the development discourse when the Sustainable Development Goals (SDGs) were adopted by world leaders at a UN Summit in September 2015, and came into force on 1 January 2016 (UN n.d.). As the World Health Organization (WHO) describes them,

> Sustainable Development Goals (SDGs) aim to transform our world. They are a call to action to end poverty and inequality, protect the planet, and ensure that all people enjoy health, justice and prosperity. It is critical that no one is left behind. (WHO n.d.)

The essence of leaving no one behind can be summed up in two main points.

1.2.1 Putting the Most Disadvantaged First

Prominently in the 2030 Agenda for Sustainable Development, the signatories assure readers: “As we embark on this great collective journey, we pledge that no one will be left behind … And we will endeavour to reach the furthest behind first” (UN 2015). The second part of the pledge has been taken up regularly by others. For instance, “Reaching the furthest behind first is the answer to leaving no one behind” was the key message of a panel of prominent civil society activists, global experts and local leaders attending a meeting of the High-Level Political Forum on Sustainable Development (UN-DESA 2017). The UN plea to put the furthest behind first is reminiscent of John Rawls’s “difference principle”.

Simplified, the difference principle makes benefits for the least advantaged the decisive factor in agreeing on whether a society is just, or, as Rawls put it, “the higher expectations of those better situated are just if and only if they work as part of a scheme which improves the expectations of the least advantaged members of society" (Rawls 1999: 65). According to van Parijs (2003: 200),

> Few components of John Rawls's political philosophy have proven so epoch-making as what he somewhat oddly called the "difference principle". None has exercised as great an influence outside the circle of academic philosophers.

Similarly, in the words of Mahatma Gandhi: "Recall the face of the poorest and the weakest person you may have seen and ask yourself if the step you contemplate is going to be any use to them" (Watkins 2014). (In this book we use the terms "most disadvantaged" and "most marginalised" as synonyms for "furthest behind" and "least advantaged".)

1.2.2 Including the Voices of the Most Disadvantaged

Not only are the most disadvantaged to be helped first, but the process of formulating the SDGs also "paid particular attention to the voices of the poorest and most vulnerable" (UN 2015). This is reminiscent of a groundbreaking book published by the World Bank, *Can Anyone Hear Us? Voices of the Poor*, which collected the voices of over 40,000 poor people in 50 countries, who were asked what poverty meant to them and how it should be measured (Narayan et al. 2000). This type of inclusion namely, listening to those whose challenges are to be overcome is also a cornerstone of equitable research (Schroeder et al. 2019).

The next section explores what leaving no one behind in *research* could mean.

1.3 Leaving No One Behind in Research

Leaving no one behind *in research* can mean many things. Table 1.3 summarises the main possibilities. The list may not be complete but will suffice to show where the book's focus lies and identify the origin of the protection-inclusion dilemma, which will be discussed later. The elements of the table align with the stages of the research process, and each of these points is discussed in more detail below. Smith (1999: 10) touches on all the issues when she asks:

> Whose research is it? Who owns it? Whose interests does it serve? Who will benefit from it? Who has designed its questions and framed its scope? Who will carry it out? Who will write it up? How will the results be disseminated?

Table 1.3 Example meanings of leaving no one behind in research

No.	Source	Quote	Goal
1	The 10/90 gap (Kilama 2009)	"90% of the world's investment in health research addresses only 10% of the global health problems."	Research focus matching research needs
2	*Nature* special issue on racism (Nobles et al. 2022)	"For centuries, science has built a legacy of excluding people of colour and those from other historically marginalized groups from the scientific enterprise."	Non-discriminatory access to research positions
3	The TRUST code (TRUST 2018)	Art. 2: "Local communities and research participants should be included throughout the research process."	Equitable engagement with communities and participants
4	Task force on research affecting pregnant women, report to US congress (PRGLAC 2018)	"Include and integrate pregnant women … in the clinical research agenda. … Remove pregnant women as an example of a vulnerable population."	Inclusion of vulnerable populations
5	Universal declaration on bioethics and human rights (UNESCO 2005)	Art. 15(1): "Benefits resulting from any scientific research … should be shared with society as a whole and … in particular with developing countries."	Access to research benefits for all

1.3.1 Research Focus

The research enterprise commonly starts with decisions about which areas and topics are to be researched. For instance, in 1990, the Council on Health Research for Development discovered that only 10% of health research resources were spent on countries that saw 90% of preventable deaths worldwide (CMAJ 2004): the 10/90 gap. Thirty years later, "the imbalance between research needs and research efforts persists as most of the research effort concentrates on diseases affecting high-income countries" (Yegros-Yegros et al. 2020). In the context of leaving no one behind in research, it would clearly be in the interests of marginalised people if research efforts were better matched to their research needs.

1.3.2 Research Positions

Who has designed the research questions and framed their scope?[1] Who will carry out the research? Who will write it up? These questions from Tuhiwai Smith are

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[1] For the purpose of this brief overview, it is not necessary to distinguish between funders who design research questions with very prescriptive calls and the researchers carrying out the research.

about the researchers, the vast majority of whom are based in high-income countries with a high statistical likelihood of being white and male. "Taken together, the G20[2] countries boast 88.8% of the world's researchers, 93.2% of research spending and 90.6% of scientific publications" (Naujokaitytė 2021). In a 2021 *Nature* survey among scientific researchers, "82% of respondents in the United Kingdom, 81% in Germany and 74% in the United States identified themselves as White" (Woolston 2021). At the same time, fewer than 30% of researchers worldwide are women (Shannon et al. 2019). Even though researchers generally have a university education and are therefore unlikely to be among the most disadvantaged that the "leaving no one behind" agenda targets, it is crucial that leaving no one behind in research includes ending all forms of discrimination or biased practices, such as appointing people who are similar to oneself (affinity bias) (Gibney 2022).

1.3.3 Involving Communities and Participants in Research

The research enterprise often includes local communities—as in the case of climate change research, which requires access to soil (Jansson and Hofmockel 2020)—or research participants, as in the case of most medical research. As Apolot (Nelson et al. 2021) notes in the context of leaving no one behind in research:

> Your life as a researcher will get much easier if you listen … when you design and do everything with the community, instead of imposing your ideas on them, then the process will work much better.

Equitable engagement with local communities and research participants brings leaving no one behind in research into the realm of research ethics. It is not only beneficial for the research, as Apolot notes, to work closely with local communities and research participants, but also fairer, especially when vulnerable people and power imbalances are involved (Schroeder et al. 2019).

1.3.4 Involving Pregnant Women in Research

At first sight, the demand to include pregnant women, and by implication their foetuses, in research (possibly as an example for other vulnerable populations) looks very similar to all the other calls, as though equity reasons should drive inclusion demands. Pregnant women are commonly regarded as a vulnerable group (Table 1.1), and this perception has led to their widespread exclusion from research (Ballantyne and Rogers 2016). According to Ballantyne and Rogers (2016), there is a tendency towards blanket exclusion rather than risk mitigation, because how

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[2] "The G20 or Group of Twenty is one of the most powerful multilateral platforms today. It plays an important role in shaping and strengthening global governance on all major international economic issues". (Chaturvedi et al. 2023)

pregnancy renders a person vulnerable is not well defined. The result of this blanket exclusion from research is a gap in medical knowledge, with repercussions for medical practice. In this example, excluding pregnant women from research leaves the knowledge base on safe and effective medication for use during pregnancy missing or incomplete, potentially resulting in significant harm to pregnant patients in general (Zur 2023).

A closer look reveals that pregnant women are left behind as a *group* because it may be too risky for certain *individual* pregnant women to take part in medical research. However, if *some* pregnant women were to accept the risks of potential harm for themselves and their foetuses, *all* pregnant women and public health could gain. This distinction between the individual on the one hand and the group and public health on the other hand is different for the other cases listed in Table 1.3, as explained below. It explains the essence of the protection-inclusion dilemma. Let us look at the last possibility for not leaving groups behind in research before we return to that point.

1.3.5 Research Benefits

Who will benefit from the research? This is one of Tuhiwai Smith's most powerful questions. "Those who are paid to do the research" is one narrow answer, aligned with Tuhiwai Smith's (1999: 3) criticism that unwanted research in her community "suggested things that would not work, and made careers for people who already had jobs". However, in line with the Universal Declaration on Bioethics and Human Rights (UNESCO 2005), we take the benefits of research to mean the fruits of research: for instance, insights into how to improve processes, or innovative products and services.

The *Leave No One Behind: Strengthening Health Systems for UHC and the SDGs in Africa* report by WHO Africa (2017) calls for health services that are "responsive to the population needs and provided in a manner that guarantees equitable access" (WHO 2017: 3). This aligns with access to the fruits of research, in the sense of, for instance, access to medical products for everybody.

According to Jeffrey Sachs, "there is enough in the world for everyone to live free of poverty and it won't require a big effort on the part of big countries to help poor ones" (Xinhua 2018). Access to the fruits of research is possibly the most urgent of the five goals discussed here, as it has the potential to reduce preventable mortality and morbidity in the most disadvantaged populations most quickly. And it does not have to be medical research. Poor nutrition, indoor air pollution and lack of access to proper sanitation and health education are major contributors to poverty-related preventable mortality and morbidity, and questions about reducing indoor air pollution could be addressed, for example, through research undertaken by engineers (Smith 2002).

Based on the distinctions drawn in Table 1.3, we now explain the protection-inclusion dilemma in research.

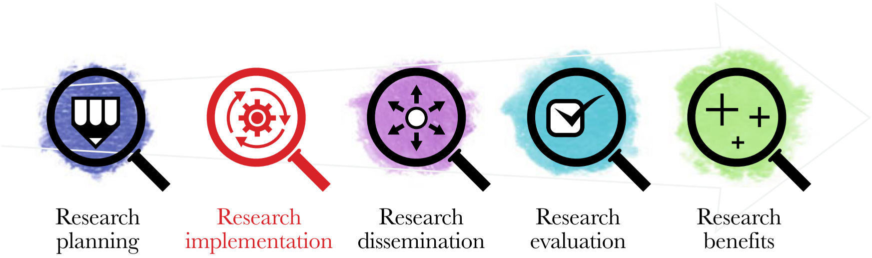

Fig. 1.2 Main stages of research

1.4 The Protection-Inclusion Dilemma in Research

The protection-inclusion dilemma occurs at one particular research stage, implementation (Fig. 1.2).

Research implementation has been highlighted in red in Fig. 1.2 for the following reason. Of the five stages of research[3] listed, *only one* can often be risky and burdensome, and then only for a subset of the people involved, and that is research implementation. While research implementation can carry some risks for researchers, such as health and safety risks in work with infectious agents, it is mostly research participants who endure risks and burdens in research. By taking part in research, they enable the process of science and wider community benefits such as new products, services and processes.

This dilemma is similar to other dilemmas where the wider community benefits from the actions of a small group. For instance, Germany now generates over 40% of its electricity from wind, sun, water or biomass (BMWK n.d.), yet individual villages are often opposed to wind farms "in their back yard" (Bürgerbegehren Rettet den Dömlingsberg n.d.). A typical argument from such a village is that while the benefits of green electricity may be enjoyed by all, wind generators uglify *their* particular landscape (Bürgerbegehren Rettet den Dömlingsberg n.d.). This is the scenario from which the protection-inclusion dilemma derives.

Inclusion is often regarded as an incontrovertibly good thing. For instance, UN Women argue, referring back to the 2030 Agenda and the SDGs, that "women's equal participation and leadership in political and public life are essential to achieving the Sustainable Development Goals by 2030" (UN Women 2023). And inclusion is clearly a good thing for four out of the five stages set out

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[3] This is a simplified diagram. Often there is no separate stage of research evaluation (e.g. Could the methods be improved for the next project? Could resources be used more efficiently?), and research evaluation may occur before research dissemination. However, these facts are not relevant to the point being made here.

in Table 1.3—inclusive research focus, inclusive hiring of researchers, inclusive research engagement and inclusive research benefits for humanity—but not when it comes to the inclusion of vulnerable groups or individuals in research.

The inclusion of research participants in research (and of villages among the locations of wind farms for the benefit of the broader community) is not necessarily a good thing for *all* involved, because potential harms and burdens are carried by a small group for the benefit of a larger group.

The fact that in research some carry risks and burdens for the benefit of others is a dilemma that is particularly pressing when research participants are from a vulnerable group. The Declaration of Helsinki therefore imposes significant restrictions on such research:

> Medical research with a vulnerable group is only justified if the research is responsive to the health needs or priorities of this group and the research cannot be carried out in a non-vulnerable group. In addition, this group should stand to benefit from the knowledge, practices or interventions that result from the research. (WMA 2013: Art. 20)

In other words, the Declaration of Helsinki protects vulnerable individuals from potential harm and exploitation by *excluding* them from most medical research, which is protection through *exclusion*. Because leaving no one behind is the diametric opposite of exclusion, we consider in the next section how the two constituent parts of leaving no one behind identified earlier can assist in addressing the protection-inclusion dilemma in research.

1.4.1 The Most Disadvantaged First in Research?

The first point we identified from the "leaving no one behind" mission of the 2030 Agenda was the ambition to put the most disadvantaged first. How would that work in research implementation, and what implications would it have for research ethics?

Staying within the framework of Rawlsian analysis, the "most needy members of society [are those that]… lack basic necessities such as food, shelter, and safety" (Green 2013: 124). This Rawlsian-inspired definition of the most disadvantaged aligns with the first two SDGs, which aim to fight poverty and hunger (UN-DESA n.d.).

One could argue that the protection-inclusion dilemma is at its harshest in this group. To avoid a double burden, one could reasonably say, those who are already highly disadvantaged should not be burdened with involvement in research. Table 1.4 provides examples of types of research that have harmed research participants in the past 20 years, with one example from 30 years ago. All examples focus on vulnerable populations as listed in Table 1.1.

The cases listed in Table 1.4 focus on adults who had the ability to provide informed consent and who took part in a variety of research studies, not just clinical research. They were harmed as a result. Being involved in research is not

Table 1.4 Studies in which vulnerable populations have incurred harm through research involvement

Type of research	Study	Harm incurred
1. Placebo-arm research	From 1998 to 2015, health research in India examined whether higher-cost cervical cancer screening could be replaced with an examination undertaken by trained health care workers. The Indian standard of care for testing for cervical cancer is cytology screening. However, the standard of care for the study was misconstrued as no screening. As a result, 141,000 women were placed in a no-screening arm of the study. At least "two hundred and fifty-four women in the no-screening arm died due to cervical cancer" (Srinivasan et al. 2018)	Deaths
2. Health examination as part of clinical study	In 2006,[4] a Chinese patient involved in a clinical trial for anticoagulants needed to be resuscitated, not because of the drug testing regime but because of double lower-limb vein angiography that was part of the study protocol and to which she reacted severely (Cong 2018). She was only compensated seven years after the event and only after protracted legal action	Severe harm to health and equity issue about protracted delay of compensation

(continued)

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[4] In 2006, China's GDP per capita was US$2099. It has since grown sixfold to US$12,720 (Macrotrends n.d.). This puts China in 2006 into the lower-middle-income bracket, according to the World Bank lending group categorisation (World Bank n.d.), which is the why the elderly Chinese research participant would likely have been labelled as belonging to the vulnerable group of "impoverished people" at the time.

Table 1.4 (continued)

Type of research	Study	Harm incurred
3. Genetic research	Genetic research involving four illiterate San elders led to a *Nature* publication in 2010 (Schuster et al. 2010), which had the potential to lead to "embarrassment, discrimination and collective psychological damage" (Chennells and Steenkamp 2018) for the San. No community approval had been obtained, pejorative words like "bushmen" were used, the San were grouped as Khoisan, an unacceptable (to the San) lumping together of different groups coined in 1928 by a foreign researcher, and pejorative statements were made, such as "many Bushmen women tried to uplift their status via marriage to Bantu men". Requests from the San leadership to see evidence of informed consent from the four illiterate San were not acted upon by the researchers	Discrimination and potential collective psychological damage of an already disadvantaged group Disrespect to local leadership structures
4. Biological sample research	In 1993 and 1994, a South African hospital automatically enrolled all patients who were admitted to their intensive care unit in a research study. The study examined whether HIV/AIDS patients had a worse health outcome than those without the virus. Upon admission, the patient's HIV status was determined, without their consent, thus creating a "risk of having their HIV status disclosed" (Bhagwanjee et al. 1997)	Stigmatisation, and right not to know disrespected

(continued)

Table 1.4 (continued)

Type of research	Study	Harm incurred
5. Medical anthropological research	In 2014, survivors of Ebola virus disease (EVD) in Liberia were involved in the collection of research data by a foreign researcher without ethics approval. The "researcher used the cover of 'emergency research' to avoid the review process" (Tegli 2018). When the researcher tried to obtain retrospective ethics approval to publish the results, it became clear that "the autonomy of the EVD survivors who were research participants had been breached" (Tegli 2018)	Exploitation of unwitting research participants during times of crisis
6. Socio-anthropological research	A socio-anthropological study undertaken by a humanitarian non-governmental organisation identified criminal acts (female genital mutilation) in the context of exploring health-seeking behaviours to address child malnutrition. The research led to community complaints as the "community felt betrayed because the research did not respond to their needs and priorities, and contributed to stigmatizing their culture" (Luc and Altare 2018)	Stigmatisation without local benefit

(continued)

Table 1.4 (continued)

Type of research	Study	Harm incurred
7. Psychological research	A study published in 2013 undertook an experiment with a deliberately unprofessional researcher who displayed “a brusque demeanor” and “made little or no eye contact” (Boynton et al. 2013). Feedback from the research participants, who were psychology students, reported negative perceptions of their study experience and negative emotions (Boynton et al. 2013)	Negative emotions
8. Social science research	A “woman publicly exposed as a sex worker can face severe life-threatening consequences, such as arrest, eviction from home, violence, [and] social boycott” (Sinha 2017). Such exposure can occur through personal data collection for research purposes (see Chap. 4)	Violence

only potentially harmful but also burdensome in the time required for the study itself and for the informed consent procedure. For instance, a study evaluating the informed consent process for clinical research in the UK and Ireland found that the “mean time taken for the research participant’s last informed consent discussion was 51 min” (O’Sullivan et al. 2021). For one person, the discussion took 300 min (O’Sullivan et al. 2021).

Given the above examples of harm done to individuals from vulnerable populations who took part in research, protection through exclusion seems to be an approach that makes sense for the most disadvantaged groups, the target of the “leaving no one behind” agenda. In terms of the Declaration of Helsinki, research involving these groups would still be possible if it could not be undertaken on a non-vulnerable group, if it aligned with the health needs of the vulnerable group and if the results of the research were accessible to the group (WMA 2013: Art. 20). However,

> A central challenge at the heart of planning and reviewing research involving vulnerable populations is a paradox that overprotection can block needed research, while research without adequate support and benefits can worsen vulnerabilities. (Molyneux et al. 2021)

One answer to the protection-inclusion dilemma that has been emerging strongly over the past decade consists of avoiding the categorical approach to vulnerability (Gordon 2020) and focusing on *situations* that make people vulnerable rather than labelling entire groups as such (Gordon 2020). Hence, it is wrong to use a black-and-white approach which assumes that somebody is either vulnerable and ought to be excluded from research or not vulnerable and therefore fit to be included in research. Such an approach

> does not account for variation in the degree of vulnerability within the group based on individual characteristics, and classifies certain persons as vulnerable rather than identifying situations in which individuals might be considered vulnerable. The alternate contextual approach allows for a more nuanced understanding of the nature of the vulnerability than the categorical approach and therefore a more focused approach to safeguards. (Gordon 2020)

A contextual approach also takes account of the significant difference between those people who are vulnerable because they lack the ability to defend themselves against exploitation (e.g. those with very advanced Alzheimer's disease) and those who lack the means to defend themselves against exploitation (e.g. impoverished, illiterate people). The situation of the latter group may be transient, in that they may learn to read and may find a way of making a secure living. In that case, they would previously have been in a *situation* of vulnerability. We fully agree with this approach, which has also been taken by some ethics guidance drafters.

For instance, in 2018, the International Ethical Guidelines for Health-Related Research Involving Humans by the Council for International Organizations of Medical Sciences (CIOMS) noted that they did not want to label “entire classes of individuals as vulnerable” (CIOMS 2016: 57). Instead, they wanted to look at “specific characteristics that may render individuals” prone to harm or exploitation and then identify mechanisms for better protection (CIOMS 2016: 57).

We would like to turn to another approach to resolving the protection-inclusion dilemma for at least some types of research and at least some vulnerable groups. We want to focus on the *minimal risk, minimal burden* element of research. This exemption from involvement in research for vulnerable populations even applies to those who are unable to consent. The Oviedo Convention (Council of Europe 1997) allows research involving participants who are unable to consent if the research has the potential to benefit the group and if it “entails only minimal risk and minimal burden for the individual concerned” (Council of Europe 1997: Art. 17(2)(ii)). Likewise, the Declaration of Helsinki allows research with those unable to give consent if it can “promote the health of the group represented by the potential subject, the research cannot instead be performed with persons capable of providing informed consent, and the research entails only minimal risk and minimal burden” (WMA 2013: Art. 28).

It might be assumed that research entailing minimal harm and minimal burden can always involve vulnerable individuals if all other relevant requirements are observed (a match to research needs, informed consent, community approval and access to results). However, this is not the case. Such research can be blocked for a variety of reasons, all related to the *labelling* of particular groups as vulnerable and the recommendation to protect them through exclusion. Research can even be deterred for the sole reason that research ethics committees are likely to exclude vulnerable groups from research anyway.

For instance, a UK study found that the reason why prisoners were rarely involved in research was not so much that it was impossible to address ethics concerns, but that researchers regarded the burden of overcoming governance hurdles as too great (Charles et al. 2016: 1). Or, as we will see in Chap. 2, research involving vulnerable populations in low- and middle-income countries (LMICs) is blocked by research ethics committees from high-income countries (HICs) in an act of "remote paternalism" aiming to protect via exclusion. This can also happen because the "culture of ethics review … has been considered overly risk averse" and "protectionist in nature" (Friesen et al. 2023).

Instead, as the CIOMS (2018) guidelines recommend, better mechanisms for protection in research are needed as a more nuanced way to protect vulnerable populations. If the research only involved minimal risk and minimal burden, this would be an ideal way of moving forward.

One possible obstacle to this approach is that not much research seems to satisfy the criterion of minimal risk and minimal burden. In fact, as the Declaration of Helsinki notes: "In medical practice and in medical research, most interventions involve risks and burdens" (WMA 2013: Art. 16).

We believe that the potential exists to increase the number of research studies that could meet the description of minimal risk and minimal burden, if scientists were willing to look critically at their methods. In other words, opportunities for minimally risky and minimally burdensome research involving vulnerable populations could be increased by deprioritising traditional methodological scenarios.

As we will see in Chap. 4, many Nairobi sex workers are highly reluctant to take part in research that collects personal data. There is a particular fear that involvement in research will reveal to third parties, such as landlords or family members, that the person earns his or her living with sex work. An even greater fear, taking into account that sex work is illegal in Kenya, is that personal data will be revealed to law enforcement agents. Chap. 4 will explain some of the consequences of revealing sex work as an occupation to outsiders—consequences that include rape and other violent abuse.

By undertaking research without personal data collection, one can prioritise research participants' interests over researchers' interests. Working with two communities that suffer from high stigmatisation, we sacrificed—from a researcher's perspective—the benefit of obtaining personal data from research encounters with these communities. Research for this book involved data from 239 South African

Indigenous San community members, 19 highly marginalised Nairobi sex workers, and just under 90 delegates from both groups who took part in consultation workshops, but no personal data were recorded for research purposes.

South African San community members are also often reluctant to take part in research because of previous community experiences of exploitation. When recounting the drive towards the San Code of Research Ethics, San leaders recalled:

> The San peoples … have been the object of much academic research over the past centuries. In recent years San leaders have, with increasing confidence, arrived at the conclusion that most academic research on their communities was neither requested, nor useful, nor protected in any meaningful way. In many cases, dissatisfaction if not actual harm was the result. (Chennells and Schroeder 2019: 4)

Tailoring our methods to the needs and wishes of the San community, and trying to respond to the mistrust generated by prior encounters with researchers for whom the extraction of knowledge, samples or data had been paramount (Chennells and Schroeder 2019), we obtained all data through community researchers, and there was no in-person engagement between community members and overseas researchers.

We applied the two approaches—no collection of personal data and all research engagement conducted through community researchers—to our research in both communities. We hoped that these two measures would *increase* the possibility of conducting research with vulnerable groups in a minimally risky and minimally burdensome way. This would then counteract the exclusion approach to protecting vulnerable groups in research sometimes taken by research ethics committees (Chap. 2). Why? Because the Oviedo Convention and the Declaration of Helsinki both allow minimally risky, minimally burdensome research that is tailored to local research even when the participants are *unable* to provide consent (Council of Europe 1997: Art. 17(2)(ii), WMA 2013: Art. 28). Hence, it should certainly be acceptable for those who are regarded as vulnerable but still able to consent.

1.5 Voices of the Most Disadvantaged Heard?

The second part of the mission to leave no one behind set out earlier is the obligation to ensure that the most disadvantaged are heard. From a research benefit perspective, this aligns with best practice whenever a service is developed for the disadvantaged. For instance, Lathrop et al. (2022) observe: “Respecting people, hearing their stories, and inviting them to share their stories” can contribute to the empowerment of marginalised communities. Livingston (2018) advocates listening to the marginalised as a way of supporting them, when he says that “by listening to individuals’ concerns, we not only connect with their need, but help personalise the experience of support provided” (Livingston 2018).

However, one of the main challenges of this approach is mistrust of researchers on the part of communities and individuals. The following factors have all contributed:

- long-standing, including colonial, exploitation (Smith 1999)
- 21st-century ethics dumping (Schroeder et al. 2018)
- the impact of exploitation by non-researchers, e.g. the media, on the relationship with researchers (Chennells and Schroeder 2019: 19)
- patronising or culturally inappropriate practices (Schroeder et al. 2021).

These factors are also why a considerable literature exists on how to reach hard-to-reach groups (Van der Ven et al. 2022).

In the cases of the two highly stigmatised and marginalised groups represented in this book, the South African San and the Kenyan sex workers, we found a way to listen while not intruding unnecessarily into the private spheres of those who contributed to the research.

Working closely throughout all research stages with the two communities, who are also represented among the authors of this book, we prioritised research participant needs over researcher needs, aiming for minimally risky and minimally burdensome research as well as increased trust in researchers. This involved foregoing the collection of personal data and obtaining all research input through community researchers. It led to an alternative to exclusion from research, namely research *led by* vulnerable groups *for* vulnerable groups. We hope this book shows that the approach worked, at least for ethics research on the topic of vulnerability and within the domain of non-clinical health research (e.g. an increase in HIV infections). Table 1.5 summarises the structure of the book.

