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The *World We Want,* leaving no one behind: did the *Go4Health* project represent the voices of marginalised communities into the post-2015 global health discourse?

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Abstract

The evolution of the Sustainable Development Goals (SDGs) has given rise to a critical post-2015 discourse around what the UN refers to as the *World We Want*. The unfinished business of the Millennium Development Goals (MDGs) remains conspicuous, with the recognition that inequity has increased, despite its gains. Sustainable development was framed early as a universal agenda, with an imperative to *leave no one behind*. But how do we hear those who have been left behind? In response, *Go4Health*, a collaboration between academics and health rights NGOs, was commissioned by the European Union to track the development of the post-2015 goals and specifically to identify the essential health needs of marginalised communities. This thesis is nested within that research, but differentiates itself from it. In a reflexive exploration of how marginalised peoples were heard through the *Go4Health* project into the post-2015 SDG policy-making discourse, I examine the voices of two marginalised communities in Bangladesh and the Philippines, representing comprehensively what they offered around their lived experience, their understanding of health, their perceived essential needs, and tracking these voices through the *Go4Health* research output into the global discourse.

The objectives of my research are to examine understandings of marginalisation; to explore the experience of marginalised communities with reference to their perceptions of health and health needs; and to review the representation by *Go4Health* of the voices of the marginalised in the post-2015 discourse. For my primary research, I employed qualitative techniques: focus group discussions with lay community people and key informant interviews with service providers, local leaders, and members of civil society. I further examined whether *Go4Health* did what it set out to do—to hear and represent the voices of the marginalised in the post-2015 discourse, to establish if the *left behind* are able to be heard. Through a systematic review and thematic analysis of *Go4Health*'s publications, I demonstrate that *Go4Health* did enable the voices of the marginalised to be heard in this global discourse.

My engagement and dialogue with communities in the Chittagong Hill Tracts and in the Autonomous Region in Muslim Mindanao exposes the dynamic intersectionality of marginalisation. Lived experiences in their social, environmental and political context bring to light issues around livelihoods, land tenure, and access to basic services, including health care. In the Chittagong Hills, communities described identity and everyday life as shaped by the geography of the region, that also pushes them to the margins—a geography that is remote and difficult, and "justifies" the

limited state infrastructure provision, the militarised violence, the confiscation of lands resulting in the loss of community livelihoods, but a geography rich in large tracts of forest and arable land, and natural sources of water—sources of sustenance for the communities. In Mindanao, a different scenario, defined by armed violence in a complex interplay of local, regional, and national conflict. Communities live in a typhoon belt, where the only certainty is uncertainty—food security issues in a region known for agricultural production and export, housing that is frequently destroyed or abandoned, and peace that is elusive—where change is only possible through informal connections with the local elite. The concerns of these communities, and of those in 7 other countries, are all synthesised in *Go4Health*'s reports and publications targeted to the post-2015 SDG discourse. Sometimes homogenised and filtered, their voices *are* heard, represented in global health discourse, and even acknowledged by the UN. Yet the marginalised continue to be marginalised: politically pushed aside with promises of change with little or no follow through from state governments, their capabilities for exercising freedom of agency and well-being in contexts of structural violence are severely constrained.

I conclude that representing the voices of the marginalised in wider discourse is possible. But they also need resources for critical health literacy and capability enhancement, which requires substantial change in social, political, and economic structures. Enabling the marginalised to truly *speak*, to have agency in their own communities and states, requires the kind of global change that the rhetoric of the SDGs speaks to: end poverty in all its forms; achieve food security and improved nutrition; achieve gender equality; ensure healthy lives; ensure water and sanitation; ensure access to energy; inclusive economic growth that entails full and productive employment; build resilient infrastructure; reduce inequality within and among countries; make human settlements inclusive, safe, and resilient; ensure sustainable production and consumption; combat climate change; protect and restore terrestrial and marine resources and ecosystems; promote peaceful and inclusive societies; and strengthen the means of implementation for a global partnership for sustainable development. Overarching all of this is the precondition of global—and national and local—political will and good governance. Only then can meaningful engagement and participation occur for realizing the *World We Want.*

Declaration by author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

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Publications during candidature

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1	**Hussain, Sameera**, and Lara Gaultier. 2015. "International Health Policies." *Health in the Post-MDG Era: What "paradigm shift" are we talking about exactly?* April 3. http://www.internationalhealthpolicies.org/health-in-the-post-mdg-era-what-paradigm-shift-are-we-talking-about-exactly/.
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6	**Hussain S**. *Can the marginalized get heard in the post-2015 agenda?* Oral presentation (Pre-Conference Satellite Session) for Third Global Symposium on Health Systems Research. 30 Sep–3 Oct 2014. Cape Town, South Africa.
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SDGs, global health, global health policy, inclusion, marginalised communities, social exclusion, marginalisation, structural violence, post-2015

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List of Abbreviations used in the thesis