Table 1.5 Structure of book

	Summary of content
This chapter	Introduction of the protection-inclusion dilemma in the context of leaving no one behind in research
Chapter 2	Analysis of 57 ethics guidance documents which advise on the involvement of vulnerable populations in research Interview study with researchers experienced in involving vulnerable populations in research, with a particular emphasis on their collaboration with research ethics committees
Chapter 3	Results of community-led workshops and surveys on what vulnerability means for the South African San community
Chapter 4	Results of community-led workshops and conversations on what vulnerability means for the Nairobi sex workers
Chapter 5	Overview of “engaged research” with a special emphasis on involving community researchers in research. A case study of 12 San community researchers provides rare input from a lower-income setting
Chapter 6	Recommendations and conclusions

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The Exclusion of Vulnerable Populations from Research

2

Abstract

What do ethics codes and guidelines tell us about who is vulnerable in research? To what are they vulnerable? And how might this vulnerability be addressed? These questions guided our analysis of 57 research ethics codes and guidelines that mention the involvement of vulnerable persons in research. The chapter draws upon the findings from this analysis to help explain how and why some people might be excluded from research *unnecessarily*. The investigation is also informed by the findings from an empirical study into the perspectives of 22 researchers who have extensive experience of undertaking research with vulnerable individuals. Their encounters with research governance measures, including research ethics approval and research ethics codes, expose challenges that can exacerbate unnecessary exclusion from research. We learn from the researchers and the research ethics codes that governance measures intended to protect the vulnerable from exploitation in research can lead to unfair exclusion when applied in a blanket fashion. Research governance guidelines and processes must encourage a more nuanced understanding of what it means to be vulnerable in research to ensure that people are not left behind unnecessarily.

Keywords

Research governance • Research ethics codes • Excluding vulnerable populations • Types of vulnerability in research • Unfair exclusion in research • Paternalism in research

2.1 Introduction

The main purpose of this chapter is to explain how some groups of vulnerable people are left behind in research *unnecessarily*. This can happen when regulatory and governance mechanisms, including research ethics codes and research ethics

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committees, serve to exclude or restrict the participation of vulnerable persons in ways that could be avoided. The chapter is informed by findings from an empirical investigation into the experiences and opinions of researchers who work with vulnerable individuals, as well as a review of research ethics codes and guidelines to find out what they have to say about the inclusion or exclusion of vulnerable persons in research.

2.2 The Regulation and Governance of Research

In Carol Levine's often repeated statement, research ethics was "born in scandal and reared in protectionism" (Levine 1988: 167), and its evolution has followed a pattern of crisis and response (Marshall 2002). Early medical experiments by physicians and biomedical scientists led to great advances in healthcare such as the discovery of a vaccine for smallpox in 1796. However, as science advanced, cases came to light of the use of vulnerable individuals as human guinea pigs, including enslaved black women (Wall 2006), orphaned children and prisoners (Lederer 1995).

Revelations about the exploitation of people in the name of science motivated the development of the first ethics codes and governance mechanisms in research. The Nuremberg Code was formulated in 1947 as a direct response to the abhorrent medical experiments by Nazi and Japanese doctors during the Second World War (Shuster 1998), and in 1964 the World Medical Association published the Declaration of Helsinki (WMA 2013). This declaration is a statement of 37 principles for medical research involving human participants, human materials and human data, and remains the most influential ethics code globally. Despite its enduring influence, the Declaration of Helsinki has not brought exploitation to an end, and the development of research ethics codes and guidance has continued. For instance, revelations about dishonesty and the withholding of treatment in the notorious Tuskegee Syphilis Study (1932–1972) (Heller 1972) prompted the development of the Belmont Report in the US in 1978 (Beauchamp 2008).

Nowadays, there is a plethora of ethics codes for professional organisations, businesses, government agencies and other institutions around the world with around 4000 examples held in the Ethics Codes Collection (ECC), the world's largest online collection of codes of ethics and ethical guidelines (CSEP n.d.). Many of these codes are devoted to or include matters of research ethics. Different professional associations, government agencies and universities have adopted specific codes, rules and policies for ethics governance in research (Resnik 2020).

In addition to research ethics codes, research governance mechanisms typically include a system of ethics approval for individual studies, with the development of these systems also prompted by ethics scandals. In 1966, the United States medical profession "was hit with a bombshell" (Stark 2016: 2374) when Henry Beecher published an article exposing 22 unethical studies in biomedical research. Beecher (1966) revealed that many participants never had risks explained to them, nor did they know that they were participants in an experiment. His revelations about unethical research prompted the implementation of federal rules governing the conduct of human experimentation in the United States (Harkness et al. 2001). At that point, ethics-related regulations were introduced for nearly all American-funded research around the world (Stark 2016). In the United Kingdom, where researchers were in receipt of American funding, ad hoc committees were introduced hastily, and in May 1967, the newly established Committee on the Ethical Supervision of Clinical Investigations in Institutions (set up by the Royal College of Physicians) met for the first time. The recommendations from the meeting included that each hospital authority had "a responsibility to ensure that all clinical investigations carried out within its hospital or institution are ethical and conducted with the optimum technical skill and precautions for safety" (Hedgecoe 2009: 336).

Today, research ethics committees (RECs)—also referred to as institutional review boards (IRBs) or ethics review boards (ERBs)—and REC review are commonly regarded as synonymous with research ethics. However, research governance in its entirety consists of a complex network of ethics codes and guidance, funder requirements and legal requirements, which can differ according to discipline, country and level of international collaboration, as well as individual institutional policies and systems of oversight (see Fig. 2.1). Together, these requirements, guidance documents and systems of oversight are designed to help maintain appropriate standards in research ethics and research integrity.

Figure 2.1 provides an overview insight into the research governance landscape that a researcher must navigate, which is particularly complex when the research being conducted crosses borders and disciplines and involves people who are considered vulnerable.

In the broadest sense, *research ethics* includes all issues of a moral nature that are associated with the planning, conduct, dissemination and impacts of research, while *research integrity* has a more demarcated meaning, specifically concerned with research quality and forms of research misconduct like fabrication, falsification and plagiarism (Poff 2014).

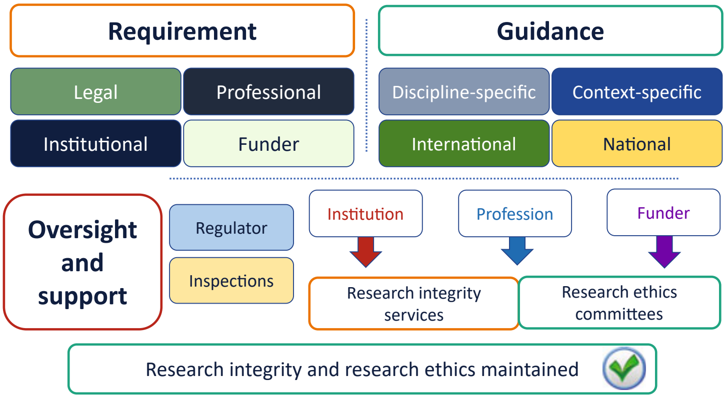

Fig. 2.1 Research governance overview

As the focus of this book is on vulnerable research participants and vulnerable groups that might take part in research, the next section reports on researchers' opinions and their experiences of ethics approval systems when seeking to conduct research with vulnerable individuals.

2.3 Research Ethics Approval Systems and Vulnerability

In recent years research ethics approval processes have been the subject of a fair amount of criticism, with many researchers expressing frustration about their experiences of seeking ethics approval. For instance, ethics review has been described as a dreaded bureaucracy (Pickersgill 2012) and as a hurdle to overcome and a power game (Roets 2017), with researchers feeling they have to "play the game" in order to obtain approval (Vermeylen and Clark 2017). Frustrations have been ascribed to inconsistency between different ethics committees (Guta et al. 2013) and REC overreach in commenting on issues viewed as beyond the scope of ethics review (Gunnison and Helfgott 2021). Other concerns relate to a perceived lack of transparency in the ethics review process, with some researchers believing that ethics committees can "behave like county sheriffs—with no rhyme or reason in the assessment decisions made between boards" (Calfano 2016: 304). In addition, it is reported that many research ethics committees have "routinised" the ethics review process, leading to a checklist-based approach to assessing the sometimes complex ethical implications of research projects (Cox et al. 2020). Consequently, it is maintained, researchers go through the motions of ticking the "right boxes" or "saying the right thing" rather than thinking through the relevant ethical principles (Dyer and Demeritt 2009).

Against the backdrop of these criticisms, we investigated the experiences and opinions of researchers about governance measures that apply to the inclusion (or exclusion) of vulnerable populations in research. Their insights are essential for analysing how systems and processes work in practice and where changes might be needed. We know that research ethics approval mechanisms generally incorporate a protectionist approach (see Sect. 2.4), but can they also provide an enabling environment for the ethical inclusion of vulnerable populations? To inform this perspective on research governance we spoke with researchers around the world who are highly experienced in working with vulnerable populations. What follows is a brief overview of how we conducted this investigation and what the researchers had to say about the ethics approval process.

2.3.1 Investigating the Experiences and Perspectives of Researchers Who Work with Vulnerable Populations

2.3.1.1 The Method

Researchers with experience of working with vulnerable populations were identified via reputation, existing networks or snowballing (recommendations from other researchers). We wanted to include people with wide-ranging experience, who worked with different groups, across different fields and in different countries. It was important to us that at least half of the final number should have experience of working with vulnerable populations in low- and middle-income countries (LMICs).

Initial contact was made via an email, with an information sheet attached, which invited interested researchers to consent via Microsoft Forms. The method of interaction with the researchers and data collection was experimental to some extent, because we were seeking to explore ways of working that minimised power imbalances. Unlike traditional qualitative interviews, this investigation employed peer-to-peer conversations, similar to "participatory conversations" that involve interactive dialogue between the researcher and other(s) (Swain and King 2022), but also resembling "conversations with a purpose" as used in anthropology (Burgess 1988). The approach taken to the conversation was informal: a discussion between peers rather than a researcher–interviewee interaction, but with a specific purpose in mind.

Conversations took place online via Microsoft Teams and lasted around 45 min. To try to reduce the processing of personal data, an audio recording was made, but this was not transcribed verbatim as would be routine for interview research. Instead, notes were made from the recording to summarise the primary findings. After this, the recording was destroyed. For one researcher, who did not want to be audio-recorded, notes were made during the online conversation. These measures helped to minimise the processing of personal data. Data analysis was undertaken in an iterative manner. For this chapter, only the information related to experiences and opinions about ethics approval were extracted and themed.

2.3.1.2 The Findings

Conversations were held with 22 highly experienced researchers who had collective experience of working across a wide range of fields with persons from the following groups:

- Refugees
- Pregnant refugees
- Asylum seekers
- Undocumented migrants
- Evacuees from armed conflicts
- Homeless people
- People with mental health concerns
- Domestic abuse survivors
- People with cognitive disorders
- Unconscious patients
- Prisoners
- Young offenders
- Sex workers
- People with drug dependency/substance abuse
- People with post-traumatic stress disorder (PTSD)
- Members of minoritised ethnic groups
- People living in extreme poverty
- People with stigmatised conditions like HIV, TB and syphilis
- People who engage in activities that are against the law in their country, like men who have sex with men
- Indigenous communities
- People with multiple traumas

Additionally, several researchers mentioned that intersectional, complex vulnerabilities were the norm for participants in their projects. Of the 22 researchers, eight conducted their research in high-income countries (HICs)—four of these with refugees and asylum seekers—nine conducted their research in LMICs and five had experience of working in both HICs and LMICs.

Most of the researchers we spoke with employed social science/qualitative approaches, and many spanned disciplines (for instance, midwifery and social science, or nursing and anthropology). The type of research they undertook did not necessarily reflect the field in which they had originally been trained. While most were involved in health or wellbeing-related research, only three of the 22 were exclusively involved in clinical research.

2.3.1.3 Challenges

Insights from the researchers revealed that most had encountered challenges with the research ethics approval process, although experiences and opinions varied widely. The five most significant challenges are shown in Table 2.1 and explained further below.

Different Priorities The researchers we spoke with noted a divergence in priorities between themselves and the REC members when RECs demanded compliance with institutional requirements while the researchers wanted to prioritise a community's wishes and perspectives: for instance, when RECs insisted that legal information about data processing be added to the information sheets in a certain format while the researcher knew that legalistic language would raise fears and could act as a barrier with specific populations (e.g. undocumented migrants), or required all information to be written on the information sheets even when

Table 2.1 Perceived challenges when seeking ethics approval for research involving vulnerable individuals

Challenge	Meaning
1. Different priorities	The researchers and the REC members prioritise different things
2. Subjectivity	REC review is subjective and varies according to who is reviewing the proposal
3. Time taken	Approval processes can lead to long delays
4. Understanding the methods/approach	The REC members might not be familiar with the proposed methods/approach
5. Paternalism	REC members take a paternalistic and risk-averse approach

this was likely to be overwhelming or not understood. In general, there were concerns about the application of generic institutional ways of protecting participants, rather than a nuanced approach. Often RECs had established ways of doing things, the researchers noted, and they could struggle when people wanted to do things differently.

Subjectivity in the Process Most of the researchers we spoke with had experience of seeking approvals from a number of different RECs. It was a common observation that RECs fared differently in terms of level of scrutiny, the time taken to review, the questions asked and the rigour with which proposals were reviewed. It was also noted that review depended largely upon which particular members of the committee were looking at the application, because people from different backgrounds would bring their own beliefs with them. Mostly, researchers regarded the quality of feedback from their RECs as good, but sometimes there were requirements and remarks that they saw as nonsensical: for instance, asking for information about women being trafficked, when the research had nothing to do with trafficking.

On the subject of vulnerability, the researchers noted that some REC members were more risk-averse than others, meaning that ethics approval for the inclusion of vulnerable individuals in research was harder to obtain from those members. This might depend upon the familiarity of the REC members with the location, population or specific circumstances of the study concerned. Two researchers commented that they had observed a big difference between African RECs and those in the UK, Europe and the US. They noted that RECs in these HICs were more ready to label approaches as unethical.

Time Taken Some of the researchers had experienced months of delays associated with ethics approval, leading to obvious frustration. They ascribed this to a number of factors:

- delays early in their research careers, before they became used to the ethics approval systems

- approval being sought from a number of different committees
- approval being sought from an under-resourced committee
- disagreements/negotiations between the researcher and the REC regarding certain processes (such as informed consent processes).

Difficulties Understanding the Methods or Approach A common observation was that RECs can push back if the proposed research methodology does not fit in with their understanding of what approach should be taken in the research and how the study should be conducted. This seems to be a greater problem for co-created, participatory forms of research than for other approaches because it is more difficult to provide a clearly defined protocol at the proposal stage. For participatory research, the proposal has to be developed and/or refined in conjunction with the research participants, and this often happens in the early phases of the study, *after* ethics approval. It can also be a problem in research with Indigenous populations—a problem that some of the researchers associated with colonialist perspectives and a lack of appreciation for Indigenous research methods and knowledge creation.

Several had experienced condescending attitudes, with REC members asking, "What's the point of this research?" or making pejorative statements like "This is not research!" Among those researchers who engaged in participatory research, there was the perception that ethics approval faced more challenges than other types of research, especially with RECs that were unfamiliar with the approach.

Paternalism and Risk-Averse Attitudes A common theme to emerge in conversation concerned the risk-averse and sometimes paternalistic attitude of some REC members. RECs are concerned with protection: when they spot the inclusion of a "vulnerable" group, they want to know why it is included, the risks involved and the special protective measures to be taken. According to the researchers in this study, these demands sometimes go too far. For instance, RECs can be concerned about traumatisation during an interview and automatically take the stance that the participants will be upset. Interestingly, researchers in this study, who worked with highly vulnerable individuals, had not experienced this as an issue. In fact, the opposite had been observed, namely, that people were able to report their traumas without becoming overly distressed and appreciated someone taking the time to listen to them. If these people were to be excluded from research for paternalistic reasons, they said, they would effectively be silenced.

The unjust exclusion of people perceived as vulnerable was viewed as paternalistic, as was the tendency to lay down too many conditions or ask for unnecessary changes to the protocol. It could seem as if there was no confidence in the capacity of the vulnerable to make wise decisions. Researchers who had experience of both HIC and LMIC RECs had observed paternalism only from HIC RECs, even where the research was to be based in an LMIC: thus, a type of remote paternalism. Getting the balance right between protection and inclusion was generally regarded as a challenge (see also Chap. 1), but not an insurmountable one.

2.3.1.4 Benefits

Insights from the researchers also brought to light benefits associated with going through the research ethics approval process. While most had experienced some challenges, a few had only positive things to say about the REC approval process. Indeed, most of the researchers expressed deep-felt appreciation for the feedback and support they received from experienced RECs. The primary benefits included:

- the REC's careful consideration of every detail of the study
- a heightened understanding of the research and its justification through having to explain it to the REC
- increased confidence that the ethical issues of the research were being addressed
- increased awareness of the ethical and legal implications of the research
- learning through doing.

The last two benefits enumerated above—increased awareness of, and learning about, research ethics—appeared to be extremely important to the group of researchers who expressed appreciation for the research ethics approval process. Most had had very little, if any, formal training in research ethics, and the process of applying for ethics approval had played a significant role in their education and development.

Another common theme was that applying for ethics approval had become easier over time as their careers progressed. This appeared to be thanks to two complementary factors: the researchers becoming more familiar with the process and requirements, and their RECs becoming more familiar with their research.

2.3.1.5 Research Ethics Codes

During the conversations, all researchers were asked which research ethics codes or guidelines they were familiar with and applied when undertaking research with vulnerable individuals. Their responses were surprising. More than half of the researchers (13) replied that they did not consult research ethics codes or guidelines beyond those of their institution.

This aligns with our finding that most had learned "on the job", developing their skills and understanding while applying for ethics approval, as well as in the field. Aside from a range of national and/or professional codes, the most commonly mentioned codes and guidelines were:

- Declaration of Helsinki—World Medical Association (WMA 2013) (5)
- International Ethical Guidelines for Health-related Research Involving Humans—Council for International Organizations of Medical Sciences (CIOMS 2016) (3)
- Good Clinical Practice Guideline—International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use (ICH 2023) (2).

As a statement of ethical principles for medical research involving humans, the Declaration of Helsinki is the most widely used research ethics guidance in the world; the CIOMS guidance is also used internationally but provides much more breadth and depth; and, as the name suggests, the ICH requirements apply specifically to the pharmaceutical industry. It is noticeable that these three documents focus heavily on (clinical) medical research. This was surprising, given that the disciplines of most the researchers were non-clinical (see Sect. 2.3.1.2), but also predictable, given the alleged "medical dominance within research ethics committees" (Humphreys et al. 2014).

The overall impression from our conversations was that the majority of researchers did not use ethics codes or guidance regularly. This might also be true of some of those who did mention specific codes. For instance, of the three researchers who used CIOMS, one stated that it was hard to use regularly because there were too many nuances, and another noted that they did not refer to the guidelines very often because they had been working in the field for so long.

In the next section, we turn to research ethics codes and guidelines, and what they have to say about the inclusion of vulnerable persons in research.

2.4 Vulnerability and Research Ethics Codes and Guidelines

Historically, the inclusion in clinical studies of individuals perceived as being vulnerable has been the primary motivation and focus of concern for the development of protectionist codes and guidelines (Levine 1988). In this respect, the protection of vulnerable individuals can be regarded as inherent within ethics codes for research with human participants. But debate is ongoing, especially regarding these questions:

- *Who* should be deemed especially vulnerable in research?
- *To what* precisely are they vulnerable?
- *How* can this vulnerability be addressed?

These questions are important because ethics codes and processes that aim to protect vulnerable populations can also lead to the exclusion of certain individuals if they are wrongly labelled as vulnerable, or if the researchers do not understand how to mitigate their vulnerability in research.

For our investigation, a search was undertaken to see what current research ethics codes and guidelines have to say about who should be deemed vulnerable, to what they are vulnerable in the context of research, and how this might be addressed. Not all ethics codes and guidelines mention vulnerability, so the first step was to identify those that do. The search was limited to English documents and official English translations of guidelines and documents of the following databases:

Table 2.3 Numbers and owners of relevant research ethics codes and guidelines

Owners of documents	Number included
Professional associations	10: Australia 1, Canada 1, UK 4, USA 4
National governmental agencies	34: High-income countries (HICs) 9, low- or middle-income countries (LMICs) 25[a]
International organisations	10: CIOMS 1, ICH 1, UNAIDS 2, UNESCO 1, WHO 4, WMA 1
European Union	1
Non-governmental organisations	2

[a] We identified HICs and LMICs according to the list at Wellcome (n.d.)

- Ethics Codes Collection (n.d.)
- Office of Human Health Protections (US Department of Health and Human Services): International Compilation of Human Research Standards (HHS 2022)
- UNESCO Digital Library: Standard-setting instruments (UNESCO n.d.)
- World Medical Association: Medical Ethics (WMA n.d.)

The following search terms or parameters were used: vulnerability; vulnerable; vulner*; high-risk; high risk; “groups at risk”.

In total, 57 current versions of ethics codes and guidelines were identified as relevant. Table 2.3 provides an overview of the numbers and types of authors or owners of the codes and guidelines.

Once the relevant codes and guidelines had been identified, their guidance on the involvement of vulnerable people in research was extracted and analysed. There is a very wide variation in the extent to which vulnerability is addressed in the codes and guidelines, ranging from a single sentence to whole chapters. The following provides a summary of our findings.

2.4.1 Who is Vulnerable?

Most codes and guidelines do not offer a precise definition of vulnerability or of who is to be considered vulnerable, but there are certain commonalities. The most striking, regarding *who* is vulnerable, is the suggestion that vulnerability can stem from belonging to a certain group. When vulnerability is mentioned, it is commonly accompanied by examples of the sorts of groups to which it applies. For instance, the International Council for Harmonisation (ICH) Good Clinical Practice Guideline (ICH 2023) defines “vulnerable participants” as follows:

> Individuals whose willingness to volunteer in a clinical trial may be unduly influenced by the expectation, whether justified or not, of benefits associated with participation or of a retaliatory response from senior members of a hierarchy in case of refusal to participate. Examples are members of a group with a hierarchical structure, such as medical, pharmacy, dental and nursing students; subordinate hospital and laboratory personnel; employees of

> the pharmaceutical industry; members of the armed forces and persons kept in detention. Other vulnerable participants may include persons in nursing homes, unemployed or impoverished persons, patients in emergency situations, ethnic minority groups, homeless persons, nomads, refugees, minors and those incapable of giving consent.

The groups most commonly mentioned are set out in Fig. 2.2, together with the number of documents (out of 57) in which they are named.

More than half (32/57) of the codes and guidelines we examined give examples of groups that are vulnerable, but as we can see from the ICH guideline (ICH 2023), these groups are often specified in the context of participation in clinical trials. Ethics codes and guidelines originated in the biomedical domain, so it is hardly surprising that opinions about who is vulnerable in research have been influenced strongly by clinical research ethics. However, as explained in Chap. 1, this book is primarily concerned with adults who are able to provide informed consent but whose decision-making power may be constrained by other factors.

A problem with the naming of particular groups, even as examples, is the implication that people are to be considered vulnerable simply by virtue of belonging to a certain group. This can render the term unhelpful and patronising. For example, the labelling of impoverished people as vulnerable in resource-poor regions means that virtually the entire population is to be considered vulnerable. Nowadays, there is (at least implicit) acknowledgement across many codes and guidelines that determining *who* is vulnerable requires a more nuanced approach because vulnerability can stem from a range of factors—for instance, power differentials between researchers and participants, capacity to understand and unrealistic expectations.

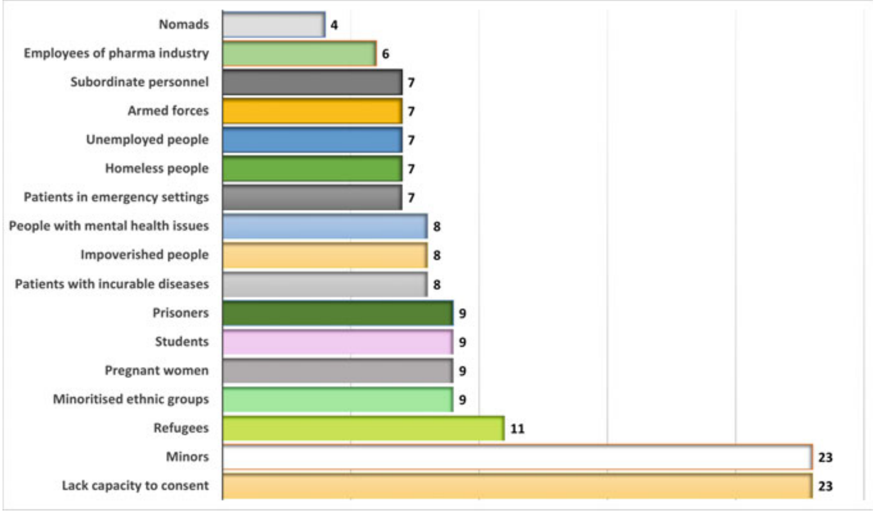

Fig. 2.2 Mentions of vulnerable groups across 57 research ethics codes and guidelines

The British Association for Counselling and Psychotherapy (BACP) Ethical Guidelines for Research in the Counselling Professions (Mitchels 2019) highlights three primary lines of vulnerability that are broadly acknowledged, in that “participants may be particularly vulnerable, for example, as a result of their innate characteristics, the context of their life or the research or the type of research undertaken” (Mitchels 2019: 61). This adds a third dimension to the definition of vulnerability we are using in this book, namely:

> To be vulnerable means to face a significant probability of incurring an identifiable harm while substantially lacking ability and/or means to protect oneself. (Schroeder and Gefenas 2009: 117)

People with innate characteristics that make them vulnerable in research are likely to be those who are unable to provide informed consent because of, for instance, severe cognitive disabilities. These are people who lack the ability to protect themselves from harm and exploitation in research. When the context of a person’s life makes them vulnerable in research, this may be because they live in severe poverty, reside in a refugee camp without humanitarian protection, or work in a strict hierarchy—the military, for instance. These are people who might lack the means to protect themselves from harm and exploitation in research.

Where the research or the type of research places people in a vulnerable position, this might include high-risk clinical studies. For instance, human challenge studies for COVID-19 could be called high-risk clinical studies as “wildtype SARS-CoV-2 can cause severe disease and death and there is no rescue therapy” (Weijer 2024). This third dimension to vulnerability highlighted by the BACP would make it possible for anybody to be vulnerable to harm or exploitation, depending on the study they enter.

There is also evidence of a shift away from reliance upon the naming of groups in the biomedical domain, for instance in the fourth version of the CIOMS (2016) guidelines:

> A traditional approach to vulnerability in research has been to label entire classes of individuals as vulnerable. The account of vulnerability in this Guideline seeks to avoid considering members of entire classes of individuals as vulnerable. (CIOMS 2016: 57)

Similarly, the Canadian Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (known as TCPS2) cautions that:

> individuals should not automatically be considered vulnerable simply because of assumptions made about the vulnerability of the group to which they belong. Their particular circumstances shall be considered in the context of the proposed research project. (CIHR et al. 2022: 73)

Hence, while the labelling of specific groups as vulnerable in research—a tendency that has its roots in biomedical research—continues in many research ethics codes and guidelines, there are a growing number of calls for a more individualised approach.

2.4.2 To What Are They Vulnerable?

To be useful in research ethics, the question “Who is vulnerable?” needs to be supplemented with the question “What they are vulnerable to?” Many ethics codes and guidelines adopt a very similar, if not identical, description of vulnerability to that of the ICH guidelines (2023), including national guidelines from Bulgaria, India, Malaysia, Nigeria, Philippines, Saudi Arabia, Sierra Leone, Singapore, Tanzania and Zimbabwe. This description concerns the voluntariness of participation in research when the potential participants are people who might be unduly influenced “by the expectation … of benefits” or of a “retaliatory response from senior members of a hierarchy in case of refusal to participate” (ICH 2023). These are essentially consent-based matters, as are the vulnerability-related concerns about the inclusion of people who lack capacity to consent and the inclusion of minors in research. Hence, what they are vulnerable to is taking part in research without having given the proper consent.

Undoubtedly, vulnerability as described in the codes and guidelines that were analysed focuses overwhelmingly on whether or not free and informed consent can be given (Bracken-Roche et al. 2017). In fact, some prominent ethics codes do not refer to vulnerability at all and make the inability to provide informed consent the *only* criterion for special protective considerations. For instance, the Council of Europe’s Convention on Human Rights and Biomedicine, also called the Oviedo Convention, makes specific protective provisions only for “persons not able to consent to research” (Council of Europe 1997: art. 17).

There is scant information about why groups like pregnant women and impoverished people are included as examples of vulnerable populations, when they clearly have the cognitive abilities to provide informed consent. Addressing this issue, Coleman (2009) helpfully distinguishes between three types of vulnerability in research: consent-based, risk-based and justice-based.

2.4.2.1 Consent-Based Vulnerabilities

Most groups that are mentioned in research ethics codes and guidelines are vulnerable to consent-based violations that can be associated with innate characteristics (e.g., those with severe cognitive dysfunctions) or with their circumstances, which might impact upon the voluntariness of their consent (e.g. the existence of strong power differentials between them and the researchers). This conveys the message that informed consent cannot be obtained from certain groups. However, there is a significant difference between people who are intrinsically unable to provide consent and people who possess full cognitive capabilities but are in a situation that makes them potentially vulnerable to undue influence. Hence, we refine Coleman’s distinction, splitting consent-based vulnerabilities into two types: *intrinsic consent-based vulnerability* (e.g. babies, or adults with severe cognitive impairment) and *extrinsic consent-based vulnerability* (e.g. prisoners or students) (Rogers and Ballantyne 2008; Schroeder and Gefenas 2009). This makes it possible to apply a more nuanced approach to consent-related matters for inclusion in research.

Importantly, we are not arguing for refining or changing the approach to the inclusion of those who cannot provide informed consent because they lack the ability to do so. We are arguing for changing the approach to the inclusion of *some* of those who are adults with the cognitive abilities to provide consent, but may lack the means to protect themselves from harm or exploitation (see our recommendations in Chap. 6).

2.4.2.2 Risk-Based Vulnerabilities

In Coleman's (2009) second category, vulnerability stems from being at increased risk of mental or physical harm. For instance, the exclusion of pregnant women from clinical studies is likely based on the health risks to those women and their unborn foetuses, but there are also many other reasons why people might be at increased risk of harm from to their involvement in research. The Australian National Statement (NHMRC 2023) provides an extensive list of the sorts of harm to which a research participant might be vulnerable, as shown in Fig. 2.3.

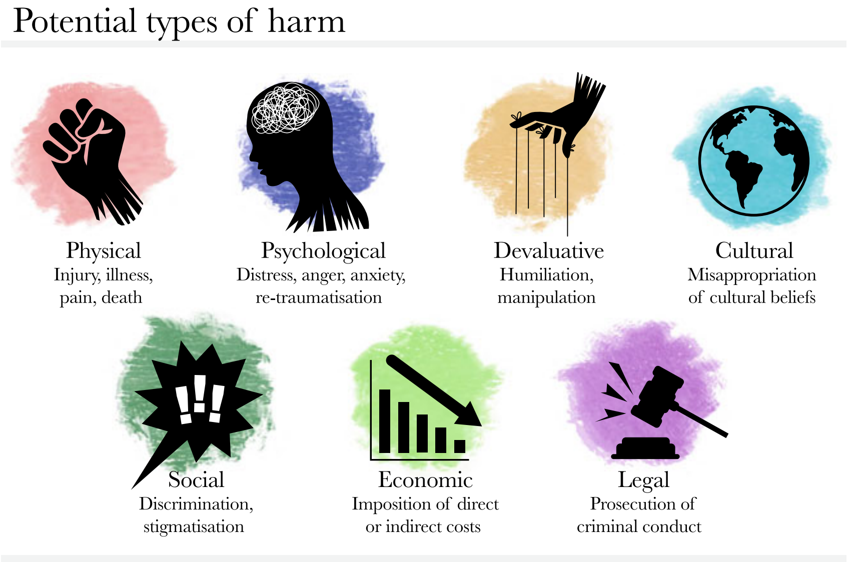

Fig. 2.3 Potential types of harm. *Source* Figure produced using Australian National Statement (2023) available under CC-BY 4.0

2.4.2.3 Justice-Based Vulnerabilities

Coleman's (2009) third category of vulnerability, justice-based vulnerability, refers to unfair inclusion or exclusion from research. This type of vulnerability is the least frequently mentioned across the codes and guidelines, but some describe it at length. For instance, CIOMS (2016) notes:

> In the past, groups considered vulnerable were excluded from participation in research because it was considered the most expedient way of protecting those groups (for example, children, women of reproductive age, pregnant women) … This has resulted in a serious injustice. Since information about the management of diseases is considered a benefit to society, it is unjust to intentionally deprive specific groups of that benefit. (CIOMS 2016: 8)

Inclusion in research can also be unfair in circumstances where there is no, or limited, potential for benefit, for instance pharmaceutical research in regions where the local population would have no access to the resultant medication:

> Inequity is created when particular groups fail to receive fair benefits of research or when groups, or their data or their biological materials, are excluded from research arbitrarily or for reasons unrelated to the research question. (CIHR et al. 2022: 9)

We need to understand clearly *what* it is that people are vulnerable to in order to identify how it should be addressed. This is outlined in the next section.

2.4.3 How Should Vulnerability Be Addressed in Research?

One way to deal with vulnerability in research would be to exclude everybody to whom a given vulnerability might apply. However, none of the codes and guidelines examined proposes that vulnerable persons should *always* be excluded from research. Indeed, some codes explicitly warn against this, such as the Norwegian Guidelines for Research Ethics in the Social Sciences and the Humanities (NNESH 2022), which states that "excessive protection of weak and vulnerable groups is inappropriate. This might result in their perspectives being excluded in research, and society might not gain knowledge about important topics" (NNESH 2022: 29). Likewise, the Canadian Code of Ethics for Psychologists (CPA 2017) stipulates that research activities should be designed in such a way that they "do not unfairly exclude those who are vulnerable or might be disadvantaged" (CPA 2017: 13).

However, most codes and guidelines offer little more than generalised guidance about how to ensure ethical inclusion for vulnerable participants. The Declaration of Helsinki states: "All vulnerable groups and individuals should receive specifically considered protection" (WMA 2013: art. 19), and the Malawian Framework of Guidelines for Research in the Social Sciences and Humanities advises that when vulnerable persons are involved, "researchers … shall be required to obtain extra protections or safeguards for their safety and welfare" (NCST 2011: 8). Precisely what these extra protections or safeguards might be is largely left up to the researcher. Special protections, to the extent that they are further elucidated, generally include measures to promote voluntary decision-making and to limit the risk of harm, with researchers and RECs both having a role to play in ensuring that these special measures are put in place.

An overriding message across the codes is that inclusion should be restricted, often along the lines of the Declaration of Helsinki requirement:

> Medical research with a vulnerable group is only justified if the research is responsive to the health needs or priorities of this group and the research cannot be carried out in a non-vulnerable group. (WMA 2013: art. 20)

Of course, one could argue that the first part of this requirement, as a matter of fairness, should apply to *all* research, as in the TRUST Code: "Local relevance of research is essential and should be determined in collaboration with local partners. Research that is not relevant in the location where it is undertaken imposes burdens without benefits" (TRUST 2018: art. 1). This speaks to a form of justice-based vulnerability (Coleman's third criterion), or *unfair inclusion* in research. The second part of the requirement (that only research that cannot be undertaken with a non-vulnerable group may be conducted with a vulnerable group) is aimed primarily at Coleman's risk-based vulnerabilities. For instance, clinical investigations into certain diseases that have a high likelihood of being fatal in children (e.g. Fanconi anaemia) might involve a risk of harm to the participants, but it is impossible to undertake all of the necessary research with another group. This proviso is intended to prevent unnecessary harm. Nevertheless, certain vulnerable groups have been excluded from research because of this proviso, even though there is no scientific reason for it. For example, people living with HIV are routinely excluded from lymphoma clinical trials even though they are at increased risk of developing the disease (Venturelli et al. 2015). Seeking to avoid a risk-based vulnerability can create a justice-based vulnerability (unfair exclusion).

While most research ethics codes and guidelines have something to say about the inclusion of vulnerable people in research, in general they promote the same two messages: first, that most vulnerabilities are associated with voluntariness, and second, that certain groups should be awarded more protection than others. Beyond exclusion, precisely how this protection should be afforded is unclear. A minority of longer and more detailed codes and guidelines (e.g. CIOMS and TCPS2) warn against blanket exclusions and offer more nuanced advice, but these codes are not applied universally, nor would it be practical to recommend that all research ethics codes be made longer and more detailed. Furthermore, we know from our conversations with researchers that many, if not most, rely upon their own institution's requirements and processes rather than appealing directly to research ethics codes. In the last section of this chapter, we consider the implications of the findings from our review of the codes and our conversations with researchers. We analyse further what we have learned and look at how this might inform research governance to help reduce exclusion and promote ethical inclusion,

2.5 Promoting the Ethical Inclusion of Vulnerable People in Research

Often cited as the cornerstone of research ethics (Xu et al. 2020), the requirement for informed consent in research was recognised as early as the nineteenth century, when the development of clinical medicine was accompanied by an increased demand for experimentation on humans, who were often included without their permission (Vollmann and Winau 1996). Consequently, an enduring message throughout the history of ethics codes has been that people who, for whatever reason, are unable to provide informed consent must be awarded special protection because they are at increased risk of being exploited or harmed in research. Yet, one of the most striking points to emerge from our conversations with researchers was that it could seem to them as if REC members had no confidence in the capacity of adult vulnerable individuals to make reasonable decisions about their involvement in research. In their efforts to protect research participants, RECs can stray into paternalism, defined by Dworkin (1972: 65) as "the interference with a person's liberty of action justified by reasons referring exclusively to the welfare, good, happiness, needs, interests or values of the person being coerced".

Of course, there are times when a blanket approach to protection is warranted for entire groups, such as babies and young children, or for adults with severe cognitive impairment. However, this protectionist stance is often applied to groups of people who *do* have the capacity to provide consent (such as prisoners). So why does this happen? To answer that question, it is helpful to remember that research ethics codes originated in the biomedical domain and were intended to prevent the kinds of abuses exposed by Beecher (1966), in which people might be subjected to a high risk of harm in research, even without their knowledge or consent. The resolve to protect people from exploitation in research runs deep, and it is widely acknowledged that RECs remain dominated by the ethics requirements that were originally set down for biomedical and experimental research (Pelek et al. 2023). These requirements and processes have been extended to non-clinical research involving human participants, including humanities and social science studies, even though research in these fields does not generally pose equivalent risks (Doyle and Buckley 2017).

The ways in which vulnerability is described in codes and guidelines, with repeated reference to certain groups, has the inevitable impact of ringing protectionist alarm bells when people from these groups are being considered for inclusion in research. This raises the question of whether it might be best to avoid the naming of groups altogether, and to address vulnerability as a matter that pertains purely to individuals rather than to groups. However, Coleman (2009) claims that it would be a mistake to characterise vulnerability as either an entirely individual or an entirely group-based phenomenon. In Coleman's view, consent-and risk-based vulnerabilities make more sense when conceptualised as individual issues, but justice-based vulnerabilities are more likely to concern groups or communities.

But this is not the message that is conveyed by most codes and guidelines. Most do not distinguish between individual and group vulnerabilities, nor do they distinguish between different types of vulnerability. In our view, the blanket labelling of groups as vulnerable is only relevant in two scenarios:

- where there is consent-based vulnerability, and this vulnerability is of an intrinsic nature (e.g. including babies or adults with severe cognitive impairment), hence where there is a lack of ability to consent
- where there is justice-based vulnerability that has implications for entire groups.

As previously mentioned in this chapter, justice-based vulnerabilities can manifest themselves in either unfair inclusion or unfair exclusion. Unfair *inclusion* can occur when research is undertaken with a group to whom the research is not relevant. For instance, Kenyan prisoners were going to be enrolled in a medical study undertaken by HIC researchers for the sole benefit of the HIC's military at home. Only the vigilance of a local Kenyan REC prevented this research (Chatfield et al. 2021). This is why the Declaration of Helsinki adds to its requirements on vulnerability the stipulation that any group involved in research "should stand to benefit from the knowledge, practices or interventions that result from the research" (WMA 2013: art. 20). There must be a fit with local health needs and priorities plus access to the results. Similarly, CIOMS guidance (2016: 63) refers to the potential for "group vulnerability" in, for instance, some resource-limited countries or communities. These types of situations often bring to light justice-based vulnerabilities that require actions at the community level, for example agreements for benefit sharing (Schroeder 2007).

Other justice-based vulnerabilities take the form of unfair *exclusion*. This might be due to a paternalistic stance on the part of the RECs—and paternalism is not a rare phenomenon being "quite common and present wherever global compassion has become institutionalized" (Barnett 2012: 487). Given this tendency, it is extremely important for RECs to be aware that protectionist measures intended to address vulnerability in research can result in unfair exclusion. The protectionist exclusion of vulnerable people from research can result in serious injustice and may also be contrary to the wishes of individuals or groups (Friesen et al. 2017).

While unfair exclusions can be motivated by a desire to protect, they can also be related to matters of convenience. For instance, Charles et al. (2016) analysed research applications involving UK prisoners, augmented by a survey of UK researchers and REC members. They found that "pragmatic concerns regarding the perceived burden of including prisoners [in research] are far more prominent in motivating their exclusion than ethical concerns" (Charles et al. 2016: 1). In other words, obtaining REC approval for research with prisoners can be considered too burdensome.

Likewise, De Poli and Oyebode (2023) found that for qualitative, participatory and collaborative research, perceived or expected barriers at the ethics approval stage could deter researchers from involving vulnerable groups:

> At worst, it could undermine the role of qualitative, participatory, and collaborative research in promoting research inclusivity and social justice, and in answering research questions that no other research methods could address. (De Poli and Oyebode 2023: 3)

The findings from our conversations with researchers echo the challenges associated with seeking ethics approval that are articulated in the published academic discourse, as noted above. However, certain issues are likely to be even more tricky to navigate when the research involves vulnerable individuals. Among the researchers there were obvious frustrations associated with these challenges, which might be perceived as hindrances to research involving vulnerable individuals, especially for researchers with less experience.

The routine identifying of groups as vulnerable can blind researchers and RECs on occasions when there is a need for a more nuanced approach. Treating vulnerability as a group-based phenomenon only makes sense when it applies to *all* members of a group (e.g. babies), and that is often not the case for the many people who are excluded from research because of a particular label (e.g. prisoners, Indigenous populations, sex workers).

Most of the researchers we spoke to regard the ethics approval process as a major point of learning and do not consult research ethics codes and guidelines beyond those of their institutions. This highlights the importance of the role that RECs play in research ethics. Well-informed RECs with a clear understanding of who can be vulnerable in research and how this vulnerability might be addressed can help to ensure that unnecessary exclusion is avoided. This might also contribute to the minimisation of convenience exclusions.

Ethics Approval The empirical study was approved by the Health Ethics Review Panel at the University of Central Lancashire, reference: HEALTH 0313.

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3

What Does "Vulnerability" Mean? San Representatives Define Vulnerability for Themselves

> *People's hearts can be broken in so many ways, all make us vulnerable.*
>
> *—San respondent to survey*

Abstract

The Indigenous San peoples, often referred to as South Africa's "First Peoples", experienced a violent history of displacement and genocide. Modern-day San still suffer from the intergenerational trauma inflicted by colonists as well as discrimination, marginalisation and impoverishment. In addition, the South African San are collectively labelled as a vulnerable group, whose inclusion in research should be reduced to a minimum if one follows traditional protection mechanisms from research ethics. The purpose of this chapter is to let the San define "vulnerability" for themselves through workshops and community-administered surveys. It became clear that San representatives did not perceive the word "vulnerable" to be pejorative per se. On the contrary, it served as a useful umbrella term to cover a vast range of issues and problems. However, it also became clear that the term is perceived as negative when external actors block research—in a potentially patronising manner—that could be beneficial to the community. Equitable research partnerships between researchers and South African San community members, facilitated by the South African San Council and guided by the San Code of Research Ethics, can lead to rich data that have the potential to assist the community in finding ways out of vulnerability. Externally labelling them as "vulnerable" as a group and blocking access to research cannot be the solution.

Keywords

Vulnerability • Exploitation • Research ethics • San peoples

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3.1 Introduction

Ethics guidance is gradually changing on the topic of who belongs to a vulnerable population in research. While large groups of people used to be labelled "vulnerable" without further reflection on the potentially negative impacts of this labelling, some drafters of ethics guidance are now changing their approach (see also Chaps. 1 and 2).

In research ethics, Indigenous peoples used to be labelled as a vulnerable group. For instance, the 2012 UNAIDS Ethical Considerations in Biomedical HIV Prevention Trials noted:

> Examples of populations that may have an increased vulnerability include women, children and adolescents, men who have sex with men, injecting drug users, sex workers, transgender persons, *indigenous populations*, the poor, the homeless, and communities from resource-poor settings in high-income and low- and middle-income countries. (emphasis added) (UNAIDS and WHO 2012: 31)

The 2021 UNAIDS Ethical Considerations in HIV Prevention Trials no longer labels Indigenous populations as vulnerable, but instead points out the social and political contexts of vulnerability (UNAIDS and WHO 2021: 37). The guidance also makes suggestions on how to reduce risks for those involved in research, for example by developing risk mitigation plans early on in the research process (ibid).

This chapter has two aims. First, it introduces the Indigenous San community from South Africa, who have complex experiences of participation, inclusion and exclusion in research. Second, it lets San representatives define "vulnerability" for themselves in workshops and through a survey administered by 12 community researchers.

3.2 The South African San Community

The San peoples, often referred to as South Africa's "First Peoples", experienced a violent history of displacement and genocide following the colonial occupation of the country from 1652. Early Dutch settlers regarded the San peoples—whom they called Bosjemans (Bushmen)—as less than human, due to their click languages and allegedly primitive ways. (In click languages, some of the consonants are clicks, which can sound alien to outsiders, especially those accustomed to European languages.) This demeaning position paved the way for their genocide (Adhikari 2011: 23–24). Research has examined the state-driven decimation of early San communities, where, for example, official hunting parties of farmers obtained licences to "clear the land", the phrase being a euphemism for the extermination of the prior inhabitants. As Nigel Penn has summarised, hunter-gatherer societies were almost completely destroyed by colonialist farmers during the eighteenth and nineteenth centuries (Penn 2015: 159). Thousands of San were killed as the Cape colony expanded, some of the children and young women being "spared" for slavery (Gordon and Douglas 2000).

In modern times the discrimination and exploitation of San peoples has been less extreme in form, but no less tangible, resulting in the much-reduced San population now living largely in poverty in the semi-desert Northern Cape province of South Africa. The !Khomani, living in the Northern Cape north of Upington, number about 3000, whilst the !Xun and Khwe, both settled near Kimberley, are estimated at about 6000 and 2000 people respectively. Descendants of the extinct Xam are widely spread, with the San Council having no reliable estimate for their numbers. Hence, the known San population in South Africa is estimated at approximately 11,000, far reduced from the approximate 50,000 who lived in the Cape in 1652 (Adhikari 2011). The countries of Southern Africa are home to an estimated 105,000 San, comprising 50,000 in Botswana, 38,000 in Namibia, 11,000 in South Africa, 4000 in Angola and 2000 in Zimbabwe and Zambia.

Of the South African San, only the !Xun and the Khwe still speak their Indigenous "click" languages. They were settled in South Africa, away from their homelands in Angola and Namibia, in 1990, after fighting in the South African Border War, also known as the Namibian War of Independence (1966–1990), on the side of the South Africans. The !Khomani, who are indigenous to South Africa, failed to maintain their own language during centuries of oppression, and now only speak Afrikaans, a Dutch-derived South African language.

The South African San are largely scattered in small hamlets in the Northern Cape and Eastern Cape provinces, as well as in the outskirts of larger towns such as Upington and Kimberley. Genetic research places the San as being among the oldest, if not the very oldest, ancestors of modern humankind (Schlebusch et al. 2017), and they have been much researched, not only for their DNA, but also on account of their iconic status as hunter-gatherer peoples living close to nature. Classic texts show San clans living nomadic lives in family groups without material possessions, tracking and bringing down their prey with bows and poisoned arrows. They are known for their deep understanding of the natural world, and for their non-assertive demeanour. For instance, they were given the name "The Harmless People" by the famous American anthropologist Thomas (1959).

As a result of a combination of factors shared by Indigenous peoples around the world, the San in South Africa are currently displaced, discriminated against and subject to social problems linked with poverty (Chennells 2009). Low self-esteem, lack of hope, resort to substance abuse and the resultant social breakdown are characteristics of a community suffering from intergenerational trauma, which is trauma that is transferred from one generation to the next (Smallwood et al. 2021). For these and other related reasons, San community members are generally perceived as "vulnerable" since they are at increased risk of harm or exploitation while substantially lacking the means to protect themselves (Schroeder and Gefenas 2009).

After decades of being subjected to—and, in many cases, harmed by—unwanted research, San leaders have increasingly been standing up against exploitation in research (Chennells and Steenkamp 2018), helped by the fact that the global research ethics community has recognised the need for community approval of sensitive research (Weijer and Emanuel 2000). A recent instance involved genomic research findings published as “Complete Khoisan and Bantu genomes from southern Africa” (Schuster et al. 2010). The authors of the article, which contained private and sensitive information about the San, had not obtained community approval, stating that their own process involving video consent had been approved by their ethics committees (Hayes 2011). This was seen as insensitive by San community leaders and became a further incentive for the San to develop the San Code of Research Ethics (Schroeder et al. 2019).

The initiative was taken up in order to create clear guidelines for prospective researchers on how the community were to be approached. The code sets out the required process of engagement and describes how the values of respect, honesty, justice/fairness and care are to be followed via due process (Schroeder et al. 2019: 83–87). Community approval can now be obtained via the government-recognised South African San Council, which was formed in 2001 to legally represent the interests of the three major San communities (South African San Council n.d.).

3.3 What is Vulnerability as Defined by the San Themselves? The Workshops

What is vulnerability?

The San found the question highly stimulating for discussion and had a lot to contribute. Responses to the question were sought in two main ways: first, from young San delegates in workshops, the recruitment for and implementation of which are described in Chap. 5, and second, in surveys administered by 12 community researchers.

Forty-five San were invited to three workshops to consider the word “vulnerability”, translated with some difficulty into the languages of the !Xun and Khwe as well as into Afrikaans, a language brought by the colonial powers and now spoken by the !Khomani. Given that there was no direct equivalent of the term in the San languages, some initial guidance on what the English word “vulnerability” might cover was necessary. After receiving this guidance, offered as judiously as possible by bilingual workshop facilitators, the delegates soon identified a range of descriptive terms associated with the overall concept of being vulnerable, such as “helpless”, “weak”, “woundable”, “fragile”, “anxious”, “being a victim”, “passive” and “unassertive” (see Fig. 3.1).

The topic of “vulnerability” itself elicited enthusiastic debate, and participants were not reticent about exploring the various ways in which the South African San, as a people, might be said to experience vulnerability every day. In particular, they noted, while the English word was not known to most of them initially, it was suitable to express a range of challenges they experienced in their everyday lives, whether or not involving encounters with community externals (such as researchers or the media). The clearest division was between group and individual vulnerability.

Group vulnerability for the South African San comprised the following five factors, according to the workshop delegates: public perception as “others”, economic

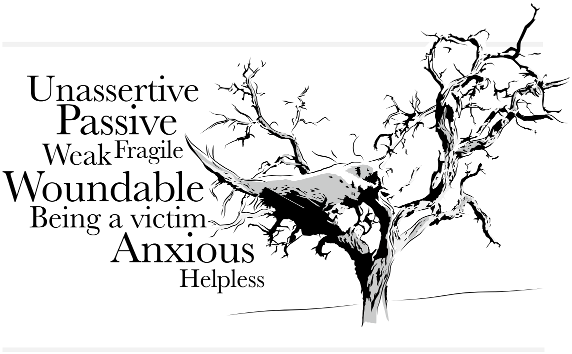

Fig. 3.1 Synonyms for "vulnerable" according to the San delegates

circumstances, social challenges, common personal traits and intergenerational trauma. These five factors were extracted from three workshop reports and then confirmed in discussions with a subset of the delegates (the community researchers who later administered a survey) in a fourth workshop.

Public perception as "others" The San are known as victims of past genocide, slavery, discrimination and exclusion by other peoples. This public perception is deeply felt by the San and is exacerbated by the distinctiveness of their often mocked click languages. A sense of "otherness", stigmatisation and victimhood persists, even now that genocides and slavery are long past.

Economic circumstances The San belong to a highly economically disadvantaged group, often homeless or living in makeshift housing without access to running water or electricity. They experience serious poverty and lack of education while being politically excluded: that is, they are not represented in local, regional or national governments.

Social challenges The San suffer to a disproportionate extent from substance abuse, joblessness and broken families, for instance families in which one or even both parents died prematurely.

Common personal traits The San are widely known to be shy, reticent and non-assertive. This trait is also often reflected and demonstrated in non-assertive leadership.

Intergenerational trauma Many South African San are aware that their predecessors were humiliated, murdered and treated as animals, or as less than human. They feel that their present feelings of inferiority are directly related to the trauma of previous generations.

The delegates also discussed the relationship between the different factors for group vulnerability, and approved the diagrammatic summary included here as Fig. 3.2.

Vulnerability at the personal level was attributed to factors which impact on one another, according to the San delegates, as represented in Fig. 3.3, approved by the delegates at a feedback session.