ARMM	Autonomous Region in Muslim Mindanao
AusAid	Australian Aid Program
BEP	BRAC Education Program
BRAC	Building Resources Across Communities
BRACU	BRAC University
CEGSS	Centro de Estudios para la Equidad y Gobernanza en los Sistemas de Salud
CEHURD	Centre for Health, Human Rights & Development
CHCP	Community Health Care Provider
CHT	Chittagong Hill Tracts
CHW	Community Health Worker
DepEd	Department of Education
DOH	Department of Health
DSWD	Department of Social Welfare and Development
FWV	Family Welfare Visitor
Go4Health	Goals and Governance for global health research project
HA	Health Assistant
INGO	International Non-Governmental Organization
IRA	Internal Revenue Allotment
MDGs	Millennium Development Goals
MoHFW	Ministry of Health and Family Welfare
NGO	Non-Governmental Organization
OWG	Open Working Group
SDGs	Sustainable Development Goals
TBA	Traditional Birth Attendant
UN	United Nations
UNHCR	UN Refugee Agency
UQ	University of Queensland
WASH	Water, Sanitation, and Hygiene
WFP	World Food Programme
WHO	World Health Organization
WP	Work Package
WP2	Work Package 2

CHAPTER 1

The post-2015 global health discourse: leaving no one behind

1.1 INTRODUCTION

This thesis examines the experience of marginalisation, and the factors that enable or constrain the voice of the marginalised being heard. It is nested in a larger research project—*Go4Health*, an interdisciplinary, multi-country, multi-institutional project exploring goals and governance in the post-2015 development discourse. That project itself is nested within the European Union's response to a global yearning for change—the desire for a *World We Want*—that would see the merging of two global development agendas: the sustainable development agenda and the unfinished business of the Millennium Development Goals (MDGs).

From 2012, it became clear that, despite economic progress in many countries of the global South, the MDGs would remain unmet by their 2015 deadline. Additionally, a rise in inequalities within the global North, coupled with global environmental concerns, became topics of discussion that were articulated in Rio +20, the United Nations (UN) Conference on Sustainable Development, a platform around universal economic and environmental challenges. With the coming together of the unfinished MDGs and the issues documented in Rio +20, a post-2015 global discourse was officially launched by the UN Secretary-General Ban Ki-moon in late 2012. The UN multi-layered campaign "*World We Want*", was supported by the Sustainable Development Solutions Network, and served as a platform for global consultations around several themes, including health. Contemporaneous assessment of the outcomes of the MDGs recognised their contribution to overall health improvements throughout low and middle income countries (LMICs) of the South. Despite this achievement, implementation has largely focused on "low-hanging fruit", improving overall health in the middle quintiles, rather than among the poorest and most disadvantaged groups. This has caused an increase in inequity and has contributed to the marginalisation of already disadvantaged groups, limiting their capability to attain improvement in health and well-being extended by the MDGs to better-off communities (UN 2015; IDS 2017).

In addressing one of the shortcomings of the MDG process, the *World We Want* platform claimed "no one left behind" as its motto for an inclusive process where national consultations and e-submissions were sought from governments, civil society, and the public. The *World We Want*

process received broad and enthusiastic support, resulting in a vibrant global discourse around health or a post-2015 global development agenda that informed the Sustainable Development Goals[1] (SDGs).

But the unfinished agenda of the MDGs did, in fact, leave many people and their communities behind, with identifiable population subsets experiencing poorer health outcomes than others. In a post-2015 agenda-setting discourse ostensibly designed to be inclusive, the voices of those population subsets were integral to the global discourse. However, whether they were—and are—being heard is a question that requires attention—first, to confirm whether their voices are heard, and consequently, how their voices are represented. This thesis sets out to examine the experiences and health needs of marginalised communities engaged by the *Go4Health* research project, and whether their voices are represented in the global health discourse.

The *World We Want* thematic consultation on health and the broader post-2015 global health discourse lead to the European Union (EU) commissioning a consortium of academic and civil society institutions known as *Go4Health*, a multi-centre research project exploring the developing post-2015 *goals,* and the *governance* structures they will require. The group laid particular emphasis on bringing attention to the health needs of vulnerable populations, consulting with a diversity of stakeholders for their input. This PhD presents its engagement with *Go4Health* and its representation of marginalised communities in the post-2015 global health discourse in two distinct parts. The first part consists of a direct dialogue with two of the communities identified as marginalised by *Go4Health*, and contributing to the research evidence represented in its products. The second is an examination of those *Go4Health* products to answer my central research question: "did the *Go4Health* project represent the voices of marginalised communities into the post-2015 global health discourse?"