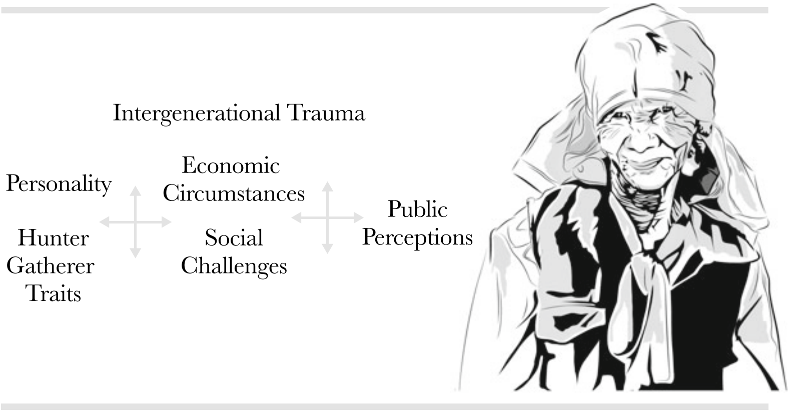

Fig. 3.2 Five factors of group vulnerability according to the San delegates

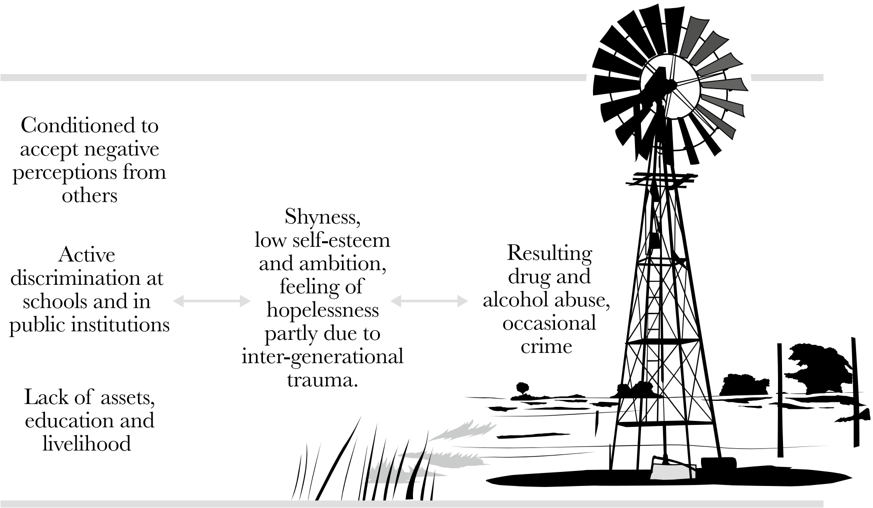

Fig. 3.3 Interconnected factors of personal vulnerability according to the San delegates

The workshop delegates reached the following consensus, specifically on collaborating with researchers. In engagements with researchers San delegates confirmed their lack of assertiveness, partly based on a lack of knowledge of the world and of their own personal rights. When researchers enter the community with questions and proposals, the San are unsure of what to do and what rights they have. They are also not sure how to manage the conversation, given that the researchers have unknown powers, such as access to money and other benefits. The status and personal power of researchers as educated people are perceived to be dauntingly high. Additionally, workshop delegates testified to a general feeling of mistrust towards researchers, based upon less than favourable experiences in the past (Chennells and Schroeder 2019).

During the workshops it became clear that the San delegates did not perceive the word “vulnerable” to be pejorative per se, or negative towards them as a people. On the contrary, it served as a useful umbrella term to cover the vast range of issues and problems they experience. They regarded the personal synonyms for “vulnerability” as challenges common to all humans, not only applicable to them. They welcomed debate and exploration around the word, as this enabled them, in particular the young delegates, to discuss steps, strategies and possibilities for improvement.

Out of the 45 delegates in the workshops, 12 were selected for further training towards an ambitious survey to be led by community researchers. The next section of this chapter presents an analysis of the survey findings. (For a discussion of the process of selecting and training the 12, see Chap. 5.)

3.4 What is Vulnerability as Defined by the San Themselves? The Surveys

In the survey, 239 San participants responded to five open-ended questions.

- Q1 What does “vulnerability” mean?
- Q2 Give three or more examples of when you as a person were vulnerable.
- Q3 Are the San people as a group vulnerable compared to other groups?
- Q4 Give examples of when other people can become vulnerable.
- Q5 What other words are similar to “vulnerability”?

The survey was administered by 12 San community researchers in Afrikaans (with additional help for the !Xun and the Khwe by the community researcher). Roger Chennells translated all outputs into English before the analysis by Hazel Partington. Issues of clarity were discussed with the community researchers so that the English translation from Afrikaans was as clear as possible. No personal data were solicited from the 239 San research participants and the research was approved by the South African San Council.

For some respondents, “vulnerability” was an unfamiliar word, but for others it could be filled with meaning.

- The first time I heard this word, I think it means injury.
- Vulnerability is something I have not yet experienced in life; I would like to learn about it.

Methodology for Analysing the Survey

The data obtained from the surveys were analysed qualitatively using thematic analysis following Braun and Clarke (2022).

Provisional themes were established from an analysis of the answers to Question 1 and then revised and added to as Questions 2, 4 and 5 were looked at in turn.

Question 3, about the San people's perceptions of their vulnerability as a group compared to other groups, was analysed later, as the overlap with other questions was much smaller. For example, issues about the San language were mentioned by ten or fewer people, each responding to Questions 1, 2, 4 and 5, but there were 98 mentions of language in response to Question 3.

Guided by the principle of authenticity, the following sections include many quotations from survey respondents that offer the reader first-hand access to content on the dominant themes (Lingard 2019) (Table 3.1).

Table 3.1 Three overarching themes constructed from the data

Themes	Main concepts in themes
Overarching themes	Subthemes
Understandings of vulnerability	Vulnerability as weakness Feeling in danger of being attacked or injured Feelings of inferiority or being a failure Feeling heartache, heartsore Vulnerability as openness to others
Examples of circumstances in which respondents have felt vulnerable or observed others to be vulnerable	Poverty Joblessness and work situations Health problems Home, family and relationship problems Drug and alcohol problems Success leading to vulnerability
From the individual to the collective: perceptions of group vulnerability	Language and culture: sources of both embarrassment and pride Unfairness and exclusion Shyness and reluctance to mix with other groups

3.4.1 Theme 1: Understandings of Vulnerability

3.4.1.1 Vulnerability as Weakness

Many respondents understood vulnerability as some sort of weakness in an individual, which then predisposed them to being vulnerable. Words describing weakness such as “weak”, “weakness”, “helpless”, “brittle” and “brittleness” were mentioned 19 times in response to Question 1, which concerned the meaning of vulnerability, and 38 times in response to Question 5, which asked for words that were similar to “vulnerability”.

- Vulnerability is when you feel weak, you don’t know if you can do it right.
- When other people point out your weaknesses.
- When a person is sick, or has lost hope, has no power to fix things, and needs assistance.

A few respondents compared personal vulnerability to weaknesses in computer systems:

- Vulnerability is like the weakness in software that can attack and destroy the integrity of your system.

“Fear”, “anxiety”, “stress” and “panic” were mentioned by some in response to Question 5 as words that were similar to “vulnerability”. These feelings could arise as reactions to sensations of weakness, to circumstances that caused weakness or to the situations described in the next subtheme of feeling in danger of being attacked or injured.

3.4.1.2 Feeling in Danger of Being Attacked or Injured

This subtheme recognises that whether or not a person feels weakness in themselves, they may still be vulnerable to threats or attacks from external forces. Community researchers at the August 2023 workshop expressed this, as reported by co-author Leana Snyders, in a project meeting.

- When we wake up in the morning, we are not vulnerable. We become vulnerable when we go outside, because of what happens when other people become involved. It is the outside forces that make us vulnerable.

Co-author Roger Chennells qualified this with the observation that these outside forces could sometimes be members of their own families, and this was borne out in some of the responses discussed under Theme 2.

Some responses in this subtheme are about fear of or susceptibility to attack, but a significant number detail *actual* attacks.

- Vulnerability is when a person is exposed to organisations or people who can injure you emotionally or physically.
- You can feel hurt as a result of what somebody says. This causes internal and emotional pain.
- When I went to work on a farm with four people from another nation, I always felt they were talking about me, I thought any moment they might attack me.
- When your private information is spread on social media.
- When you get threatened with a pistol or a knife and your life is in danger.

Other examples of when respondents had felt vulnerable or observed others to be vulnerable were instances of rape, robbery, abuse, being the victim of other sorts of crime, and being bullied, mocked or teased. Much of the scorn and mockery described was linked to the collective San experience and is discussed further under Theme 3.

3.4.1.3 Feelings of Inferiority or Being a Failure

There is an element of self-blame in this theme, in terms of people feeling inferior or a failure and often seeing their own actions as the cause.

- Vulnerability is when a person almost dies out of anxiety about what you have done. When you think there is nothing that can be done about the pain you have caused.
- Debauchery [losbandigheid] makes you vulnerable. You drink and sleep around and then you struggle because you have no money at all.
- When I blame myself for everything I have done.

Failure at school or in other educational settings was mentioned several times. However, it should be remembered that although people may blame themselves for not succeeding in school or other educational settings, it is not just their own actions that contribute to such results. Structural inequalities, language problems, poverty and other factors may all play a part in whether or not a person succeeds educationally.

- When I failed my matric I felt that my world was closing around me.
- I failed Grade 10 last year. I knew it would be bad.
- At school when a teacher does not like you and throws you out of the class.

3.4.1.4 Feeling Heartache, Heartsore

Heartache and the term “heartsore” featured strongly in the data, with heartache mentioned 25 times and heartsore 14 times across Questions 1, 2 and 4. These terms were also strongly in evidence in responses to Question 5 about words that were similar to “vulnerability”, with heartache mentioned 29 times and heartsore 10 times. However, it should be noted that some people may have used a “heart” word in response to more than one question.

- “Vulnerability” is a big word for me. I grew up in a home where you were punished if you did anything wrong, which made me unhappy and heartsore.
- Vulnerability means a lot to me. It is something secret or heavy you keep inside you that can cause pain.
- Sometimes there are those things that are just too painful to share.
- People’s hearts can be broken in so many ways, all make us vulnerable. Any person going through hard times is vulnerable.
- Because your heart gets no rest, you cannot laugh any more, and feel very vulnerable.

Also included in this subtheme are expressions of a feeling that nobody cares.

- When you are at your lowest, it seems you mean nothing to anybody, and everyone looks down on you.
- Invisibility. When you don’t feel accepted, you feel nobody cares about you.
- When your opinion doesn’t count.
- If there is no love in the home.

3.4.1.5 Vulnerability as Openness to Others

About 15 respondents expressed their understanding of vulnerability as an openness to others. This is a small proportion of the respondents, but is mentioned because of the contrast with interpretations of vulnerability as weakness. Being prepared or able to fully show oneself to others was seen by these respondents as beneficial and an antidote to weakness.

- There is a huge force in being vulnerable before people, but when we hide our weaknesses, the weaknesses become worse, and we become false.
- Vulnerability is when you stand with your hand in your heart, you hold it before you, and you say, this is how my heart looks, and it is beautiful.
- When I was hiding my weaknesses instead of working on them.
- When they climb out of their shell and to say to others: I am an independent, strong, vulnerable woman.

3.4.1.6 Summary of Theme 1

People primarily seemed to understand vulnerability as a type of weakness, and also linked it with a feeling of being in danger or being attacked. A sense of being inferior or a failure also featured strongly in the respondents' answers, and many linked the experience of being vulnerable with heartache or feeling heartsore. A counterpoint to the conceptualisation of vulnerability as weakness was evident in comments mentioning being open about one's vulnerability as a strength.

3.4.2 Theme 2: Circumstances in Which Respondents Felt Vulnerable, or Observed Others to Be Vulnerable

Respondents gave examples of when they had felt vulnerable or observed others to be vulnerable. This often centred around economic or social circumstances.

3.4.2.1 Poverty

If people are struggling to meet their own and their families' basic needs, then they are naturally liable to feel more vulnerable than those in a more comfortable situation. Many respondents described situations of poverty as making them vulnerable.

- The word "poverty" is for me the same as "vulnerability".
- Hunger. When you are hungry you are vulnerable. When you see your kids crying from hunger is painful.
- My house leaks and I have no electricity.

The impact of structural inequalities and the resulting marginalisation was clear.

- When one applies for money, and they ask for bank card details, but one does not have the money to go to town to get a bank card.

Also apparent was the sense of being trapped by poverty.

- Some San go to the community dump to try and find food to eat. Some people steal because they have no other choice to try and get food.
- When you don't have a decent house, food to eat or things don't go right, and you don't know how to get out of it.

3.4.2.2 Joblessness and Work Situations

Joblessness was clearly linked to the subtheme of poverty.

- Unemployment. When you have no work, you will become a thief.
- The joblessness that plays such a big role in our community is for me the biggest vulnerability.

Respondents found jobs hard to come by.

- When I apply for work, but I get no response nor do I get employed.

However, even for those who got jobs, low pay and poor working conditions were common. Hence, a job was not necessarily a way out of poverty.

- Working hard at work but no promotion.
- Getting a very low salary. My first job was for a very low salary.
- I worked in the garden at the clinic without any work clothes and I was not happy.

The words "joblessness" and "unemployment" both featured several times in responses to Question 5 about words that are similar to "vulnerability".

3.4.2.3 Health Problems

Respondents frequently mentioned health problems and sickness in their answers, often with a sense of hopelessness experienced during sickness.

- Sickness. When you are so sick you lose hope that you will live again.
- I had chickenpox, after which I thought I would not be able to live again.
- When I get blood tests done, I fear for the results.

There were also fears about sickness in members of the family, and the impact of sickness on the family.

- When my daughter was sick, and I could do nothing.
- When I was sick for three months, I feared who would care for my kids.

Pregnancy, including teenage pregnancy, was cited several times as a cause of vulnerability for both the family and the pregnant mother.

- I was very vulnerable when my grandchild got pregnant. I was so hoping she would finish school and study. Now she sits at home as single mother.

3.4.2.4 Home, Family and Relationship Problems

This subtheme describes the vulnerabilities that can arise from insecurities in the home and relationships with family members, whether through difficult relationships, violence, abuse, loss of relationships or bereavements.

- A person's family situation can make him vulnerable.
- My relationship makes me vulnerable because my man wants to leave me.

Many of the comments here tell very sad stories about the precarity in people's home lives.

- My parents are dead, I live with my uncle, his son gets drunk and picks on me.
- When my father assaulted my mother, I was vulnerable.
- When my mother chased me away from home I had nowhere to stay.
- When my father stabbed my brother with a knife, we were vulnerable.
- When the boss of the home gives up hope and decides not to work any more.

Stories of bereavement also featured strongly in responses to Questions 1, 2 and 4.

- Loss is a form of vulnerability. It leaves you heartsore.
- My father was my hero and taught me everything, so now without him I don't know much what to do.
- When my son hanged himself.
- When a loved one in the home dies and it feels like the end of the world.

Linked to the circumstances described under this subtheme, "unhappiness", "sadness" and "depression" were among words described as similar to "vulnerability" in response to Question 5 and can be seen as natural reactions to these and other difficult situations that respondents had experienced.

3.4.2.5 Drug and Alcohol Problems

Drug and alcohol problems featured in responses across all five questions as understandings of vulnerability, contributions to group vulnerability and examples of when respondents had felt vulnerable themselves or observed others to be vulnerable.

- Addiction. I was a tik [meth] smoker and did many things that nearly caused my death.
- When my father got drunk and caused problems.

- People don't think right when they are vulnerable. Other people drink when they feel vulnerable.
- I am vulnerable every day when my young brothers smoke dagga [cannabis] and then come home and argue with me about money.
- San drink too much, it is said.

3.4.2.6 Success Can Lead to Vulnerability

This is a minor subtheme but worth mentioning because of its contrast with the difficulties and hardships characterising the other subthemes. Being fortunate, doing good things or being successful was perceived by some as potentially leading to vulnerability because others in the community may begrudge such successes or try to take advantage of those enjoying them.

- When people are jealous of others, they do not want them to do well, speak bad of them. That is to be very vulnerable.
- Generous people are vulnerable.
- When you stand up for your community.
- A person can become vulnerable through independence and being a good leader.
- If a person has got any talent, then the others will try to break that person down.

3.4.2.7 Summary of Theme 2

This theme describes circumstances in which people felt vulnerable or saw others being vulnerable. The subthemes can be seen as associated with economic circumstances such as poverty and joblessness, and social circumstances such as family and relationship issues, addictions and (ironically) being successful. The health subtheme can potentially have both social and economic impacts in terms of isolation, possible loss of income and costs of treatment.

3.4.3 Theme 3: From the Individual to the Collective: Perceptions of the San's Vulnerability as a Group

Question 3, "Are the San people as a group vulnerable compared to other groups?" broadened the perspective to a collective view of the vulnerability of the San community, rather than individual perspectives and experiences. However, some of the answers given to this question echoed certain responses to the questions about individual vulnerability: for example, perceptions of how outsiders view the San.

3.4.3.1 Are the San Vulnerable as a Group Compared to Other Groups?

The answer to this question was a resounding yes, with 201 respondents out of 239 (84%) believing that the San were vulnerable compared to other groups. Only 21 said no (9%), the San were not vulnerable. Two respondents did not answer the question (1%). The answers in a fourth group were contradictory or inconclusive (6%) and could be described as “yes, but …” or “no, but …” or “yes and no”, as the following examples illustrate.

- No. San were the first people in the world. San is the group that most medicine knowledge in the world comes from. Overseas people want to meet with us. But … San are more vulnerable due to the treatment we receive in South Africa.
- No, but we don’t get work. We get little exposure to opportunities.
- Yes, but the San are an upcoming group.

Some participants, although very definitely in the minority, firmly rejected the notion that the San were vulnerable compared to other groups.

- No! We are a unique nation.
- No. The San are not less than others. They just think that they are. We are just the same as other people, no matter what they say or think.
- San can work with other people as long as we are treated right. We are equal to them all, I refuse to let people say otherwise.

Nearly all of the 201 respondents who said yes, the San were vulnerable as a group, gave reasons for believing this. As detailed earlier, three further subthemes were constructed from these answers:

- language and culture: sources of both embarrassment and pride
- unfairness and exclusion
- shyness and reluctance to mix with other groups.

3.4.3.2 Language and Culture: Sources of Both Embarrassment and Pride

This subtheme articulates the perception that other groups show disdain for the San’s traditions and languages. The lack of respect shown by others to their languages and culture appears to be a major influence on the collective vulnerability experienced by the San, especially when manifested as scornful or bullying behaviour.

- For example, when others hear our language at school and laugh at it.

- Vulnerability is when people scorn you or speak badly of your culture or language.
- When San talk, others laugh and ask if the San still exist. People get mocked for their San language.
- Yes. Our language is not recognised nationally. San communities (especially Platfontein) are less developed. San are regarded as illiterate, although they do not learn their own language at school.
- Whenever we speak our language in public they laugh. Wherever we go we struggle with the language issue. Nothing at all is written in our language.

Comments on language also referred to some respondents' inability to speak San languages.

- Many of us [!Khomani] are not able to speak our San language.

Other responses relating to San traditions and culture included stories of being called "bushmen" or being told they "speak Chinese" or that the San wear "skins" or "have tails".

- Other groups discriminate against us San. They say we belong in the bush, and that is why we San feel inferior and vulnerable.
- We are scared to wear traditional clothes because we are shy.
- Yes, others are racist against San people. They say the San people don't own possessions. They think the San are stupid. They say the San do not deserve a better life.

However, some respondents did express a sense of pride in both the culture and languages of the San.

- No, the San are not more or less vulnerable than other groups. We are the same as other people, I don't see the difference. I have the right to speak my own language, as they also have the right. Nobody is better than others, God made us all.
- San speak their language in front of other groups. When it's a cultural celebration we do our own dance in front of others. Even at school, San learners are not scared to speak their home language in class.

3.4.3.3 Unfairness and Exclusion

This subtheme covers a wide range of examples of unfairness and exclusion.

- We are less developed than other groups. Joblessness is high in our community.
- Service delivery is poor, the clinic closes early.

- Yes. The San are very vulnerable. We are very few, and these days the government does not care about us.
- Yes, San are vulnerable. They have to stand up against other groups to have their voices heard. We have to fight for our rights.

Respondents complained about a lack of representation and opportunities. They felt excluded and discriminated against in many situations, including workplaces and the education system.

- There are no San in parliament or prominent positions. Wrong information is spread about us. Other groups always say that we know nothing.
- The government ignores us. We are not treated the same as others. We are only less vulnerable when we are in our own suburb.
- We don't have privileges like others. We are stuck in a corner. Feel we are not a part of the South African citizens.
- We apply for work in many places but when they see the home address, we do not get the job. Others get government assistance and we do not. We do not have any teachers at school who speak our language.
- We are excluded because of our language. We are under pressure because we are not educated. We feel not as good as the others. We seem unable to do better.

There was also a sense of intergenerational injustice and trauma.

- Our people get misused for their information. Our people were chased off their land.
- They discriminate against us. We have harder lives than other people. We were treated like animals, we were sold as slaves in the old days.
- For years we were kept on one side and not treated like other groups. We feel important, but we are never taken seriously.

Some expressed regret about changes they had witnessed in the San culture.

- The other people are always on our case and exploit us. We never misused drugs in our past in Angola and Namibia, but now, near these other groups, we do.

3.4.3.4 Shyness and Reluctance to Mix with Other Groups

Shyness frequently came up as an issue that affected San people as individuals and as a group.

- Being shy is a form of vulnerability. Then even though you are hungry or have problems, you might be too scared to ask others for help.

Fig. 3.4 Word cloud capturing word use in survey responses

- Yes. San people are vulnerable because they don't want to be with others. San people like their own people a lot and do not like other people.
- Yes. San are vulnerable compared to other groups They always want to be with their own people. San are also shy to be with other people and groups.

There were many comments about the San's reluctance to mix with other groups, this is hardly surprising, given how they understood themselves to be perceived by other groups (see Sect. 3.4.3.2 on the subtheme of language and culture). Hence, their reluctance to engage with other groups can also be seen as a protective mechanism and not just a result of shyness.

- Yes, San people suffer. No change in our circumstances We always walk in a group.

3.4.3.5 Summary of Theme 3

This theme moves the focus from individual vulnerabilities to the collective vulnerability of the San as a group. An overwhelming majority did indeed see the San as a vulnerable group, although a minority disagreed. The San languages and culture were seen as sources of both pride and embarrassment, with many respondents describing how they had been mocked or teased when speaking in a San language. There was a strong sense of unfairness and exclusion, both historically and currently. Not surprisingly, the characteristic shyness of the San as a group and their reluctance to mix with other groups were strongly in evidence.

The word cloud in Fig. 3.4 represents the frequency of words used in response to the survey.

Being ostracised and humiliated due to attitudes towards the original San languages dominates this representation, but joblessness and poverty also clearly create stress and heartache.

This chapter was discussed with 11 of the 12 community researchers who administered the survey. They were invited to a one-day workshop to give feedback on the survey analysis. After the discussion, some refinements were made to the chapter: for instance, Sect. 3.4.1.5 on the subtheme discussing openness to others was made clearer and additional quotes were selected for Sect. 3.4.3.3 on unfairness and exclusion. We would like to end this chapter with a thought that was expressed at the workshop by one of the community researchers.

Who is Vulnerable?

While the majority of community researchers agreed with the respondents to the survey that the San are a more vulnerable group than others, one workshop participant said: “Imagine that a major catastrophe destroys all civilisations as we know them. The only people who survive are the San and Harvard professors. If this happens, who will be vulnerable?”

3.5 Conclusion

When asked to define “vulnerability” for themselves in workshops and a community-administered survey, South African San representatives stressed two things. First, they did not perceive the word “vulnerable” to be pejorative per se, or negative towards them as a people. On the contrary, it served as a useful “umbrella term” to cover the vast range of issues and problems they experienced. Second, while the term could be useful in that way, the San did not want it to be employed to exclude them from research they needed and wanted.

The potential for San community members to be exploited by researchers is real, and the survey shows why. A very insightful observation came from one of the San community members who took part in the survey.

> The word “poverty” is for me the same as “vulnerability” or “hunger”. When you are hungry you are vulnerable. When you see your kids crying from hunger is painful.

Parents who cannot feed their children will be open to almost any kind of “incentives” to procure food. Giving researchers video-recorded consent to gather information (data) in return for a cash payment (that is unlikely to have been declared to a research ethics committee) seems an obvious way to obtain money for food. San community elder Petrus Vaalbooi referred to researchers “who come and tempt us with ten rand or five rand” (five rand being equivalent to €0.24 or £0.20) (Andries Steenkamp and Petrus Vaalbooi Interviews 2018: 00:57). At the same time, this type of exploitation perpetuates distrust of researchers, even if it is only a small minority of them who use the exploitability of San community members for extractive research.

One way to resolve this is to block the participation of vulnerable peoples in research, which is the traditional way of protecting potential research participants from harm and exploitation. However, it also cuts off access to useful research.

Researchers, including community researchers, might be able to help formulate and refine ways out of the conditions that cause exploitability. To do so, outside researchers need to build trusted relationships with the community, a process that they can facilitate by involving community researchers throughout the research process[1] and by employing research methods that make research less risky for those involved (e.g., by not involving personal data).

San community leader Collin Louw, a co-author of this book, emphasises that it is highly important to distinguish between two uses of the term "vulnerability". The first is the potentially patronising *external* use of the term, which involves blocking access to research, instead of reducing the risks of research involvement through careful study planning, methods centred around community needs rather than maximum data extraction, and engaging community involvement in long-term relationships of trust. The second is the *internal* use of the term to facilitate communication *within* the San community on factors that make it vulnerable to exploitation and also to the social challenges that can lead to drug abuse and hopelessness (see Figs. 3.2 and 3.3).

Equitable research partnerships between researchers and South African San community members, facilitated by the South African San Council and guided by the San Code of Research Ethics, can lead to rich data that have the potential to assist the community in finding ways out of vulnerability. Externally labelling them "vulnerable" as a group and blocking access to research cannot be the solution, even if almost 85% of San survey respondents consider themselves a vulnerable group. None of the community researchers believed this to be a reason for not involving the San in research, but they were convinced that any research involving the San should be on locally relevant topics and carried out in the right way.

Ethics Approval The research described in this chapter was covered by approval from the South African San Council.

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[1] The community researchers involved in our research, from grant writing to publication and evaluation, including the writing of this book, were Joyce Adhiambo Odhiambo, Collin Louw and Leana Snyders: Collin and Leana for the San community and Joyce for the sex worker community in Nairobi.

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4

Vulnerability Among the Nairobi Sex Workers, and Undertaking Community-Led Research Without Collecting Personal Data

> *I didn't know that a discussion forum where personal details are not collected can be so liberating! We spoke without fear and poured our hearts out. It is the first time I have been able to talk about being threatened with death.—Sex worker during workshop*

Abstract

Sex work is one of the most stigmatised professions in many parts of the world. In Kenya, where it is also illegal, sex workers can even face rape and abuse at the hands of law enforcement agents when it becomes known how they earn a living. As a result, sex workers rarely disclose their profession to family members, let alone outsiders. This means that the involvement of Kenyan sex workers in research over the years has been highly risky, as most research efforts collect personal data. This chapter describes a four-stage investigation into how sex workers define vulnerability for themselves. The approach was community-driven, community-led and, in the main, community-analysed. Importantly, no personal data was collected, and all engagement was undertaken by trusted facilitators and a sex worker community researcher. Findings showed that structural vulnerabilities are intersectional and stigma-aggravated. At the root may be poverty, but the stress created by being stigmatised can lead to mental health problems which, in turn, can aggravate poverty and stigma. The Kiswahili term *mnyonge* may capture the essence of vulnerability, expressing a sense of weakness without the ability to defend oneself.

Keywords

Vulnerability • Sex workers • Kenya • Stigmatisation • Discrimination

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4.1 Introduction

The Open Society Foundations, a group that funds civil society groups around the world to advance justice issues, describes sex work as “consensual sexual services or erotic performances” between adults in exchange for material gain, whether in money or goods (OSF 2019). It also observes that financial gain is the main reason for involvement in sex work, as the majority of those involved use these activities to earn a living (OSF 2019). The International Union of Sex Workers estimates that there are 52 million people worldwide engaged in sex work, of whom about 80% are female (IUSW 2023). In the following sections we outline how sex workers can routinely experience stigma, violence, poverty and difficulties accessing health services, as well as mental health issues.

4.1.1 Stigma

Sex work is one of the most stigmatised professions in many parts of the world (Hammond and Kingston 2014; Ma and Loke 2019; Benoit et al. 2020; Benoit and Unsworth 2022). Goffman describes “stigma” as something that is deeply discrediting and puts people in a situation of being “disqualified from full social acceptance” (Goffman 1963: Preface). Issues that impede the full social acceptance of sex workers may arise from historical, societal and cultural attitudes, religious beliefs and/or regulatory and legal structures. Hatzenbuehler et al. (2013) define stigma as “the co-occurrence of labeling, stereotyping, separation, status loss, and discrimination in a context in which power is exercised”. In other words, the assignment of stigmatised labels or stereotypes to groups such as sex workers results in marginalisation, inequalities, loss of status, experiences of discrimination and other violations of human rights (Wong et al. 2011).

Sex workers are likely to experience both felt and enacted stigma.

> Felt stigma (internal stigma or self-stigmatization) refers to the shame and expectation of discrimination that prevents people from talking about their experiences and stops them seeking help. Enacted stigma (external stigma, discrimination) refers to the experience of unfair treatment by others. Felt stigma can be as damaging as enacted stigma since it leads to withdrawal and restriction of social support. (Gray 2002: 72)

Examples of enacted stigma may be found in the complexity of legal situations relating to sex work in many countries, where sex work is illegal or “limitedly legal” (ProCon 2018). For instance, it may be legal to provide sexual services, but illegal to solicit, live on the proceeds of sex work, or pay for sex (Brooks et al. 2023). The criminalisation of sex work is considered to have a major impact on the marginalisation of sex workers (Tsertekidis 2023), many of whom already belong to marginalised or vulnerable communities such as the LGBTQ + community, minoritised ethnic populations, and migrants who may have been trafficked. Belonging to a stigmatised group adds a burden on top of those already experienced by people from disadvantaged populations (Hatzenbuehler et al. 2013).

The study by Wong et al. (2011) of female sex workers in Hong Kong describes their various attitudes to disclosing their occupation to those close to them. Although some had been open with family members, most felt that family and close friends would not be able to accept their work and would judge them. This had led to many sex workers feeling unable to disclose their occupation and taking steps such as working in a different location to keep their secret.

4.1.2 Violence

The criminalisation of sex work in many countries contributes greatly to the stigmatisation endured by sex workers and negatively affects their interactions with the police and the justice system. Benoit et al. (2018) cite multiple studies recounting incidents of harassment, abuse, public humiliation and physical assault by the police, both during and outside the sex workers' working hours. Such a fraught relationship with the police and justice system can make sex workers reluctant to report incidents of assault and even rape.

> Sex workers … report a hesitancy, and often absolute refusal, to access protective services after being victimized. Workers say they worry the police will insult them, ignore them, or charge them with a criminal offense … This is particularly the case for sexual assault victims, who sometimes face the false assumption held by some police officers that sex workers cannot be raped. (Benoit et al. 2018)

4.1.3 Poverty

Many sex workers live in areas afflicted by poverty and high unemployment rates (Brooks et al. 2023). The need to earn a living and to meet family responsibilities, combined with a lack of other opportunities or means to earn money, often makes poverty a driving force for people to engage in sex work (Tsertekidis 2023). Being in a situation of economic vulnerability can impact on sex workers' ability to negotiate with their clients regarding their fees and insistence upon condom use. This has obvious implications for both living standards and health, with the prevalence of HIV and sexually transmitted infections (STIs) disproportionately burdening the sex worker community (Shannon et al. 2015).

4.1.4 Access to Health Services

Accessing healthcare services can be difficult for sex workers, particularly in countries where sex work is criminalised. Sex workers may be afraid to seek medical treatment in case they have to disclose their occupation and then encounter discrimination or are reported to the authorities. The survey of 469 healthcare providers in Germany by Langenbach et al. (2023) revealed that the health professionals held similar levels of prejudice towards sex workers to those of the wider population, suggesting that better training is necessary to sensitise healthcare staff to the needs of sex workers seeking treatment and support.

4.1.5 Mental Health

Sex workers have been shown to experience high rates of problems such as mood disorders, anxiety, post-traumatic stress disorder, personality disorders, suicidal behaviour, distress, substance abuse disorders and other psychiatric conditions (Martin-Romo et al. 2023). Martin-Romo et al. (2023) report that sex workers under 20 years old appear to have a higher vulnerability to mental health issues than their older colleagues.

Undoubtedly, routine stigmatisation, combined with poverty, violence and difficulty accessing health services, as well as mental health issues, places many sex workers in positions of vulnerability.

The next section introduces the Nairobi sex workers and the research clinics where they can access health services. This is followed by the description of a four-stage community-led investigation to uncover what vulnerability means to the Nairobi sex workers.

4.2 The Nairobi Sex Workers and the Ten Sex Worker Clinics

We use the term “Nairobi sex workers” for the more than 40,000 sex workers who are registered in ten STI/HIV prevention, treatment and research clinics in and around Nairobi. Joshua Kimani, one of the co-authors of this book, is the clinical director for those clinics, described below, and another co-author, Joyce Adhiambo, is a peer educator (see below) and community researcher among the Nairobi sex workers.

Most of the Nairobi sex workers have no income or support other than the meagre income derived from sex work. They live in small tin shacks, work well into middle age and accept dozens of clients every day because the payment from each is very low (Lucas et al. 2013). In addition to poverty, social circumstances such as the loss of parents to HIV/AIDS, domestic violence and the need to provide for children and extended families in an environment where jobs are scarce conspire to force them into sex work (Lucas et al. 2013).

As a group, they face difficulties accessing health care and essential medicines, partly due to the criminalisation and high stigma associated with sex work in Kenya. They can, however, access health services at programme and research clinics specialising in the treatment of STIs, for example the Sex Workers Outreach Programme (SWOP) clinics located in Nairobi County. These clinics provide care and medical treatment for STIs in an effort to control the spread of HIV in the country. Some of the sex workers also enrol in research studies as volunteers, sharing information and samples needed for specific studies. Through an active community and engagement process, some also enrol in clinical studies, for instance about pre-exposure prophylaxis for HIV (Bailey et al. 2023).

The initial research cohort of sex workers was formed in around 1984, when researchers from the University of Manitoba (Canada) and the University of Nairobi joined forces to conduct studies on STIs. It was at this time that the sex worker community first attracted the attention of international scientists, when some of them tested positive for HIV. In the early 1990s, it was also found that a small percentage of the sex workers repeatedly tested negative for HIV infection, despite their consistent high-risk behaviour (AIDS Anal Africa 1995). The research scope rapidly moved to seeking a cure for HIV/AIDS, as well as a better understanding of the epidemiology of HIV and risk factors associated with its spread.

With additional resources made available through the Centers for Disease Control and Prevention (CDC) and the US President's Emergency Plan for AIDS Relief (PEPFAR) since 2005, the number of research clinics has grown to ten in Nairobi. From 2009, men who have sex with men (MSM) have been seeking HIV prevention and treatment services from the same clinics. Like sex work, their sexual activity is illegal and highly stigmatised in Kenya.

In August 2023, the numbers enrolled in the programme stood at 33,720 female sex workers and 13,147 MSMs. Most of the MSMs enrolled are also sex workers trying to secure a living. These numbers represent about 65% of the female sex workers and MSMs residing and working in Nairobi. Unlike other parts of the world, in Kenya sex workers generally work independently, not through pimps.

Due to the need for effective mobilisation, engagement and communication between clinic staff and potential research participants, peer educators are selected from the community with two main tasks. First, they help educate potential research participants on the types of research studies that are run, the process of informed consent and safe sex practices, such as condom use. Second, they represent the interests of the community when dealing with researchers and government agencies.

While the outreach clinics provide access to health services for sex workers and MSMs, their lives are still highly precarious owing to their considerable economic disadvantage and the legal situation in Kenya. There is no statutory prohibition on the sale of sexual services in Kenya, but the law forbids "living on the earnings of sex work" and "soliciting or importuning for immoral purposes" (UNAIDS 2020), thereby indirectly prohibiting sex work. Kenya's Penal Code and Sexual Offences Act do not define "prostitution", nor do they directly prohibit "prostitution" (FIDA Kenya 2008). However, many local authorities across Kenya have elected to address sex work under their subsidiary legislation.

For instance, Section 19(m) of the Nairobi General Nuisance By-Laws (2007) provides that "any person who in any street – loiters or importunes for purposes of prostitution is guilty of an offence" (KELIN 2016). Most of these by-laws are vague and leave the determination of the exact offence to the imagination and interpretation of arresting officers. Thus, sex workers enrolled in the SWOP clinics regularly report violations of their human rights and suffer extra-judicial abuse at the hands of law enforcement agents, including rape without the use of condoms. This puts those raped at high risk of contracting HIV and other STIs, in addition to unplanned and unwanted pregnancies. At times, when those living with HIV and on antiretrovirals are locked up in police cells, they miss their medications, which further violates their rights to the highest attainable standard of health.

The clinics are mostly funded by external donors, in particular from the United States government through PEPFAR, the Joint United Nations Programme on HIV/ AIDS (UNAIDS), the Global Fund to Fight AIDS, Tuberculosis and Malaria, the Bill & Melinda Gates Foundation and other sources through the University of Manitoba. The programmes currently running are mostly about HIV prevention and treatment and some are about research ethics, such as the Wellcome Trust grant that has funded the research for this book.

The primary objectives of research undertaken in the ten SWOP clinics focus on the health and wellbeing needs of the sex workers. They include identifying and describing key characteristics that place sex workers at high risk of infection and describing how sex workers can be reached and served by various health programmes. Despite this clear link to local health needs, many sex workers are highly reluctant to take part in research that collects personal data. There is a particular fear that involvement in research will reveal to third parties—such as landlords, colleagues and family members—that they earn their living through sex work. An even greater fear is that personal data will be revealed or shared with law enforcement agents.

While it is obvious that privacy and confidentiality are key issues when undertaking research involving sex workers,

> there has been reluctance among scholars to comment on their research process, especially with regard to how they deal with the protocols for research ethics when conducting … studies among female sex workers. (Sinha 2022)

In our activities, we therefore respected the clearly reasonable fear of many sex workers that their personal data could be misused and increase stigmatisation, discrimination or even violence. We prioritised this question: is it possible to obtain meaningful information without the processing of personal data through a community-led consultation exercise that involves workshops and one-to-one conversations?

4.3 What Is Vulnerability as Defined by the Sex Workers Themselves? A Community-Led Consultation Exercise

Community-engaged approaches are often promoted in social science research to prioritise the knowledge of the communities most impacted by research (Beckett et al. 2022). Thompson et al. (2021) view the multiple forms that engagement activities can take along a continuum, from simple outreach and education to full partnership, reflecting the degree of meaningful involvement of the community in question. All types of community-engaged approaches to research traditionally involve two parties: non-academic community stakeholders and academic researchers. As discussed in Chap. 5, a central tenet of engaged research is that communities must be involved on their own reasonable terms (Fawcett 2021), which requires flexibility and sensitivity in any work undertaken. To address the question of how sex workers define vulnerability for themselves, we went beyond community engagement in the traditional sense. Instead, we opted for an approach that was community-driven, community-led and, in the main, community-analysed.

A novel approach to inquiry was trialled with the sex worker community in Nairobi, one that fell somewhere between community engagement methods and social science research methods. While our approach had much in common with both, it did not involve the coming together of two parties (as in community engagement), nor did it adopt the kind of systematic approach that might be expected in social science research. Community engagement in research is often employed to address mistrust, misunderstandings or power imbalances as partners from different standpoints come together (Holzer et al. 2014). Our intention was to avoid these issues altogether; so our community-led consultation was undertaken by the community, for the benefit of that community.

The community-led consultation exercise that we engaged in was facilitated by Joshua Kimani and Joyce Adhiambo, who are both deeply embedded in the sex worker community in Nairobi. Each stage in the process was informed by findings from the previous stage and designed with local preferences and needs in mind. This meant that meaningful information was obtained in a manner that was sensitive to the fears and wishes of the sex worker community, in a space that was considered safe and by people who were trusted. The shape of the consultation was not set at the start. This evolved as the consultation progressed through the four stages shown in Table 4.1.

The findings from the four stages of the community consultation exercise are explained below, after a section that describes how a safe space was created for the community workshops.

4.3.1 Creating a Safe Space

Safe spaces were created for the workshops after consultation with sex workers at the clinics and according to the criteria set out below. When selecting venues and making arrangements, we took all these factors into account. The workshops took place in meeting rooms of Nairobi hotels.

Table 4.1 Stages in the community-led consultation exercise

Stage of consultation	Participants	To discuss
Stage 1 February 2022 Three workshops	Three workshops with 15, 13 and 14 sex workers (42 in total)	Inviting thoughts on why HIV infections are increasing, with a broad opening question: “What is going on?”
Stage 2 March 2022 Workshop	20 attendees from the Stage 1 workshops	A follow-up workshop to help attendees delve deeper into the topic of the earlier workshops and gain a better understanding of their dilemmas, discussing: “What does all this tell us about sex workers?”
Stage 3 June 2022 Workshop	20 attendees from the Stage 1 workshops	More focused on the topic of vulnerability, with the topics: “Finding the Kiswahili word equivalent to ‘vulnerability’” and “What could help minimise vulnerability in research?”
Stage 4 5 Sep to 25 Nov 2023 One-to-one conversations	19 attendees from the Stage 1 workshops	A deeper dive into what vulnerability means to individuals

4.3.1.1 Approved Hotel Location

Most sex workers in Nairobi live in informal settlements and use public transport for their work, so hotels had to be easily accessible from the major public transport stops. Hotels in the central business district and within reach of key bus stops were preferred, as were hotels located near well-known landmarks. Nairobi has no house numbering system as used elsewhere, and therefore landmarks are useful in identifying meeting venues.

4.3.1.2 Approved Hotel

Mindful of the high risk of stigmatisation, the sex workers who were consulted about workshop venues pointed out that the non-stigmatising attitude of staff (security team, reception and waiters) at some hotels would create confidence and the right environment for inclusive discussions.

4.3.1.3 Soundproof Room

To maintain a high level of confidentiality, the sex workers preferred to meet in a room that was soundproof or at least equipped to ensure that the discussions were not overheard.

4.3.1.4 Private Toilet Facilities

In past encounters, some hotel managers had accused sex workers of not being clean. Hotel venues with private toilet facilities for the duration of the meetings were therefore strongly preferred because they obviated contact with other guests. Such private facilities tended to lower the tension among the participants, which improved the mood and productivity of meetings.

4.3.1.5 Good-Quality Refreshments

Given that many sex workers who use the ten research clinics are highly impoverished, they preferred hotels that served substantial and tasty meals, snacks and beverages during meetings.

4.3.1.6 Familiar Meeting Facilitators

It was highly important to the sex workers that the meeting facilitators should be familiar faces from the community. This was especially the case for the Stage 1 workshops, which dealt with HIV infection among the sex workers.

4.3.1.7 Chatham House Rule

No one would be allowed to share personal information disclosed at the venue, a fact emphasised ahead of the meetings by the familiar meeting facilitators. (We did not use the term “Chatham House Rule” in our discussions with the sex workers, but have added it here for clarity.)

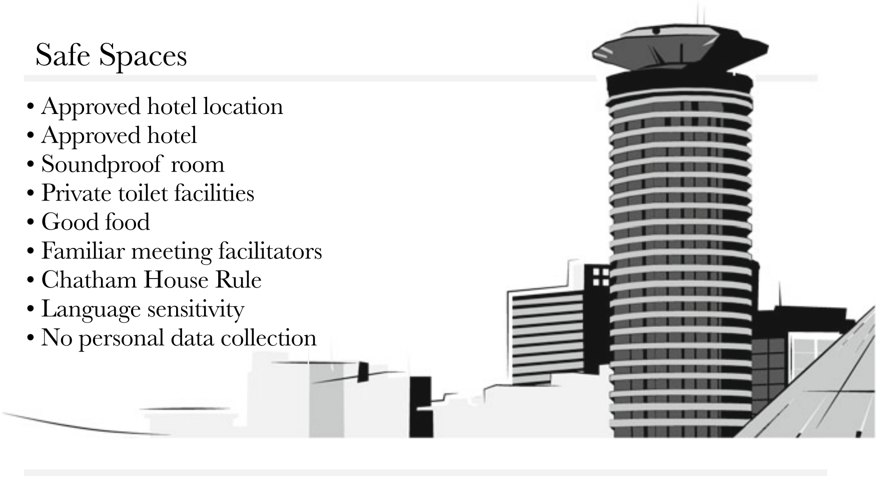
4.3.1.8 Language Sensitivity

For the best outcomes in any discussion with the sex workers enrolled in the ten clinics, a blend of Kiswahili and English (known as Sheng) is always used. Most sex workers are very comfortable with that medium since it allows them to express themselves without feeling inhibited.

4.3.1.9 No Personal Data Collection

It was made clear from the start, in the invitation to the workshop, that no personal data would be obtained or video or audio recordings made, as the sex workers greatly feared the unwanted release of personal data. The only record of the meetings would be the notes taken by the familiar meeting facilitators. This decision proved decisive, as it freed participants to share experiences such as sexual abuse and violence.

Figure 4.1 summarises the measures taken to create a safe space for the workshops.



Safe Spaces

- Approved hotel location
- Approved hotel
- Soundproof room
- Private toilet facilities
- Good food
- Familiar meeting facilitators
- Chatham House Rule
- Language sensitivity
- No personal data collection

Fig. 4.1 Measures to create safe workshop spaces

Is it possible to create a safe space at the workshop so that participants feel free to engage honestly and authentically with each other and with the facilitators? The participants noted that they felt recognised and useful, and requested that similar open consultations be held regularly. One delegate's observation was recorded in full.

> I didn't know that a discussion forum where personal details are not collected can be so liberating! We spoke without fear and poured our hearts out. It is the first time I have been able to talk about being threatened with death by a family member and a former regular client to anyone. We need more of such discussion to improve our healing process.

4.3.2 Community Consultation Stage 1: HIV Infection—A Major Vulnerability

Prior to the first workshops in Nairobi, informal discussions around the word "vulnerability" revealed that there was no equivalent word locally. Hence, it became obvious that we could not arrive at a definition of the term applicable to the sex workers simply by asking them what vulnerability meant to them, so the decision was taken to begin by focusing on a shared vulnerability. At the time of planning the workshops, a rise in HIV infections had been reported at the ten clinics for almost two consecutive quarters. The risk of HIV infection is a life-threatening vulnerability that sex workers constantly have to navigate for themselves, their partners and their clients, and it appeared to be increasing. Thus, the rise in infections was chosen as a topic that was relevant to the community and of potential benefit to it, and one that would resonate with it immediately, without any explanation needed. It was anticipated that examination of this major vulnerability-related challenge could lead to the identification of trigger factors and exacerbators of this vulnerability.

To encourage a free flow of thoughts and conversation, Joshua Kimani opened the discussion by outlining the topic and then asking just one question: *What is going on?* This question led to some serious and heated discussions about what could have contributed to the high number of HIV infections noted in the community. The interest and enthusiasm of the community members about sharing their perspectives was consistent across the three meetings.

Following the three meetings, the facilitators summarised the meeting notes, identifying the 41 main reasons (see Appendix) why the sex worker delegates thought that the number of HIV infections had risen in the last quarter and was continuing to rise. (The workshops also included discussions about how to overcome the problem, a matter that is not part of this book.)

NVivo software was then used to code and theme the 41 reasons identified for the increase in HIV infections, a task undertaken by UK members of the team. Thematic analysis revealed two primary trigger factors or root causes of the increase in HIV infections: poverty and stigma. The dual burdens of poverty and stigma were believed to exacerbate vulnerability to HIV infection either directly or indirectly. For example:

- self-stigma, increasing mental health issues and leading to risky sexual behaviours.
- a loss of livelihoods, eroding empowerment and capacity among sex workers to negotiate and avoid risky sex.

At the time of the workshops, the impacts of the COVID-19 pandemic were still at the forefront of people's minds. During the pandemic, the pressures of poverty and stigmatisation for sex workers had increased, and consequently the pandemic also exacerbated many of the identified reasons. For instance:

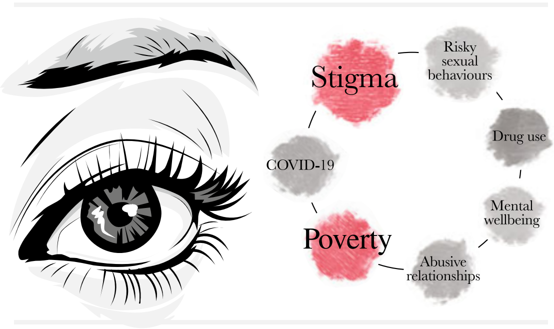
- an increase in poverty, due to the loss of livelihoods for the sex workers caused by COVID-19, leading to risk-taking behaviours.

The interlinked nature of many of the identified reasons revealed clear pathways to increased vulnerability to HIV infection, as shown in Fig. 4.2.

All the identified pathways appear to be rooted in either poverty or stigma or, usually, both. However, as the elements in these pathways are linked, exacerbation at any point could lead to increased vulnerability to HIV infection.

In line with the literature outlined in Sect. 4.1, vulnerability to mental health issues was identified as a major problem, as was vulnerability to violence from a range of abusive relationships, including those with clients, the police and partners. Additionally, the findings revealed that many sex workers turn to alcohol and/or drugs, which, in turn, serve to increase their vulnerabilities.

Fig. 4.2 Poverty and stigma pathways to increased vulnerability to HIV infection



Aside from these interlinked pathways, several other reasons for the increase in HIV infections were identified, including a lack of understanding of and incorrect information about safe sex practices, a lack of proper support from peer educators, support groups or clinical staff, and a lack of access to condoms.

It is clear from the findings that many of the contributory factors to increased HIV infections are beyond the control of the sex workers themselves. Intervention at a higher level is needed to alleviate the pressures that arise from poverty and the stigma associated with sex work. As Nobel Laureate Amartya Sen (2005: xii) puts it, “Preventable diseases can indeed be prevented, curable ailments can certainly be cured”—and HIV infection is preventable. But where poverty and stigma intersect for the Nairobi sex workers, structural violence leads to life-threatening disadvantages. Among the 41 reasons the sex workers provided in the workshops, many point to structural violence, for example a lack of access to condoms, sexual violence by police officers, difficulties adhering to antiretroviral medication due to hunger—a known complication in achieving adherence in antiretroviral therapy (Weiser et al. 2010)—and lack of understanding about safe sexual practices. Poverty and stigma pathways to increased HIV infections are reminiscent of the structural violence described in one of the most powerful books published on poverty in the early twenty-first century: *Pathologies of Power* by Paul Farmer (2005).

> [N]o single axis can fully define increased risk for extreme human suffering … Today, the world’s poor are the chief victims of structural violence – a violence that has thus far defied the analysis of many who seek to understand the nature and distribution of extreme suffering. (Farmer 2005: 49, 50)

Structural violence involves.

> harm caused by embedded social structures rather than by violent physical acts. Socioeconomic and political factors that disadvantage certain individuals or groups are embedded into the structure of society, and cause harm to those individuals or groups by denying them the same privileges and life chances as the rest of society. (Bohm 2018)

Aside from insights into the structural violence that serves to enhance the sex workers' vulnerabilities, the workshops also provided insights into their felt sense of vulnerability. For instance, attendees referred to an "erosion of self-worth", to "poor self-esteem" and to "self-stigmatisation". These feelings are deeply enmeshed in the structures that create poverty, stigmatisation and so on, which were further explored in Stages 2 and 3.

4.3.3 Community Consultation Stage 2: Living with Structural Violence

For Stage 2 of the community-led consultation exercise, 20 of the attendees from the first workshops were invited to attend a follow-on workshop. The facilitators were keen to engage the attendees in deeper discussions about why the sex workers were still at a higher risk of HIV infection, despite heavy investments by donors in Nairobi and Kenya in general. After hearing a summary of the findings from the first workshops, the attendees were asked: *What does all this tell us about sex workers?* We hoped that this question would provoke reflection upon the sex workers' own situations and help them gain a better understanding of their dilemmas.

Although the COVID-19 control measures were at the forefront of people's minds, the workshop participants were quick to note that although COVID-19 had had some major impacts on livelihoods and the ability of clients to pay for sexual services, the excess HIV infections pointed to deeper, underlying issues. Notes taken during the workshop and later summarised by the facilitators revealed 15 underlying issues that, for the sex worker population, contributed to their vulnerability. Thematic analysis of these issues revealed four major stresses associated with living with the types of structural violence that the sex workers experienced, as set out in Table 4.2 and graphically depicted in Fig. 4.3.

These major stresses all served to increase vulnerability, and the persistently high stress levels among the sex workers were believed to have led to substance abuse and risky sexual behaviours.

4.3.4 Community Consultation Stage 3: Thinking About Vulnerability

For Stage 3 of the community-led consultation exercise, 20 of the attendees from the first workshops were invited to explore issues around vulnerability. The objective was to discuss vulnerability issues encountered in their day-to-day lives and when participating in research studies.

The discussion began with attendees sharing how they were affected at a personal level. Many had difficulties handling the stigma, discrimination, marginalisation and exclusion meted out by relatives, friends and members of the wider population. To cope with these challenges, some individuals had taken to drug and

Table 4.2 Four major stresses described by sex workers

Stress	Experience
Stigmatisation	Because sex work is criminalised in Kenya, sex workers felt as if they were constantly operating in the shadows. When attempts to hide their profession from important others (like their children or landlords) were thwarted through exposure by neighbours or others, this could have damaging consequences for entire families. For instance, some sex workers believed that the resultant relationship breakdown with their children was a cause of childhood delinquency
Discrimination	The extent of the discrimination that sex workers were subjected to was extreme. They reported discrimination by landlords, school heads, healthcare providers (in the public sector), the police and even government officers. For instance, at the height of COVID-19 control measures and restrictions, some government officers reportedly kept sex workers and their families from having access to any of the socio-protection services available to others
Marginalisation	The sex workers reported being marginalised at the community level because they engaged in "immoral" or "taboo" activities. Marginalisation even occurred within familiesfor example, at family events—where they were called names because of the work they did
Abuse	The sex workers reported that their human rights were frequently violated by law enforcement agents, for example by police demanding sex. Powerful people (like politicians) were also said to be a threat to sex workers, who reported being violated and/or raped while the perpetrators seemingly remained above the law

Fig. 4.3 Four major stresses described by sex workers

substance abuse, leading to self-stigmatisation, self-isolation, low self-esteem and suicidal thoughts, aggravating the perceived marginalisation at individual level.

Many of the sex workers had been forced to take measures such as working in a different location to reduce the risk of being exposed as working in the sex trade. These circumstances also weakened their resolve to accept their HIV/AIDS status and/or disclose it to their peers. The lack of support from family and friends could lead to self-hate and no or poor compliance with HIV/AIDS medication.

Marginalisation was also reported to be rampant among sex workers. Some said they felt disrespected and/or despised at the community level, especially on

Table 4.3 "Vulnerability" in Kiswahili

Kiswahili	English
Watu ambao wako kwa hatari au mateso	People who are in danger or suffering
Watu walioadhirika	Affected people
Watu dhaifu	Weak people
Watu ambao wamenyanyapwa	People who have been stigmatised
Watu wanyonge	Poor people

housing issues. In some housing estates, women from the general population would gang up against them since they were viewed as potential threats to marriages. It was reported that some landlords had even evicted them for no reason other than their being sex workers. This affected their self-esteem and sense of self-worth.

Following this emotional discussion, an exercise was conducted to try to identify a Kiswahili equivalent for the word "vulnerability". Since the locally used languages, including Kiswahili, had no single word for vulnerability, the descriptive phrases set out in Table 4.3 were suggested by the sex workers.

What is particularly striking about the phrases chosen is that they reflect the types of structural violence that impose life-threatening disadvantages on sex workers. They are affected by stigmatisation and poverty, and live in a state of danger or suffering. The immense stresses that are part of their lives can create a sense of weakness, but "weakness" might also refer to their inability to change the socioeconomic and political factors that cause them harm.

The final workshop activity involved a group discussion on what could be done to help minimise vulnerability in *research*. Seven key points were summarised.

1. *Ensure confidentiality*. This was regarded as a top priority. It is needed to ensure that those who have not revealed their profession or health status to others cannot be harmed by privacy breaches.
2. *Ensure meaningful engagement and involvement in research*. This helps build capacity in the sex worker populations and affirms that the engagement is not only being undertaken as tokenism.
3. *Engage members of the community throughout*. They must be engaged at every stage: before the study is initiated, during the conduct of the study and when results are being interpreted and disseminated.
4. *Implement community education on the research subject matter*. This was seen as the surest way to improve agency in potential study participants. Education was also noted as the best route to recruitment, as it can improve informed decision-making.
5. *Act with honesty and fairness*. Some researchers show up in the community, collect data and pictures, and then disappear. Later, photos appear in reports about issues that were not mentioned in the stated study objectives.

6. *Look after the research participant's welfare.* This might, for example, be through psychosocial support following interviews about painful lived experiences.
7. *Be trustworthy.* This was regarded as the best way to build good relationships between researchers and research participants.

4.3.5 Community Consultation Stage 4: What Does Vulnerability Mean to You?

Delegates from the Stage 1 workshops were invited to take part in individual conversations. Nineteen conversations with sex workers were conducted by Joyce Adhiambo, a peer educator and community researcher. The conversations were thus conducted.

- by a known and trusted peer
- sensitively, with Joyce listening carefully to glean new information from the sex worker
- with no record kept of personal data
- at a safe pace
- in a suitable language
- with findings recorded only as written notes.

Seven questions were asked during the conversations.

1. What does vulnerability mean to you? In your own words.
2. Give three or more examples of when you were made to feel vulnerable as a person.
3. Would you consider sex workers in Kenya as a group vulnerable in relation to other groups? In other words, are the sex workers more or less vulnerable than other groups?
4. A person (not you) can be vulnerable in many ways. Give examples of when other people can be made vulnerable.
5. In your opinion, what other words have a similar meaning compared to the word "vulnerability"?
6. At the SWOP clinics level, how can the vulnerability of sex workers be minimised?
7. How can vulnerability among sex workers attending or accessing HIV prevention and treatment programmes in Kenya be minimised?

For the purposes of this chapter, data analysis focuses on Questions 1 to 5 to construct an understanding of how Nairobi sex workers perceive and experience vulnerability. Data from Questions 6 and 7 is drawn on where it contributes to this understanding.

Conversations were conducted in Kiswahili or a blend of Kiswahili and English (Sheng), whichever suited the person being spoken to. The information was then translated and typed up from Joyce's notes into English with a few Kiswahili phrases. The scripts were then checked by Joshua Kimani before being forwarded to Hazel Partington, a co-author and UK member of the team, for thematic analysis. Google Translate was used to translate the few Kiswahili phrases, and these meanings, along with a few other contextual queries, were later checked in a meeting between Hazel, Joyce, and the person who supported the community researcher (Polly N Ngurukiri, see Acknowledgements).

Methodology for Analysing Conversation Data

The data obtained from the conversations was analysed qualitatively using thematic analysis following Braun and Clarke (2022). Data was uploaded to NVivo for the initial coding phase. The second phase of coding entailed the tentative codes from NVivo being reduced and refined, and then exported to Word documents for the codes to be finalised and the themes developed. The themes were discussed with all co-authors of this book.

Three main themes were constructed from the data. These are listed in Table 4.4 with the concepts encompassed by each theme.

Table 4.4 Nairobi sex workers' understandings and experiences of vulnerability

Themes	Main concepts in the theme
Vulnerability means stigmatisation, discrimination and marginalisation	Stigmatisation, discrimination and marginalisation from: • society • organisations • family members • police and other officials
Vulnerability means being at risk or in danger	Taking risks to meet family responsibilities or to survive Dangerous situations connected to sex work, problems with clients, exploitation Risks connected to poverty Risks connected to health
Vulnerability means ***mnyonge***	*Mnyonge*: this Kiswahili word is variously translated as "poor", "wretched", "frail", "weak" and "miserable" Feeling weak or unable to do something Feeling unable to speak up for oneself or defend oneself or others Being short of basic needs Lacking information

Table 4.5 Aspects of stigmatisation, discrimination and marginalisation

Aspects of stigmatisation, discrimination, and marginalisation	Examples
Discrimination was felt from society at large	The society that we live in stigmatises us simply because we are sex workers and sidelines us because of some health conditions we have. They even go about backbiting us, and that makes us feel bad
Discrimination was experienced from organisations that participants might have expected to be able to turn to for support	I am discriminated against in church when giving tithe and offerings because I am a sex worker
Stigmatisation can come from their own families	Family members look down upon me because of the sex work I do and there is no respect
The impacts of the stigmatisation can extend to their children	Children born to sex workers face stigma and discrimination in all forms
People are also discriminated against and marginalised within their families	In my family I am not included in decision-making simply because I am a sex worker
Marginalisation is exacerbated by the legal situation in Kenya	Sex work in Kenya is illegal, it is considered taboo
Many reported feeling vulnerable in their dealings with the police	When females are arrested the police start harassment by touching your private parts, without even bothering who is looking, in the pretence that they are doing a warrant search When I was arrested by the police, I did not have access to medication, and I could not bail myself out of the police cells
Sex workers fear being stigmatised by healthcare professionals	You go to the hospital after you are raped, but fear to disclose to the doctor about the rape

4.3.5.1 Vulnerability Means Stigmatisation, Discrimination and Marginalisation

The sex workers' understanding of the meaning of vulnerability was shaped by their experiences of being stigmatised, discriminated against and marginalised. All 19 referred to stigmatisation, discrimination or marginalisation. Table 4.5 provides an overview of the various aspects, coupled with examples from the conversations with the sex workers. The examples are authentic, but not verbatim quotes, as they are drawn from notes of the conversations.

4.3.5.2 Vulnerability Means Being at Risk or in Danger

All of the sex workers mentioned feeling at risk or in danger, either as a meaning of vulnerability or as an example of when they have felt vulnerable or observed other people to be vulnerable. They described vulnerability in many ways, for instance as being at a high risk of violence, as being attacked or as something

Table 4.6 Aspects of risk or danger

Aspects of risk or danger	Examples
Poverty contributes to many risks and risk-taking behaviours	The economy has put us in a situation of risky behaviours
Poverty increases pressure on those with family responsibilities	I felt vulnerable when a client wanted to have unprotected intercourse, since I was desperate for the money, especially right now with the low economy and life constraints
Interactions with clients may result in physical attacks and risks to health	I was once beaten by a client simply because of a small misunderstanding We might have many or multiple sex partners of different unknown HIV status and might be forced to do what one is not willing to do
The environments which sex workers conduct their work in can be dangerous	The bar owners or managers want you to part with something or money so as to give you permission to work in that hotspot and sometimes take advantage of you and want to have sex in exchange for favours

risky that can get or catch you unaware. Table 4.6 provides an overview of the various aspects, coupled with examples drawn from the conversation notes.

4.3.5.3 Vulnerability Means Mnyonge

The Kiswahili word *mnyonge* is variously translated as “poor”, “wretched”, “frail”, “weak” or “miserable”. Two of the SWOP outreach workers explained that it describes a state of being vulnerable, not able to defend oneself, not able to speak for oneself, lacking information and having low self-esteem. This word, which was mentioned by some participants as being similar in meaning to “vulnerability”, encapsulates a nuanced sense of a state of being vulnerable. Table 4.7 provides an overview of the various aspects, coupled with examples drawn from the conversation notes.

In terms of group vulnerability, all the sex workers agreed that they were more vulnerable than other groups. There was an acute sense that risk and danger also extended beyond perceptions of individual risk to perceptions of danger for the whole group. This was viewed as being related to the work they were doing and being viewed as outcasts. As noted during one of the conversations, sex workers are at high risk of violence, rape and unprotected sexual intercourse that can lead to infections like HIV and AIDS, and other STIs. They are also vulnerable because the wider community does not protect them and instead violates their human rights. When sex workers report these cases, the relevant authorities, such as police and government officials, do not take it seriously.

Table 4.7 Aspects of *mnyonge*

Aspects of *mnyonge*	Examples
Over half of the participants linked vulnerability with feelings of weakness or inability to do something	Vulnerability means human weakness Lack of strength and knowledge to approach something, whether positive or negative
The feeling of weakness can manifest as difficulty in speaking up for oneself or defending oneself	Vulnerability means being taken, like you cannot speak for yourself, or you don't have an idea of what is going on When l am unable to say no when I am supposed to say no
Vulnerability can arise from sex workers being unable to satisfy basic needs to look after their health and be able to continue working	I feel vulnerable if I cannot afford basic needs, healthcare services, and do not get the opportunity to be heard or express myself
A sense of lack also extends to a lack of information	As a sex worker I might be doing something without understanding or realising the consequences

4.4 What Vulnerability Means to the Nairobi Sex Workers

Through the successive stages of the community-led consultation exercise, we were able to delve deeper and deeper into what vulnerability means to the Nairobi sex workers.

Stage 1 showed that structural vulnerabilities are intersectional. At the root may be poverty and/or matters related to stigmatisation. These both cause and are made worse by other forms of structural violence. For instance, the stress created by being stigmatised can lead to mental health and drug abuse problems, which, in turn, can aggravate both poverty and stigma. It is not possible to untangle the vulnerability that sex workers experience from the social, economic and political structures that bind them.

Stage 2 helped us distinguish four major stresses for the sex workers. What was viewed as stigmatisation in Stage 1 can be further broken down into stigmatisation, discrimination, marginalisation and abuse.

Stage 3 told us more about how the sex workers viewed vulnerability through their choice of phrases in Kiswahili that have meanings similar to “vulnerability”. Again, the themes of poverty, stigmatisation and the sense of being at risk or in danger were apparent. But this exercise also highlighted the felt sense of weakness associated with living with the significant stresses that are the norm for sex workers.

The one-to-one conversations in Stage 4 permitted deeper exploration of the sex workers’ lived experiences. Their revelations further confirmed and illustrated what had emerged from the workshops regarding stigmatisation, discrimination, marginalisation, violence and abuse, and the pressures of living in poverty. These conversations also gave us further insight into the sex workers’ felt sense of vulnerability, especially through the theme of *mnyonge*. The above-mentioned felt sense of weakness was expressed in various ways, including not being able to express or defend oneself, not understanding all that was happening, and a general lack of mental strength.

4.5 Conclusion

Many Nairobi sex workers are reluctant to take part in research, even when the research is directly linked to their health needs. One of the main reasons for this reluctance is the collection of personal data. Where a person can lose a tenancy or be abused by law enforcement agents for being a sex worker, it is paramount that such information not be disclosed unnecessarily. In essence, this means that the most ethical way to undertake research with Nairobi sex workers is to do so without collecting personal data, wherever possible.

With the sex worker community in Nairobi, a novel approach was developed that connects community engagement with social science research methods. Instead of the traditional bridge-building between (overseas) researchers and local communities through various pre-set encounters, our community-led investigation was undertaken by the community, for the benefit of the community. This meant that the process was planned iteratively, starting at Stage 1 with unusually open questions to 42 sex worker delegates—*What is going on? Why are HIV infections on the increase in the community?*—and culminating in Stage 4 with 19 inclusive, sensitive conversations between a community researcher and a subset of the delegates to explore the term “vulnerability”.

Socioeconomic and political structural vulnerabilities create obvious poverty and stigma pathways to HIV infection and other forms of harm. Some of the findings were positive and potentially of great benefit, such as discovering how to create a safe space so that participants felt free to engage authentically with each other and with the facilitators. However, the stories of exploitation, rape, lack of condoms in a high-risk setting and abuse were shattering. As a research team, we always want to make a difference where we engage, and in this setting the hurdles seemed insurmountable. Nevertheless, the participants declared that they felt recognised and useful, and they requested that similar open consultations be held regularly. Importantly, they also suggested ways out of vulnerability, and, once this book has been completed, we will take those forward in collaboration with the community researchers from the San community (see Chap. 3).

What seemed absolutely obvious to us is this: we were party to research engagement with possibly one of the most vulnerable populations in the world. These sex workers struggle to satisfy their basic needs; they cannot always access life-saving drugs; sometimes they are unjustly imprisoned or do not report violent crimes like rape to the police for fear that this will aggravate their situation. In our experience, this group is highly likely to be excluded from research by overprotective research ethics committees from higher-income settings playing the “vulnerable” card. Our reply to any future blocking attempts is that it depends on how the research is undertaken and how precisely it is tailored to the needs and preferences of the vulnerable individuals in question.

The Kiswahili term *mnyonge*, used in our conversations with sex workers to explain the term “vulnerability”, expresses a sense of weakness without the ability to defend oneself. Defending oneself means that this group must not be left behind in research, but instead must benefit from co-building approaches that generate new knowledge without increasing risks and burdens.

Ethics Approval The four-stage community-led investigation described in this chapter was covered by ethics approval KNH/ERC- P258/09/R/2008.

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Engaged Research: Strengthening Research Teams Through Community Researchers

5

Abstract

Engaged research, which strengthens research teams through community researchers, offers many opportunities and challenges. From better access to community members who are hard to reach, to the collection of more meaningful and authentic data, and greater trustworthiness of research findings, the benefits for research are manifold. However, research has also shown that community researchers might be overtly biased, only collect superficial data or lack the confidence to probe deeply enough, among other challenges. Simultaneously, the literature on community researchers is heavily biased towards high-income countries, and there is very little to be found on experiences from low-and middle-income countries that goes beyond assistance in obtaining informed consent. This chapter starts to close that gap by presenting a case study involving 12 community researchers from the South African San community. Collecting no personal data and obtaining all research input through community researchers shows that research *led by* vulnerable groups *for* vulnerable groups is possible. It is one way of ensuring that the San, and wider research communities, have access to research they can trust.

Keywords

Research ethics • Community researchers • Engaged research

5.1 Introduction

In recent decades, a range of research methods have evolved that aim to conduct “research with” rather than “research on” individuals and communities (Olshansky et al. 2005; Ganann 2013). From participatory action research (Baum et al. 2006) to patient-centred outcomes research (Garces et al. 2012), co-creation (Greenhalgh

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Fig. 5.1 Engaged approaches to research

et al. 2016), inclusive research (Walmsley et al. 2018) and community-based participatory research (Goodman and Sanders Thompson 2017), all approaches aim to make research more engaged (see Fig. 5.1).

Trying to achieve the same goal, some communities now require community approval for research conducted among their members. For instance, the San Code of Research Ethics is the first research ethics code drafted by an Indigenous community in Africa (Callaway 2017). It requires—in alignment with the global research ethics literature (Weijer and Emanuel 2000)—that the community leadership be consulted before research is undertaken on South African San communities. Community advisory boards are similar protection mechanisms developed by communities themselves: researchers seek their advice before enrolling individual research participants in studies (Newman et al. 2011).

One approach to engaged research is to open research teams to community or peer researchers—that is, to "members of the target population [who] are directly involved in the research process" (Guta et al. 2013). This chapter has four aims:

- to provide an overview of what is meant by "community researchers" and explain why further work in this area is important
- to describe the benefits and challenges of using community researchers by drawing on the wider literature

- to introduce a case study involving community researchers from the South African San community in vulnerability discussions
- to draw out lessons learned from the case study in the context of the wider literature.

As a central tenet of engaged research is to involve communities on their own reasonable terms (Fawcett 2021), we emphasise the importance of flexibility and sensitivity in how any work is undertaken. What we describe here is not offered as a tick list of "how to do it", but rather as promising possibilities to help build an evidence base for engaged research. This is particularly important for international collaborative research in low- and middle-income countries (LMICs) (Memon et al. 2021).

5.2 Community Researchers

The past few decades have seen the involvement of community researchers proliferate in research in high-income settings, especially in health research (O'Fallon and Dearry 2002; Memon et al. 2021). One of the key reasons for this relates to disappointing results from new, research-based public health interventions and an appreciation of the fact that more valuable findings might have been obtained had the relevant research activities been informed by the target community (Flicker et al. 2017). Participation and collaboration with community members are now key requirements for some funding applications (Wellcome n.d.; Ganann 2013).

Community researchers are members of the target community who are directly and actively involved in the research activities (Ryan et al. 2011; Southby et al. 2022). These researchers work alongside academics and can be involved through all research stages (Ganann 2013). They can help shape the research design, provide support in data collection and data analysis, and contribute to knowledge translation (Kemmis 2006). However, the level of involvement can vary (Hemming et al. 2021).

The engagement of community researchers challenges traditional top-down methods of knowledge creation by academic experts, and values knowledge that is socially co-created with those directly concerned (Ganann 2013). It is underpinned by the work of Paulo Freire, a Brazilian educator and philosopher, who aimed to reduce power imbalances and achieve social change through reciprocity, mutuality and collaboration (Freire 1970).

Various terms are used to describe community members who are part of research teams, including co-researchers/lay researchers, community researchers and peer researchers (Vaughn et al. 2018). These terms also reflect subtle role differences, as outlined in Table 5.1.

Table 5.1 Different terms for involving individuals from communities directly in research

Term	Description
Co-researcher/lay researcher	A lay member has a general interest in the study area and brings a "public" view (Entwistle et al. 1998)
Community researcher	A community researcher is a member of the general community that is being studied (Cummings 2014)
Peer researcher	A peer researcher shares the same characteristics and/or experiences as those being researched (Guta et al. 2013)

The motivations for individuals to undertake this role include:

- developing transferable skills for employment purposes (Van der Velde et al. 2009)
- contributing for altruistic reasons, such as strengthening their community, enabling individuals' voices to be heard and supporting advocacy efforts to shape and develop services, policies and legislation (Van der Velde et al. 2009), for instance the decriminalisation of sex work (Lobo et al. 2021)
- the remuneration.

Engaged research methods (such as involving community researchers in research) are almost always developed in high-income countries for high-income country settings (Dietrich et al. 2017; Mulvale et al. 2019), for instance as "considered best practice … in research involving indigenous peoples in New Zealand, Australia and Canada" (Goodyear-Smith et al. 2015). However, where knowledge systems differ considerably, it is particularly important to develop and employ co-design or engaged methodologies (Aguirre-Bastos et al. 2019) such as the involvement of community researchers. A potential lack of models for engaged research with marginalised populations in LMICs is therefore a serious concern, with two immediate problems.

First, established models for engaged research, such as community advisory boards, focus mostly on consultation and input on *existing* protocols to obtain meaningful consent (Strauss et al. 2001; Newman et al. 2011; Manda-Taylor 2013; Ortega et al. 2018; Zhao et al. 2019). Co-design or engaged research methods such as inviting community members into the research team as active co-designers of the research go far beyond consent (Francoli et al. 2015; Aguirre-Bastos et al. 2019; Asari 2019).

Second, current approaches to the meaningful engagement of marginalised populations in LMICs in research are almost exclusively about *clinical* research (Macklin 2004; Dickson 2006; Hawkins and Emanuel 2008; Ravinetto et al. 2011, 2015; Shivayogi 2013; Tindana et al. 2015, 2019; Weigmann 2015; Joseph et al. 2016). Applying these methods to non-clinical research could reproduce a "medical dominance" scenario (Humphreys et al. 2014)—that is, the adoption in non-clinical settings, without adequate changes, of ethics processes originally developed for clinical research.

The next two sections of this chapter, which discuss the benefits and challenges of involving community researchers in research, therefore need to be read in the knowledge that the wider literature is biased towards knowledge created in high-income countries. That makes our case study from the South African San community particularly useful as a contrast.

5.3 Benefits of Involving Community Researchers in Research

The advantages of involving community researchers in research are important for all parties. Community researchers are "insiders" who can help research teams gain access to study participants, particularly when research is undertaken in sensitive study areas, and when marginalised population groups are targeted (Lobo et al. 2021; Southby et al. 2022). As community researchers are likely to have trusted relationships with community members, this can lead to more meaningful and authentic data being collected (Fleming et al. 2009, 2015). This approach also enables the research to focus on community needs and priorities, for individual, community, and social change.

Thanks to the "insider" characteristic, community researchers are likely to possess valuable local knowledge and relationships that are based on trust and connectedness with other community members (Moore et al. 2011). This means that academics working with them are able to gain access to influential others (Ryan et al. 2011; Lobo et al. 2021) and to engage those who are less represented in research (Southby et al. 2022). It also means that research can be aligned with the values and needs of the community (Lushey and Munro 2015). This is particularly important when marginalised populations report major trust issues about engaging in research due to past experiences of exploitation (Schroeder et al. 2018, 2021).

Community researchers can minimise power imbalances between researchers and participants (Murray 2006; Lushey and Munro 2015). This means that participants may be more likely to disclose issues when community researchers are involved than when dealing with academic researchers alone (Burns and Schubotz 2009; Fleming et al. 2009, 2015). For example, Lundy and McGovern explain how involving community researchers mattered "enormously" (2006: 57) in a Northern Ireland project, in a context of violence, conflict and surveillance. The fact that community researchers can bring a different level of empathy and understanding (Yang and Dibb 2020) may also increase the viability of research in more stigmatising areas such as domestic violence, sex work and addiction (Yang and Dibb 2020).

The data generated by community researchers can help academics and others to broaden their own understanding and create a shared language of cultural identities and health inequalities (Ryan et al. 2011; Lobo et al. 2021). Ultimately this can contribute to redressing power imbalances that have historically allowed decisions about communities to be formulated by an elite group of individuals, usually "outsiders" (researchers, funders, policymakers), rather than to be generated bottom-up by communities (Hemming et al. 2021). Furthermore, if community researchers become the "face of the project" (Creaney et al. 2022), informal feedback can continue to be collected and disseminated, thus enhancing the relevance and credibility of the research findings (Guta et al. 2013; Nöstlinger and Loos 2016), as well as opening up new areas of research (Cashman et al. 2008; Sweeney et al. 2013).

Billions of dollars are lost annually in health research that fails to create meaningful benefits for patients. Engaging in research co-design—the meaningful involvement of end-users in research—may help address this research waste. (Slattery et al. 2020).

From the perspective of a community researcher, being involved in research alongside "experts" can develop self-confidence and provide a sense of accomplishment and pride (Lobo et al. 2021; Southby et al. 2022), promote social inclusion (Lushey and Munro 2015), increase one's standing within the community (Jamshidi et al. 2014; Nöstlinger and Loos 2016), help one gain new insights into factors that influence the community, and develop skills conducive to employment (Lobo et al. 2021).

Community-based research is also thought to empower communities by encouraging them to identify possible solutions and actions themselves (Lushey and Munro 2015). As this form of research enables cultural and contextually relevant information to be gathered, it can inform relevant interventions with practical implications (Savage et al. 2006; Southby et al. 2022) for social change (Choudhry et al. 2002) that persist beyond the life of any project (Balcazar et al. 2009; Genat 2009). Community research can also develop social capital in local communities by creating vertical and horizontal social networks built on trust and reciprocity (Ryan et al. 2011; Teedon et al. 2015).

Table 5.2, which draws mainly from literature generated in higher-income countries, summarises the benefits of involving community researchers in research.

The literature on involving members from communities in research teams also includes some critical voices. The following overview is also based mainly on literature from higher-income settings.

5.4 Challenges of Involving Community Researchers in Research

The challenges of involving community researchers in research can be viewed from two main perspectives: the research perspective and the community researcher perspective. From a research perspective, a key criticism of engaging community researchers is that the research may lack methodological rigour, objectivity and neutrality (Kemmis 2006). This would limit the meaning, credibility and value of the research's contributions and impacts (Lushey and Munro 2015). Hence, the research might not be as good as it could have been. This seems to contradict the

Table 5.2 Benefits of involving community researchers in research

Research team (including community researchers)	Enabling …	Better access to community members including those who are influential and/or hard to reach
		the collection of more meaningful and authentic data
		opportunities to undertake research in stigmatised research areas
		greater trustworthiness of research findings
		better understanding and awareness of the issues communities face
		better focus on the needs and priorities of the community
		new research agendas and priorities
Community researchers	Building …	self-confidence and a sense of accomplishment and pride
		social relationships and networks
		standing within the community
		new understandings of factors influencing the community
		new skills
		better employment prospects
Communities	Increasing …	capacity and confidence to identify own solutions and actions
		opportunities for culturally and contextually relevant interventions
		opportunities for new relationships and networks

benefits section in this chapter, which refers to the collection of more meaningful and authentic data and the higher trustworthiness of research findings, among other benefits. We will later apply the positive and the critical voices from the literature to our case study and draw some conclusions. The second perspective, that of the community researcher, is not about the value of the research but about the experience of the community researcher, who may feel underprepared, exploited or even retraumatised, as we explain below.

5.4.1 The Researcher Perspective

The involvement of community researchers can present challenges at any stage of the research process. We focus here on recruitment and implementation.

5.4.1.1 Recruitment of Community Researchers

Recruiting academics into research is a well-established exercise combining rules that govern equal opportunities and performance-related appointments. Jobs are often publicly advertised with certain expectations of a candidate, such as a PhD, grant capture and publications. Recruiting community researchers into research is likely to be very different. For instance, where one would be forbidden by law to recruit along ethnic lines, ethnicity may have to be a factor in recruiting community researchers. Rather than meeting a detailed person specification, as required for academic jobs, the main criterion for the recruitment of community researchers is likely to be membership of a defined group. The potential lack of detail underpinning decisions can lead to complications, all of which centre on whether the most suitable members of the community joined the research team. In essence, a key problem in engaging with community researchers concerns who exactly is selected (Chavez 2008).

For instance, the social experiences and/or subjective realities of appointed community researchers may not align with other community members' perspectives (Kidd and Kral 2005; Guta et al. 2013). In a Canadian study by Greene and others, for example, the peer researchers who were living with HIV/AIDS experienced challenges when their experiences did not correspond with those of other community members (Greene et al. 2009).

While community researchers are generally appointed with the proviso that they will be able to connect with members of their community, in reality this cannot be guaranteed (Edwards and Alexander 2011). And that is not surprising, as "homogenous (local) communities hardly ever exist" (Räsänen et al. 2020). What is more worrying is when individuals are appointed who may be overtly biased or have conflicting agendas. In one study that involved Muslim youth working as community researchers in London, some of the community researchers held strong views about religion, and what they perceived as permissible religious practices, which limited what questions they were prepared to ask and what insights they would explore (Ryan et al. 2011).

Finally, there might be external obstacles to recruiting the most suitable community researchers. Depending on the population being studied, inflexible regulations may prevent certain individuals from being recruited, as in a Belgian study using sub-Saharan African migrants as community researchers (Nöstlinger and Loos 2016).

5.4.1.2 Implementation of Research Involving Community Researchers

While collecting more authentic data is one of the key benefits listed above of involving community researchers in research, criticism has also been raised in this context. Ryan and Golden (2006) argue that data collected by a community researcher who shares certain characteristics with those being researched cannot be presumed to be richer or more in-depth simply because of the assumed commonalities. There are various reasons for this. For instance, community researchers might talk mostly to individuals who are like themselves (e.g. in age or race) or only to those already known to them, or might make assumptions about who is part of their shared community (Kemmis 2006; True et al. 2017). There are also reports of community researchers only collecting superficial data, such as in a UK study working with female peer researchers in Muslim communities (Ryan et al. 2011). This could be due to a lack of confidence or to limitations in the capabilities of community researchers to do this work without formal academic training (Yang and Dibb 2020).

Bogusia Temple and colleagues, reflecting on community engagement work with individuals from different minority ethnic groups in the UK, have noted that community researchers are unlikely to be neutral when transmitting information to the research team (Temple et al. 2002). Community researchers may adapt, “edit” and/or reinterpret the data to prevent the community from being perceived negatively (Temple et al. 2002). This “self-censorship” can then lead to only partial insights being generated. While qualitative researchers generally engage in a lengthy and immersive reflexive process to consider their biases and how they influence the data generated, community researchers are unlikely to do so.

We will revisit these challenges when we compare them with those in our case study of San community researchers involved in our research team. First, we turn to the challenges from the community researcher perspective, as reported in the literature.

5.4.2 The Community Researcher Perspective

In contrast to researchers with PhDs, community researchers have not normally undergone significant training to prepare them for their role. A summary of 18 peer research projects involving residents from 12 disadvantaged communities in the UK reports that some community researchers felt unprepared for the role, attributing this to insufficient time spent on skills development (Southby et al. 2022). One recurrent challenge in training community researchers is literacy levels (Southby et al. 2022; Ganann 2013).

Community researchers may also feel disadvantaged by the way research discussions are organised. For instance, digital poverty can leave them feeling excluded when the research teams discuss important aspects in video calls, as reported in a study undertaken in Australia (Lobo et al. 2021). Or a meaningful level of collaboration with the wider academic team may be undermined when insufficient efforts are made to overcome power differentials and the voices of the community researchers continue to be silenced (Ganann 2013).

Another recurrent question is: which parts of the study should community researchers be engaged in? Involving them only in collecting data, rather than all study activities (design, data collection tools, analysis, etc.) is perceived as “tokenistic” (Jeffreys 2010).

Issues around financial remuneration for community researchers are also discussed in the literature. Good practice stipulates that community members should be paid for their involvement. In reality, however, many organisations have minimal or no funding for the involvement of community researchers (Lau et al. 2020), which can lead to the criticism that the knowledge and expertise of community researchers are being undervalued and insufficiently remunerated (Lau et al. 2020).

Negative perceptions of a project arising from what is being researched and/or reported can also be challenging for community researchers. For example, community researchers working in HIV and addiction research in the USA complained about the overemphasis on, and what they perceived as erroneous assumptions of, risky behaviours being more prevalent in urban and socially deprived communities (True et al. 2017). Peer researchers undertaking research with sex workers in Australia reported challenges when the participants held views about sex work and legislation that were inconsistent with their own (Lobo et al. 2021). Probably the worst possible scenario is that of community researchers who are exposed to information that triggers past traumas in their own lives (Caldwell et al. 2005; Cahill 2007). And finally, as evidenced in a study undertaken in a remote location in Scotland, community researchers can feel abandoned when the project ends (Creaney et al. 2022).

Table 5.3, which draws mainly from literature generated in and focused on higher-income countries, summarises the challenges of involving community researchers in research.

5.5 Case Study Involving San Community Researchers

There is a huge gap in the literature on community-based, engaged research approaches in LMICs that go beyond assistance with obtaining informed consent and are not focused on clinical trials (see above). We hope that our work in South Africa contributes to closing this gap by describing the involvement of 12 newly trained community researchers from the South African San community as a case study.

It should be noted that two lead community researchers who represent the San community and are co-authors of this book, Leana Snyders and Collin Louw, have been part of the research throughout all phases. This case study is about the 12 San representatives who were recruited as community researchers for a short community survey.

5.5.1 Overview of Case Study

We start with a photograph (Fig. 5.2). It shows 11 of the 12 community researchers in August 2023, together with Leana Snyders and Collin Louw. The group discussed, among other things, their experience of obtaining information from their communities in a survey.

Table 5.3 Challenges of involving community researchers in research

The research perspective	Recruitment	Community researchers may … • not have the same perspectives as other community members even though that was an essential reason for appointing them • be overtly biased or have conflicting agendas • be unable to be appointed due to legal restrictions
	Implementation	Community researchers may … • talk mostly to individuals who are like themselves or are already known to them • only collect superficial data • lack the confidence to explore certain issues or not probe deeply enough • adapt, "edit" and/or reinterpret data to prevent the community from being perceived negatively
The community researcher perspective		Community researchers may … • feel insufficiently trained • be disadvantaged due to digital poverty • feel silenced due to power differentials in the research team • feel exploited if they are only used to collect data • be harmed as in the case of retriggering a trauma • feel abandoned when the project ends

Fig. 5.2 San community researchers

Table 5.4 provides an overview of the entire process from the beginning.

The discussion that follows is structured around six topics. The first is not often covered in the literature, while the remaining five align approximately with the literature overview presented earlier in this chapter:

- existing relationships of trust
- recruitment of community researchers
- training of community researchers
- implementation of research
- benefits and challenges for community researchers
- benefits and challenges from a research perspective.

5.5.2 Existing Relationships of Trust Built on Fairness, Respect, Care and Honesty

The collaboration from which this book has emerged includes a UK team and two African teams (South Africa for the San and Kenya for the sex workers). The funding is from a UK source, the Wellcome Trust.

At the proposal stage, we used the values of fairness, respect, care and honesty from the San Code of Research Ethics (Chennells and Schroeder 2019) and the TRUST Code (TRUST 2018) to address in advance potential structural inequalities between the partners (Munung et al. 2017; Kok et al. 2017; Cash-Gibson et al. 2018). This was done to avoid any kind of power imbalance favouring the UK partner.

The result is as follows: the leadership team (Joshua Kimani, Roger Chennells, Doris Schroeder, Kate Chatfield) is 50% African and 50% European, 50% male and 50% female. Kenya and South Africa were allotted 55% of staff FTEs[1] and the high-income setting (UK) 45%. Taking purchasing power parity into account, 62% of the funding was budgeted for Africa and 38% for the UK.

The values of fairness, respect, care and honesty are vital to equitable research partnerships (Schroeder et al. 2019: 14) and they thrive in long-term relationships (Schroeder et al. 2019: 97). On the one hand, the fact that this case study is built on *very* long-term relationships, as illustrated in Fig. 5.3, is a major benefit. On the other hand, it potentially makes our approach harder to replicate, especially for early-career researchers. However, this is not unusual for engaged research. For instance, summarising participatory action research (PAR), Cornish et al. (2023) note: “A key issue is that PAR researchers do not strive for reproducibility, and many would contest the applicability of this construct.”

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[1] A full-time equivalent (FTE) is a unit of measurement used by an organisation to calculate how many hours an employee works in relation to the hours considered appropriate for a full-time employee.

Table 5.4 San Community Researcher timeline

Time	Description
07/2020	Principal Investigator (PI) and South African team (Roger Chennells, Leana Snyders) discuss research bid on "vulnerability" with the South African San Council. The council approves
01/2021	PI submits bid to the Wellcome Trust, with one named community researcher from the San community (Leana). A further four unnamed San community researchers were costed into the budget
04/2021	Award letter received. The research bid was successful without changes, i.e. the community researchers were approved by the funder
07/2021	Start of project. Monthly team e-meetings always included San community researcher. Zoom chosen as the platform due to less demanding bandwidth and technical requirements compared to other commonly used platforms
07/2021	Community approval of the final research plans by the South African San Council
08/2021	Affiliation of Chair of the Board of the South African San Council, Collin Louw, to the project with no budget implications, hence de facto two San community researchers from this date
09/2021	Community researchers Leana and Collin travel to the three San communities (!Khomani, Khwe, !Xun) to raise awareness about the project and identify San representatives for consultative workshops
12/2021	First in-person team meeting in Europe could not be held as South African team were refused visas due to the COVID-19 variant Omicron, first identified by South African scientists
03/2022	First workshop for 15 !Xun and 15 Khwe delegates, focusing on the topics of vulnerability, research ethics and communication skills
03/2022	First workshop for 15 !Khomani delegates, focusing on the topics of vulnerability, research ethics and communication skills
08/2022	Second workshop with seven !Khomani, six !Xun and seven Khwe delegates, selected from the earlier 45. Workshop deepens discussions about vulnerability and how to overcome it
08/2022	Workshop facilitators (Leana, Collin, Roger) evaluate second workshop and discuss the suitability of individual delegates as potential community researchers. They select 12
01/2023	Third workshop: 12 selected delegates are trained in Socratic techniques. They also co-design a survey on vulnerability
01/2023	Workshop facilitators try to select four community researchers from the 12 delegates as only four were budgeted for. However, they decide that all 12 are suitable, and ask the PI to seek funder approval
03/2023	PI obtains approval from the Wellcome Trust to appoint 12 instead of four community researchers on shorter contracts. Facilitators discuss the contracts with all 12 to manage expectations
06–07/2023	The 12 community researchers are each tasked to complete a survey questionnaire with 20 San community members over two successive months on questions of vulnerability. (239 out of 240 surveys are completed.)

(continued)

Table 5.4 (continued)

Time	Description
08/ 2023	The workshop facilitators and the PI analyse the workshop discussions
08/ 2023	Survey answers are translated from Afrikaans into English by Roger
08/ 2023	Fourth workshop: results from the survey are discussed and clarified with the 12 community researchers. The 12 also discuss the workshop analysis undertaken by the facilitators and the PI
10–11/ 2023	Hazel Partington, a member of the UK team, analyses the survey questionnaires
11/ 2023	Chapter 3 of this book is drafted
12/ 2023	12 community researchers discuss the chapter and suggest changes. They also provide feedback on their involvement in this research and offer advice to the community researcher in Nairobi

Fig. 5.3 Long-standing working relationships

5.5.3 Recruitment of Community Researchers

As noted in the recruitment section of the literature overview (Sect. 5.4.1.1), there are no established rules for recruiting community researchers as there are for recruiting academics. The most important value for this team was that of fairness, which was used to guide the approach below.

The two lead community researchers, Leana and Collin, visited the three San communities—!Khomani, !Xun and Khwe—in person to share information about the project and to recruit participants for consultative workshops. The further recruitment of community researchers was achieved through getting to know the

Fig. 5.4 Workshops overview

delegates to the workshops and applying the following criteria: passion, enthusiasm and initiative, previous participation in community activities, ability to influence and communicate with and motivate others, eagerness to participate in the project, and youth, defined as being under 30. As the engagement with the prospective community researchers and the broader San community overlapped, Fig. 5.4 lists the main purposes of the five workshops held.

The main purpose of the first two sets of workshops was to uncover what San representatives mean by "vulnerability" and how they want to be protected in research. Individuals were encouraged to talk about what vulnerability meant to them and how vulnerability might be experienced by others.

A secondary aim was to identify four community researchers. This was not done through the traditional application, short-listing and interview method, but instead through a process of engagement, observation and collaboration. This task proved difficult, as a large number of individuals demonstrated excitement about developing skills and confidence in engaging and expressing themselves, as well as a strong interest in the topic of vulnerability. After the first two sets of workshops, 12 young San representatives all seemed equally capable and interested. At the request of the South African team, the PI discussed the matter with the funder, Wellcome Trust, and a change of budget was approved. Instead of four community researchers on long-term contracts, 12 were invited on shorter contracts.

5.5.4 Training of Community Researchers

The initial two sets of workshops held to consult San representatives on their views on vulnerability were designed in such a way that they also contributed to the training of delegates in communication and engagement skills and confidence building. For most of the young San delegates, such participative workshops were a new experience. They were exposed to role play, exchanging stories, hearing new ideas, presenting their own thoughts and ideas to a group, and eliciting information from others. The workshops were designed to be fun and to build trust among participants, as well as between them and the workshop facilitators, Leana, Collin and Roger.

In all five workshops, the delegates also met the PI, Doris Schroeder, in a Zoom meeting. On each occasion, she summarised the progress of the project so far and gave short updates on what was happening in Nairobi. In the fifth and last workshop of the research cycle, she was joined by UK colleague Hazel Partington, who had analysed the survey data and presented her analysis to the community researchers.

From Workshop 3 onwards, the main purpose of the workshops was to train those who had outshone the others in energy and enthusiasm, and in their ability to engage and connect with others. Some of the 12 individuals had never been employed before, and local leaders welcomed their selection because it would offer new development opportunities. All 12 were delighted and readily agreed to continue working on the project. After their selection, they proudly dubbed themselves “The Chosen Ones”, which contributed to good team building.

The main training focus in Workshop 3 was threefold:

Bias: As part of improving their understanding of the process of obtaining information from others, the 12 learned how to avoid bias. They understood that they would have the power to influence answers, but should avoid doing so.

Socratic dialogue: The 12 performed exercises that enhanced their grasp of Socratic methods, emphasising the importance of being humble in attitude, building trust, seeking information in a spirit of curiosity and collaboration, and challenging assumptions in a diplomatic manner.

Ethical Conduct: The importance of not collecting personal data was emphasised, as was the fact that those they spoke to in the community would need to understand what the project was about and that taking part in the survey was voluntary.

5.5.5 Implementation

In Workshop 3, all 12 community researchers were involved in designing the questions for the community survey on vulnerability. A draft questionnaire was first used in an exercise, with the group divided into researchers and interviewees. This was followed by an evaluation session to discuss which questions had worked well and which were problematic. Following feedback, some of the questions were framed more simply, and the number of questions was reduced. Through this exercise the community researchers became co-authors of the questionnaire they were to use when collecting data in their communities.

On completion of the training workshop, each community researcher was commissioned to collect information from ten people per month for two successive months. A key condition was that they not consult only with people already known to them, such as family members, but extend their engagement to the wider community. They were reminded to go about collecting the information humbly, in a spirit of curiosity and without promoting their own views. They were encouraged to seek short answers, to be copied verbatim onto the questionnaire form, and reminded not to collect personal data. All 12 accepted this assignment.

Of the 240 surveys planned for, 239 were returned and translated into English. The PI and the translator, Roger, looked at all the answers and listed those that needed clarification. These clarifications were sought during Workshop 4 from 11 of the community researchers. (The 12th was unavailable.) Thus clarified, the 239 surveys were analysed by Hazel from the UK team.

What did the community researchers make of the process? The next section sets their experiences against the benefits and challenges identified in the literature and detailed earlier in this chapter in Tables 5.2 and 5.3.

5.5.6 Benefits and Challenges for Community Researchers

For the reader's convenience, the benefits and challenges for community researchers as set out in Tables 5.2 and 5.3 are summarised here in a single table, Table 5.5.

It seemed inappropriate to run a traditional evaluation on young San who had given the project time and energy and whose remuneration was not considerable (given that the number of community researchers was tripled from 4 to 12 within the original budget). Hence, we are going to present two types of feedback. The first set was obtained verbally from 12 community researchers at the end of the third workshop and covered feedback on the workshops, including the training opportunities. The second set was obtained verbally from the 11 community researchers present at the fifth workshop. (The community researcher unavailable for the fifth workshop was not the same as the one who missed the

Table 5.5 Benefits and challenges for community researchers

Benefits	Challenges
Building: • self-confidence and a sense of accomplishment and pride • social relationships and networks • standing within the community • new understandings of factors influencing the community • new skills • better employment prospects	Community researchers may: • feel insufficiently trained • be disadvantaged due to digital poverty • feel silenced due to power differentials in the research team • feel exploited if they are only used to collect data • be harmed as in the case of retriggering a trauma • feel abandoned when the project ends

fourth workshop.) Both sets of feedback were recorded in the form of notes by the facilitators.

5.5.6.1 Feedback: Workshops

At the end of Workshop 3, feedback was obtained from the group on what had worked and what had not worked in eliciting trust and ensuring a safe discussion space to enable effective participation by workshop participants. Feedback from the community researchers was recorded as follows.

> I felt very easy from the beginning with Roger, Leana and Collin. I felt that they will not judge me. Introductions were very clear and friendly. Language was made to be easy. There were many jokes, we felt safe with them.
>
> We were all strangers at first. Leana told us her story of how she found her confidence, which was inspiring. We were made to interact a lot, which gets us to know each other far better. The only negative I have is we need more exercises.
>
> I was so shy I was too scared to even speak. As we went on, I felt better and better. The trainers were friendly, encouraged us to speak up, and made us not hide behind the confident ones for them to speak.
>
> I was so very shy. More than others. The friendly manner of the trainers helped me slowly feel safer and to trust that I can relax here.
>
> We were made to be safe. Role plays helped us to mix with the others we did not know, in an easy way. We were encouraged to practise speaking more and more. I am now less shy.
>
> I was very scared at first. I felt brave to even come. This group was quickly made to feel like my community. Like a family even. We felt love while we learned. We were never made to feel unsafe. The trainers handled us with a friendly way.
>
> Trainers had smiles, were always very friendly. Topics were interesting. And vulnerability is a great topic for us to talk about our lives and to get to know each other. Talking about our vulnerability here helped us to feel more comfortable with each other.
>
> At our first meeting, I was so scared. But the workshop was friendly, and there was love and respect from trainers. I did not feel judged. We were cared for so well. We got to like all the others on the workshop. Together we all learned a lot.
>
> I first met Leana and Collin. They were friendly. Then I met Roger. There was always lots of laughter in the workshop. First, I was scared to meet the Kalahari San, as our (Khwe) Afrikaans is weak. The trainers helped us to meet each other in an easy way. Just like parents.
>
> The trainers were like kind teachers. They helped me to communicate, to trust myself that I can speak to people.
>
> I was so scared. The leadership was good. I was so vulnerable, but the trainers showed us respect, patience, friendship, acceptance. You made us feel safe.

5.5.6.2 Feedback: Survey Experience

> I was very nervous at first, but it got better. I am not used to asking other people about their problems. I have heard and learned a lot doing this work and feel that I have become a better person.
>
> It was so hard at the start. After some interactions I became less anxious, and learned how to listen to different perspectives, then to respond differently. I was deeply touched by people's stories, and I feel the process has changed my life in many ways. I feel I got to know new things about my community.
>
> Was very nervous at first. Some were very suspicious. Some made it clear that they wanted money and wanted me to help with their problems. I wanted to help but could not. It was emotionally difficult to see what my people are going through.
>
> I was very anxious at first. I did not give up despite some early disappointments. Some did not understand at first, but when they did, they enjoyed going through the questions.
>
> Some people just sent me away. I started getting better at approaching them to get the right result, and then I was invited in more and more. I felt I got better with time and enjoyed the work.
>
> Day one was hard. People see you with paper. They think you are going to promise something. I tried to explain we are not empty promises. We are doing research. Some were suspicious. You are taking information from us. Day two I got better at explaining the story, and from then on I started to enjoy doing the questionnaires.
>
> It was hard at first getting people to agree to do the questionnaire. They were full of complaints. Some sent me away and refused to answer my questions. Others at first thought I am selling something or benefiting. Some were very firm and challenging. However, I really enjoyed the process. I am keen to get better.
>
> The work was hard for me at first. People think a person visiting door to door with documents must be politics. I learned how to explain why our research is different. Some people enjoyed the discussion and thanked me when I left.
>
> It was not difficult for me. I like people. However, some people were challenging. One very difficult person I explained carefully. Translating from Khwe was not easy. Some of the answers were painful and stayed with me.
>
> The project has been so educational. People are far from me, I had logistics problems. Some were not keen to participate. I went to people I did not know too well. After hearing their stories, I learned so much, again, about the community and its problems. I had the feeling that we should be more fearless. Getting deeper information about the people was so interesting and gave me new insights.
>
> It was difficult. Some needed a lot of explanation. I learned a lot in the conversations. The second ten questionnaires were much easier. There were many surprises, and sad stories.

Three main messages come through from these sets of feedback: early struggles, swift improvement and a good learning experience in a safe space.

First, almost without exception, all community researchers found the workshops *and* the survey work difficult at the beginning. They felt shy during the workshops and nervous to approach community members with their survey questions. However, none of the difficulties can be related to the literature outlined earlier in the chapter: deficiencies of training were not mentioned; digital poverty was not relevant, as the research was recorded on paper and contact with the South African team was in person; power differentials were not experienced negatively, the facilitators even likened to parents by one community researcher; the community researchers saw the survey as a chance, rather than as exploitation by them as data collectors; many reported that the sad stories they heard in the community stayed with them, but that is different from retriggered trauma; and finally, because the project is continuing, we do not know yet whether they will feel abandoned when it ends, but we hope to find funding for a future collaboration.

Second, all community researchers declared that they improved with time. In the workshops, this happened very quickly, as the workshop facilitators made them feel safe, not judged, and even inspired as they experienced lots of laughter and, on occasion, feelings of love. In the process, they gained self-confidence and a sense of accomplishment and pride, and extended their social relationships and networks, as well as gaining new skills, exactly as the literature predicted (see benefits in Table 5.5). With one exception, they all had a difficult start to their survey work, yet they overcame these difficulties and became better with time, as they began to enjoy the experience. The fact that 239 out of 240 surveys were returned on time is an excellent indicator that the initial nervousness and struggles had been successfully overcome.

Third, the community researchers felt safe with the workshop facilitators, which freed them to use the opportunity to learn. Their feedback indicates that they gained in confidence and that several learned more about their communities and community problems. Again, this is as predicted in the literature, which assumes that community researchers can gain new understandings of factors influencing the community.

There are only two of the benefits to community researchers suggested by the literature that we cannot comment on based on the feedback recorded above, namely standing within the community and better employment prospects. However, the South African team and local leaders noted that the 12 who were selected all gained confidence, as well as skills and capabilities. This might also be evident from the fact that "The Chosen Ones" felt able to advise Nairobi community researcher Joyce Adhiambo, whose interaction with her community was slightly later than the San's with their community. The advice was:

- Be vigilant.
- Build trust.
- Respect the knowledge of your source.
- Protect the privacy of your source.
- Be very patient with your explanation of the questionnaire and process.
- Be passionate about/during the interview. If you are bored, so will they be.
- Be friendly and open.
- Don't be too hurried.
- Be well prepared on the topic, to cope with any responses.
- Be considerate, your source is giving his/her precious time.
- Expect the unexpected (dogs, outbursts).

Table 5.6 Benefits and challenges from a research perspective

Benefits	Challenges
Enabling: • better access to community members including those who are influential and/or hard to reach • the collection of more meaningful and authentic data • opportunities to undertake research in stigmatised research areas • greater trustworthiness of research findings • better understanding and awareness of the issues communities face • better focus on the needs and priorities of the community • new research agendas and priorities	Community researchers may: • not have the same perspectives as other community members even though that was an essential reason for appointing them • be overtly biased or have conflicting agendas • be unable to be appointed due to legal restrictions • talk mostly to individuals who are like themselves or are already known to them • only collect superficial data • lack the confidence to explore certain issues or not probe deeply enough • adapt, "edit" and/or reinterpret data to prevent the community from being perceived negatively

Overall, it seems that the 12 San community researchers managed to obtain almost all the benefits predicted in the literature overview without being held back by any of the challenges.

5.5.7 Benefits and Challenges from a Research Perspective

For ease of reading, the benefits and challenges from a research perspective set out in Tables 5.2 and 5.3 are summarised here in a single table, Table 5.6.

Our experience did not reflect the challenges noted in the wider literature. The involvement of 12 San community researchers to find out how the San view "vulnerability" was highly effective, in our view, and can be verified by our findings presented in Chap. 3. Of the 239 surveys which came back, five were suspiciously similar. It is possible that the person who obtained the answers injected his or her own bias or that he or she talked only to family members, but this would have been an exception. One could say that getting very short answers to five simply phrased questions might count as collecting only superficial data. But as can be seen in Chap. 3, the data was rich and highly diverse and led to conclusions that the South African team and the 12 community researchers recognised as highly poignant. There was no detectable adaptation of the data to make the community look better, given, for instance, that drug and alcohol abuse with the attendant social problems came through clearly as a subtheme.

In contrast to the challenges, the benefits of involving community researchers in research were mirrored in what the literature section of this chapter had anticipated. Information was obtained from San who only speak languages that are on the decline and which none of the authors of this book speak. Hence, access to a difficult-to-reach group was only possible through the community researchers. As many noted in their feedback, the stories they heard were very sad—which comes through clearly in Chap. 3—and the answers were authentic and trustworthy. The extent of the poverty-related problems the San face and their exclusion from broader society are devastating. These insights call urgently for new research agendas and priorities to ensure that the San are not left behind—not in research and not in life.

5.6 Conclusion

Engaged research, which strengthens research teams through community researchers, provides many opportunities and challenges. From better access to community members who are hard to reach, to the collection of more meaningful and authentic data, and to greater trustworthiness of research findings, the benefits for research are manifold. Community researchers themselves can benefit from new skills, increased self-confidence and a sense of accomplishment and pride, to name just some advantages. At the same time, community researchers might be overtly biased, only collect superficial data or lack the confidence to probe deeply enough, to name just some of the challenges.

The literature on community researchers is heavily biased towards high-income countries, and very little can be found on experiences from low- and middle-income countries that go beyond assistance in obtaining informed consent. This chapter has begun to close that gap by setting out a case study of involving 12 community researchers from the South African San community. The study has produced an astonishing result: almost all of the advantages identified in the literature could be identified in the San case study, while almost none of the disadvantages were present.

A community that still suffers from intergenerational trauma caused by genocide, and has been exploited by researchers and others for many decades (see Chaps. 3 and 1), needs the right type of research done in the right way to address its vulnerabilities. Exclusion from research to accommodate multiple vulnerabilities is not the answer, but research that is *led by* vulnerable groups *for* vulnerable groups is possible, as the case study in this chapter has shown. Collecting no personal data and obtaining all research input through community researchers is one way of ensuring that the San, and research communities more widely, have access to research they can trust.

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Vulnerability and Leaving No One Behind in Research: The Recommendations

6

Abstract

This concluding chapter summarises how we challenged the protection-inclusion dilemma in order to avoid leaving people behind in research *unnecessarily*. The fact remains that individuals from highly impoverished, stigmatised groups in lower-income settings face a high likelihood of being harmed and exploited in research. However, excluding them from research is not the answer and can also be seen as a patronising interference in the lives of people who might benefit from research and might welcome long-term relationships of trust with researchers. Achieving long-term relationships of trust requires research methods that strive to be minimally burdensome and minimally risky. In the context of working with the South African San and the Nairobi sex workers, this means that we had to avoid all personal data collection. It also required community involvement at all stages of the research. A key consideration, often lacking from the wider literature, is how community researchers are identified, trained and supported. In our work, this involved trusted community members leading the training, and the use of storytelling, humour and Socratic methods to encourage reflexivity, compassion and sensitivity. Notable findings generated from our work include that 'vulnerability' is not lost in translation, even though the English term is not readily translatable into relevant other languages, or where the main stressors—such as the stigmatisation, discrimination, marginalisation and abuse besetting the sex worker community—cannot simply be subsumed under "vulnerability", because they involve specific individual actors who bring about hardship. Our work identifies an approach for leaving no one behind in research that can stimulate a deeper understanding of how equitable research partnerships with highly marginalised groups can be achieved.

Keywords

Research ethics • Vulnerability • Leaving no one behind • San people • Nairobi sex workers

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6.1 Introduction

This book has aimed to tackle the protection-inclusion dilemma for vulnerable groups in research, with a particular focus on the South African San community and Nairobi sex workers. Both groups live in situations characterised by severe poverty, and both struggle with extreme stigma. Having secured a minimal livelihood in desperate circumstances, the Nairobi sex workers face stigmatisation, discrimination, marginalisation and abuse, as their occupation is illegal and taboo in Kenya. The South African San face unfairness and exclusion as a highly marginalised group in South Africa, stigmatised because of their languages and poverty-related social challenges.

6.2 Protection Through Exclusion Leaves Vulnerable Groups Behind in Research

For several decades, vulnerable groups have been largely excluded from research to protect them from harm and exploitation. This exclusion approach originated in medical research, which often carries risks and burdens. Imposing such risks and burdens on those already disadvantaged seemed inappropriate. Hence, the Declaration of Helsinki stipulates:

> Medical research with a vulnerable group is only justified if the research is responsive to the health needs or priorities of this group and the research cannot be carried out in a non-vulnerable group. In addition, this group should stand to benefit from the knowledge, practices or interventions that result from the research. (WMA 2013: Art. 20)

In research ethics, Indigenous peoples and sex workers are often automatically labelled as vulnerable groups, and are therefore at high risk of being excluded from research. This can mean that the groups most in need of research are excluded from it. For instance, the 2012 UNAIDS Ethical Considerations in Biomedical HIV Prevention Trials notes that “men who have sex with men, injecting drug users, sex workers, transgender persons, indigenous populations, the poor, the homeless” are populations with an increased vulnerability (UNAIDS and WHO 2012: 31).

This approach of labelling entire groups as “vulnerable” is, however, slowly being abandoned. The updated 2021 UNAIDS Ethical Considerations in HIV Prevention Trials no longer singles out Indigenous populations and sex workers as vulnerable groups, but instead points to the social and political contexts of vulnerability (UNAIDS and WHO 2021: 37).

This growing movement recognises that protection through labelling as “vulnerable” is a potentially patronising (Rogers et al. 2012) approach, which can lead to additional victimisation (Wrigley and Dawson 2016). For instance, in 2016, the International Ethical Guidelines for Health-Related Research Involving Humans by the Council for International Organizations of Medical Sciences (CIOMS) noted that the council did not want to label entire classes of individuals as vulnerable.

Instead, they wanted to look at specific characteristics that may render individuals prone to harm or exploitation and then identify mechanisms for better protection (CIOMS 2016: 57). However, this still leaves three problems: remaining possibilities for harm and exploitation; continuing reluctance to include vulnerable groups in research; and mistrust in researchers, a bottom-up version of exclusion from research, where individuals from vulnerable groups decide not to engage with researchers.

The potential remains that individuals from highly impoverished, stigmatised groups in lower-income settings face a higher likelihood of being harmed and exploited in research than privileged individuals in high-income settings.

The debate around "ethics dumping"—that is, the export of unethical research practices from higher to lower income settings—is intensifying rather than diminishing (Schroeder et al. 2019). The term was only coined in 2014, and now generates more than 700 entries on Google Scholar, the academic search engine. The extent of extreme poverty faced by the San and the sex workers might offer researchers "opportunities" to recruit them into studies against their better judgement. As noted in Chap. 3, San parents who cannot feed their children will be open to almost any kind of "incentives" to procure food. Giving researchers information (data), for instance on traditional knowledge, in return for a cash payment (that is unlikely to have been declared to a research ethics committee) seems an obvious way to obtain money for food. San community elder Petrus Vaalbooi referred to researchers "who come and tempt us with ten rand or five rand" (five rand being equivalent to €0.24 or £0.20) (Andries Steenkamp and Petrus Vaalbooi interviews 2018: 00:57).

Changes in supranational (as opposed to institutional) ethics guidance are not necessarily taken up by researchers or research ethics committees.

Laudable efforts like the CIOMS stipulation cited above—that the labelling of entire classes of individuals as vulnerable should be avoided—still face significant operationalisation challenges. As shown in Chap. 2, de facto group exclusion from research still happens. This can involve acts of "remote paternalism", when research ethics committees in high-income countries exclude vulnerable populations in lower-income countries from international, collaborative research. Or it can occur when researchers decide, at the planning stage of their research, that the perceived or expected barriers to the involvement of vulnerable groups at the ethics approval stage will be so considerable that they would rather choose to work with non-vulnerable groups (De Poli and Oyebode 2023). The latter case can arise especially in the context of overly risk-averse, protectionist RECs, whose overprotection can take the form of exclusion from research (Friesen et al. 2023).

However, it is not only top-down exclusion by RECs that blocks access to research participation.

> Individuals from vulnerable groups, potentially entire communities, can be reluctant to engage with researchers based on past experiences of exploitation and harm, whether colonial-type exploitation (Smith 1999), ethics dumping (Schroeder et al. 2018), or patronising or culturally inappropriate practices (Schroeder et al. 2021).

The result of all three problems (potential for exploitation, reluctance of researchers to work with vulnerable groups and vice versa) is the protection-inclusion dilemma (Friesen et al. 2023), which leads to vulnerable groups being left behind in research.

In tackling the protection-inclusion dilemma for the South African San and the Nairobi sex workers, we aimed to achieve our overall mission: to ensure that no one is left behind in research *unnecessarily.* To achieve this mission, we pursued both content and methodological innovations. We wanted:

- to find out how two vulnerable populations define vulnerability for themselves
- to do so with minimal risk and minimal burden to those who agreed to pursue this goal with us
- to explore how we could reduce mistrust in researchers.

6.3 Vulnerability Lost in Translation?

Trying to establish how the South African San and Nairobi sex workers defined vulnerability for themselves hit early obstacles. All three San groups (!Khomani, !Xun and Khwe) struggled with the term, because they could find no satisfactory equivalent in the relevant San languages, or in Afrikaans, the main language spoken by the !Khomani San. Likewise, there seemed to be no immediately obvious equivalent in Kiswahili, the main language spoken by the Nairobi sex workers. This experience aligned with the PI's, as "vulnerability" cannot be translated easily into her mother tongue, German, either.

6.3.1 Vulnerability Does Not Require an Agent Who Brings About Hardship

Explaining this conundrum in English is somewhat paradoxical, but possible through back-translations. As Tuhiwai Smith (1999: 36) has explained: "This is one of the ironies of many indigenous peoples' conferences where issues of indigenous language have to be debated in the language of the colonizers." In German (and then back-translated into English), the nearest equivalent term for vulnerability is "woundability", which is a less than ideal match for communication in research ethics. The lack of good equivalents in some of the languages of this author team becomes even more obvious when one translates the Afrikaans term for vulnerability, "kwesbaarheid", into German rather than English. The translation (back-translated into English) is then "sensitivity", which is wholly unusable in discussions about vulnerable populations in research.

As most co-authors involved in this book speak several languages, including English, we tried to take great care not to impose the English connotations of the word "vulnerability" onto the San and sex worker representatives who took part in our research. It was crucial to see whether there was a broader concept that could be explained and recognised across language barriers.

Sometimes a new word from a foreign language can be a gift that expresses something one understands without having previously had a word for it. This seemed to be the case, at least for the San representatives. They defined "vulnerability" as weakness, the feeling of being in danger of attack or injury, the feeling of heartache or heartsore (see Chap. 3). In workshop discussions, they discovered that the word "vulnerability" could serve as a useful umbrella term to cover the vast range of issues and problems they experienced, from severe poverty to unemployment, health problems, and family and relationship problems, as well as drug and alcohol abuse.

The Nairobi sex workers who were involved in our research had similar answers for what "vulnerability" meant, once they had overcome the hurdle that there was no obvious translation into Kiswahili. For them, it also signified being in danger, suffering, being weak and poor, but it also meant having been stigmatised. They even found a word that might be a suitable translation for "vulnerability" after all: *mnyonge*, variously translated as being poor, wretched, frail or weak. What was most striking in the Nairobi sex worker group, which included the lead community researcher, Joyce Adhiambo, is that the initial reactions were all identical, namely:

> "We are not vulnerable, we are being stigmatised, marginalised, abused and discriminated against."

The difference is obvious, as explained in the next section.

6.3.2 Vulnerability Versus Stigmatisation, Discrimination, Marginalisation and Abuse

Vulnerability, like structural violence, is a term that does not need a particular actor who brings about hardship (Vorobej 2008). The extreme poverty experienced by the San parents, mentioned above, who cannot feed their children, is not directly attributable to other people. While one might speculate about what the government could do to reduce unemployment, which in turn could reduce poverty, the direct link to particular people is missing.

It is different for stigmatisation, discrimination, marginalisation and abuse, the words emphasised by the Nairobi sex workers. These are *active* words, which require other agents to do something, namely to discriminate against or to abuse a sex worker—for instance, as recorded in Chap. 4, discrimination within the family: “In my family I am not included in decision-making simply because I am a sex worker,” or by law enforcement agents: “When females are arrested the police start harassment by touching your private parts, without even bothering who is looking, in the pretence that they are doing a warrant search.”[1]

While San representatives who contributed to the survey also spoke about being discriminated against, for instance by a teacher at school, this was much rarer than the equivalent being mentioned by the Nairobi sex workers.

> The four stressors faced by the Nairobi sex workers, as revealed through the analysis of workshops and conversations stigmatisation, discrimination, marginalisation and abuse all directly involve others. The sex workers face hardships through specific other people, from their own families to the law enforcement agents who are meant to protect them.

6.3.2.1 Is Vulnerability Lost in Translation?

Despite initial struggles with a term for which there was no obvious equivalent in languages relevant to this author team (San languages, Kiswahili, Afrikaans and German), the term “vulnerable” was not lost in translation. For the San representatives involved in our research, it became a useful umbrella term in discussions about what makes them vulnerable to exploitation by outsiders, researchers included. What they also stressed was that the term should not be used in a patronising manner to block access to research that the community might need.

> While the term “vulnerability” can be useful to groups who, for instance, struggle with severe poverty and social and economic challenges, it should not be used by outsiders to block access to research involving adult members of such a group. This is regarded as patronising interference in

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[1] These quotations are drawn from notes of conversations taken by facilitators. They authentically reflect the testimony of the sex workers, but are not a verbatim record of their words.

the lives of people who might benefit from research and who welcome long-term relationships of trust with researchers.

The research findings from the workshops and interviews with Nairobi sex workers also pointed to an appreciation of the term “vulnerability” to describe the various situations that expose them to exploitation and harm, but an emphasis on the four stressors the community face regularly was more important. They face stigmatisation, discrimination, marginalisation and abuse, which are all attributable to actions from specific people. Research by Human Rights Watch has found that

> sex workers face physical, psychological, sexual, economic, and other forms of violence from a wide range of perpetrators, including police, clients, health care providers, government bodies, and others. Our research has repeatedly found that the criminalization of sex work … is one of the underlying causes … of much of this violence, making decriminalization a critical step in the eradication of violence against sex workers. (HRW 2024)

What endangers the lives, health and mental integrity of the Nairobi sex workers is, to a large extent, the criminalisation of an activity, sex work, that is relied upon to provide a livelihood for them and their families. In a context of severe poverty where other job opportunities might not be available, the criminalisation of sex work adds the burden of stigma and violence to the lives of the Nairobi sex workers. Their vulnerability to harm and exploitation – also in research – would be much reduced if their profession was decriminalised. South Africa is taking the lead on this topic (Wheeler 2022), but other countries such as Kenya could follow.

Undertaking research with people who face extreme poverty and extreme stigma is highly challenging, which is why protective exclusion from research made sense for such a long time. Only with the inclusion movements of the twenty-first century, most notably the “leaving no one behind” mission of the UN’s 2030 Agenda, has this been questioned more broadly.

Our contribution to resolving the protection-inclusion dilemma for at least some research in some communities has been to advocate and practise the prioritisation of research participant needs over researcher needs.

6.4 Enthusiasm for Research

The enthusiasm with which our research was greeted was considerable. Those we engaged with in the San community and the Nairobi sex worker community were extremely keen to help us find out more about how their vulnerability could be defined and reduced. And they were keen to contribute their knowledge and ideas in a search for solutions that used the methods of Socratic dialogue. This was also in line with a statement from the South African San Council, which invites applications for community approval from researchers as follows:

> The South African San Council believes that research in our communities is of the utmost importance for the betterment of the people, but for years the San have been subject to exploitation from researchers. (SA San Council n.d.)

We believe that the enthusiasm for our research can be explained in two ways: long-term relationships of trust, and prioritising research participant needs over researcher needs.

6.4.1 Long-Term Relationships of Trust

The Wellcome Trust funding call for their Research Development Awards—a one-off scheme, to which we responded successfully—prioritised established relationships of trust over new collaborations by requiring evidence that the team worked well together. We thought this was an inspired move towards inclusive, equitable research. In contrast, one of the three reviewers for this book noted that “the fact that the two case studies are both from sub-Saharan Africa can be seen as a limitation”. Luckily, he or she also gave us this stamp of approval: “Excellent proposal, certainly should be published.”

However, the reviewer’s reservation still made us think. Our relationships of trust, developed over many years (see Fig. 5.2), were the reason why this team came together with these two vulnerable populations. Yet, we wondered, should we retro-engineer some kind of scientific justification for the involvement of the San and the Nairobi sex workers? We could, for instance, say that we had chosen the two communities because they represent the three main reasons for community vulnerability: severe poverty, ethnicity, and illiteracy (Gehlert and Mozersky 2018), one community based in a rural area and the other in an urban area. But this would have been tantamount to declaring that the UK team was the chooser, the group that, alone, decided which communities, and therefore which co-applicants, they wanted to work with. And yet communities and their gatekeepers have their preferences too. They prefer to work with teams with whom they have established long-term relationships of trust.

When working with vulnerable populations in research, we recommend prioritising long-term relationships of trust between the relevant communities and the research teams in any decision-making. This would also make it easier to involve representatives of the community in all stages of the research, from deciding about the topic of the research and obtaining funding through to dissemination, thereby leading to truly equitable research partnerships.

6.4.2 Prioritising Research Participant Needs over Researcher Needs

Having worked very closely with the San community and the Nairobi sex workers for many years also made it easier for us to take the next step in equitable research partnerships: to prioritise research participant needs over researcher needs.

We knew that, especially in the case of the Nairobi sex workers, any leak of personal data revealing that a person was a sex worker could bring them significant harm, even involving violence (see Chap. 4). We therefore decided to forego the collection of personal data and set out to obtain authentic input for our research that would not allow the identification of individuals. Hence, no record of names, no audio recording and no video recording. All information gathered in workshops or one-to-one conversations was collected anonymously in the form of written notes taken by facilitators known to the sex workers. As one of the sex workers gratifyingly put it:

> I didn't know that a discussion forum where personal details are not collected can be so liberating! We spoke without fear and poured our hearts out. It is the first time I have been able to talk about being threatened with death.

We are proud of the fact that we obtained excellent research results in the Nairobi sex worker community without collecting any personal data, and without any audio or video recording. Safe spaces for information exchange were created in collaboration with the sex workers. We believe this is a step that others could take to increase the number of research studies that are minimally risky and minimally burdensome, especially for vulnerable populations that are highly stigmatised.

In the San community, an aversion to personal data collection was not the main issue, but rather the San's significant mistrust due to prior experiences with researchers. Here again, we tried something innovative, namely conducting almost all research through community researchers. We made this effort both in the San community and in Nairobi, and it is described as a full case study for the San (see Chap. 5).

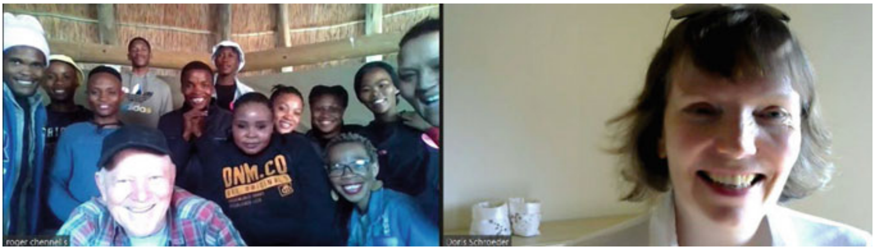

Fig. 6.1 PI Doris Schroeder meets “The Chosen Ones” again

The Nairobi sex workers who took part in workshops and one-to-one conversations never once met anybody from the wider team, either from South Africa or from the UK. For them, this was Nairobi-led research undertaken in Nairobi. Instead of the traditional bridge-building between (overseas) researchers and local communities through gatekeepers, our research was community-driven, community-led and, in the main, community-analysed.

The process was slightly different with the San community, as the PI had visited them many times and was known to many of the leaders. The South African team therefore asked her to join all workshops for short conversations via Zoom. Figure 6.1 shows such a meeting in August 2023, bringing the PI together with 11 community researchers, or “The Chosen Ones” (see Sect. 5.5.4), as well as Leana Snyders (far right) and Roger Chennells (front), two of the three group facilitators.

The younger San seen in the picture are the ones who went out into the community and obtained views on what vulnerability meant to the San. As recounted in Chap. 5, even *they* faced mistrust, but persevered, hearing many sad stories and learning about their community, and did so in an attitude of humility, building trust and seeking information in a spirit of curiosity and collaboration.

The community researchers were selected during consultative workshops for their energy and enthusiasm for the topic, and their willingness to learn and to engage with others in respectful encounters to uncover new knowledge. They were involved in confidence-building activities and exposed to role plays, exchanging information and new ideas and having to present their thoughts and elicit information from others. They also co-designed the survey they were to take back to their communities.

In a guided exercise in December 2023, “The Chosen Ones” reflected on their journey as community researchers and described powerful images of growth, confidence, movement and personal development: from walking to riding a bicycle; from a small man alone and shy with no opportunities to a flourishing flowerpot; from a sunless heart at first, shy and reserved, to a candle giving light to others.

It was a privilege to work with “The Chosen Ones” for this team, and we cannot recommend working closely with community researchers strongly enough: recruiting them via workshops and training them via stories, humour and trust-building exercises.

6.5 Conclusion

As Fatima Castillo notes in the Foreword to this book, inclusive research with vulnerable populations can increase scientific rigour *and* ethical vigour. Indeed. But we want to go even further. The Wellcome Trust, which funded the research for this book through a Research Development Award, urged researchers to add excitement and fun to research. And even though we were working with vulnerable populations whose lives were blighted by extreme disadvantage and the discriminatory actions of others, the “can do” spirit and humour that prevailed at the workshops in Nairobi and South Africa were highly inspirational. It happened this way, we believe, because there was no “othering”, no potential exploiter, in the research relationships we built. As noted earlier, the research was community-driven, community-led and, in the main, community-analysed.

While we see trusted long-term relationships as the prime prerequisite for equitable research and for obtaining authentic input on difficult-to-resolve research questions, there are three areas we plan to develop further.

First, we want to strengthen our commitment to Socratic dialogue techniques in community-led research. If successful, this might resolve some of the main challenges recorded in the literature regarding research data obtained from community researchers. Community researchers, it is said, collect only superficial data, and it has been argued that they do not have the confidence to probe deeply enough. Both challenges could potentially be addressed with Socratic dialogue techniques, and early results involving “The Chosen Ones” are promising.

Second, we would like to accredit our type of training in some way so that the community researchers who gave us their time and energy can point proudly to a certificate, and be in a position to demonstrate transferable skills and, ideally, connect with different researchers in the future. Especially in the context of our book, this would be highly desirable, as leaving sex work is a key priority for most of the sex workers we engaged with, and in the San community unemployment is a major factor in poverty-driven hopelessness.

Third—and this is more of an aspiration in a world where research funding is usually tightly linked to very specific, technical questions—we would like to organise a set of consultation workshops, like those outlined in this book, with completely open questions: “What do you see as the main problem in your community?” “How do you think researchers could help?” “What can *you* do to help the researchers?” As Castillo writes in the Foreword: “As clearly evidenced in this book, communities like sex workers and Indigenous peoples, who suffer from the intergenerational impact of intersecting factors of discrimination, poverty and exploitation, can be dynamic, effective and crucial partners in research.”

Who knows what would happen if these dynamic, effective and crucial partners took the very first decision in research: namely, what is to be researched in the first place?

We hope our work provides a framework for others to consider, recognising the value of engaging with communities through relationships built on trust, respect, humour, equity and collaboration. Our approach challenges the protection-inclusion dilemma and demonstrates how leaving no one behind in research is possible, desirable and achievable.

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Appendix: 41 Reasons for HIV Increase

At three workshops in February 2022, sex workers from Nairobi gave 41 reasons for the increase of HIV/AIDS in their communities. They were asked what had precipitated the significant increase in the number of new HIV/AIDS infections. The reasons they gave—listed below, in no particular order of importance—were recorded by note takers with whom they were familiar.

- Shortages of free condoms in the country and clinics leading to unprotected sex among the sex workers with their clients.
- Worsening poverty due to loss of livelihoods among the sex workers due to COVID-19 leading to risk taking behaviors.
- Come-we-stay marriages during COVID-19 among sex workers and their clients due to desperation to feed families. (The Kenyan Marriage Bill includes "come-we-stay"' marriages where a man and a woman live together as husband and wife without legal recognition).
- Loss of livelihoods eroding empowerment and capacity among sex workers to negotiate and avoid risky sex.
- Increase in alcohol and substance use due to stress among the sex workers and hence being in no right state of mind to bargain for safe sex.
- Ignorance by people living negatively with HIV assuming it will be easy to take daily ARVs in case they get infected,
- Increase in self-stigmatization among sex workers during COVID-19 emanating from working from their neighbourhoods due to closure of hot spots blowing their cover of what they do.
- Increase in self-stigma increasing mental health issues leading to risky sexual behaviours.
- Increase in self-stigma leading to poor self-esteem and then risky sexual behaviours.
- Poor self-esteem leading to alcohol and substance abuse increasing risky sexual behaviours.

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- Erosion of self-worth due to declining opportunities to make money to feed families leading to risky sexual behaviours.
- Increase in discrimination by family members leading to mental health issues and risk-taking behaviours.
- Increase in abandonment by regular clients leading to loss of livelihoods, increase in desperation and risky sexual behaviours.
- Lack of HIV status disclosure to sexual partners e.g. sex workers not disclosing their HIV status to their clients and more so to their regular partners.
- Pretence—sex workers pretending not to be in the trade to entice rich clients hence having unprotected sex.
- Poor adherence to ARVs among sex workers due to poor feeding and substance use increasing viral load.
- Lesbians also increasing the risk of infection by sharing sex tools.
- Increase in intimate partner violence due to loss of livelihoods leading to increase in number of sexual partners.
- Increase in gender-based violence meted on sex workers by policemen e.g. a case of sex workers having sex with the police to avoid being arrested for tramped up charges or to get released.
- Poverty and need to live lavishly among queers hence knowingly getting infected with HIV due to the support they want to get from sponsors.
- Drug burden and misuse of drug (PrEP/PEP) leading to break through infections.
- Not properly taking PrEP and PEP hence increasing risks to HIV infection.
- Increase in “stamping”: incidents by HIV positive partners—knowingly infecting people with HIV especially on campus.
- Inter-generational sex especially among university students sex workers with different partners (sugar daddies)—not knowing how to negotiate for safer sex.
- Rape by clients obtained from social media.
- Increasing use of online hooking/dating sites (tinder, Nairobi raha, Kenya raha) decreasing sex workers’ group safety nets. Men meeting sex workers on the hook up apps take the women to unfamiliar homes increasing violations and abuse.
- Loss of safety nets provided by community of sex workers at the hot spots leading to condomless sex with clients in unfamiliar areas.
- Culture (wife inheritance) and ignorance on safe sex practices.
- Fear of being exposed among transgenders hence not going to the clinic to access services.
- Poor adherence to antiretrovirals due to poverty (lack of food).
- Sharing of partners and rampant multiple partnerships.
- Increase in group sex incidents especially among the men who have sex with men and transgenders.
- Adoption of new sexual behaviours, e.g. threesome etc.by the sex workers reducing enforcement of safe sex practices.
- New sex workers being at a high risk of HIV infection due to their ignorance and being in high demand by clients.

- Irresponsible sexual practices by clients where they tear condoms knowingly…. to get their money worth by ejaculating inside.
- Geographical settings—correct information not reaching the unreached in the rural urban areas.
- HIV spread increasing at the hotspots through group sex by knowingly enticing those who are HIV negative by the HIV infected individuals.
- Peer educators not performing their duties optimally on health education with their peers hence no full information provided on the minimum HIV prevention/care and treatment package.
- Poor supervision of peer educators and dropping off peer educators by the program managers in some hotspots making it difficult for the new sex workers to engage fully with the program.
- Lack of support groups in clinics decreasing social capital among sex workers increasing loneliness and risk-taking behaviours.
- Poor rapport between clinical staff and some clients in the clinics leading to poor self esteem—no one cares or listens!

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