1.2 The *World We Want* Shall Leave No one Behind—Easier Said Than Done?

The EU's *Go4Health* project is but one response among many to the UN call for inclusivity, which began with a global conversation consisting of a series of thematic consultations to gather the views on the new, post-2015 development agenda. This process preceded the Open Working Groups—the

[1] Use of the Sustainable Development Goals logos and icons in this thesis is consistent with the guidelines for their use by non-UN entities (United Nations Department of Public Information 2017).

negotiations between UN states that ultimately determined the content of the SDGs and their targets—with the understanding that the contributions would provide evidence and perspectives to governments on the challenges people face in improving their lives and those of their families and communities (UNDP 2015). A High Level Dialogue on Health in the Post-2015 Development Agenda was part of this process and culminated six months of face-to-face and online consultations reaching out to UN member states, civil society, academics, as well as the private sector. The Dialogue on Health considered findings from three sources: background papers, papers submitted during a web-based consultation that included over 100 contributions (including one from *Go4Health*), and reports from stakeholder meetings and electronically-based surveys and discussions. Later, this informed a report to the High Level Panel of Eminent Persons on the Post-2015 Development Agenda, forming the synthesis of the process driven by the UN agencies, leading into the state-based negotiations on finalizing the UN's 2030 Agenda for Sustainable Development (UN 2013).

The *Go4Health* project was commissioned by the EU to advise on health-related development goals beyond 2015, as part of the EUs "Coordination and Support Actions Across the [Health] theme." Its purpose was to "ensure that the health-related development objectives for the period after 2015 are based on the best scientific evidence available and address the main shortcomings of the MDGs," striking a "balance between horizontal and vertical approaches to health care," and that they should indicate "an improved system for global health innovation," that would be "measurable, achievable, and sustainable" while effectively accounting for "the constraints of developing countries for improving health outcomes themselves" (van Damme, n.d.). In essence, *Go4Health*'s task has been to advance and improve the global social contract (articulated as the MDGs) and to propose goals for global health and governance for global health centred that forms a framework of shared but differentiated responsibilities among countries (Ooms et al. 2013). The breadth of its scope required the formation of a consortium consisting of 5 Working Groups with academic and civil society experts drawn from a number of disciplines, including medicine, public health policy, public health implementation, anthropology, sociology, political science, development studies, tax law, and human rights law.

The consortium specifically tasked one of its working groups—Work Package 2 (WP2)—to identify Essential Health Needs from "those whose health is most at risk" and those who "experience the worst health outcomes". This Work Package consisted of four research hubs based in Australia, Bangladesh, Guatemala, and Uganda, each with a common mandate to determine health care goods

and services based on communities' expectations and assessment of needs that should be guaranteed to all people as entitlements. The breadth of WP2's mandate to determine, as part of Essential Health Needs, the mechanisms that can ensure the human right to health, required a health systems approach that encompassed people's participation in public policy development, implementation and monitoring—in addition to essential health goods and services. Work Package 2 aimed to reach and represent marginalised communities within regional reach of each research hub. WP2 employed the descriptive paradigm of PROGRESS+ to identify the communities to engage with (standing for Place of Residence, Religion, Occupation, Gender, Race/ethnicity, Education, Socioeconomic status, Social capital and networks, and others (such as disability or sexual orientation). It saw its task as responding to the mandate drawn out for it by the EU, through the *Go4Health* project design, using a prescriptive framework for inquiry into the health perceptions and experience of health of 12 communities.

For *Go4Health*'s WP2 to determine the list of Essential Health Needs, several domains of inquiry were prescribed: community understandings of health; essential health needs; determinants of health; roles and responsibilities of relevant actors; community participation in decision making. These topics guided individual interviews and group discussions with lay community people and their service providers. *Go4Health*'s engagement was diverse, and covered indigenous communities in Guatemala and Bangladesh, older persons and sexual minorities in Uganda, migrants living in Australia and Australia's Aboriginal peoples, coastal communities in Vanuatu, communities in fragile and conflict-affected areas like Afghanistan and southern Philippines. Their responses were synthesised and recorded in *Go4Health's* research documents, and the knowledge generated from the research has been disseminated through over 50 peer-reviewed publications in the post-2015 global health literature. But accessing, working with, and representing communities, particularly those that *Go4Health* engaged with—marginalised and traditionally excluded—raises questions around whether a community can ever be adequately represented (Cosson 2010).

This PhD engaged in direct dialogue with indigenous communities of the Chittagong Hill Tracts in Bangladesh and the communities living in Mindanao, Philippines. *Go4Health* actively sought to have their voices heard in the post-2015 global discourse around the global goals. Their responses expose the dynamic intersections of the different categories of ongoing marginalisation that are evident in their daily lives. While individuals and communities were to respond to the specific questions raised by the *Go4Health* research agenda, their responses to this invitation go well beyond that, offering a more complex insight into the capabilities that arise from the intersections

between their identity and environment, as well as the opportunities and constraints they encounter in utilization and participation in decision making. They are clear about their health needs. They are also clear about the kind of change that must be brought for improvement in the determinants of their health—the changes that are required to meet their Essential Health Needs. And in my review of *Go4Health's* products, I show that the voices of these two communities are clearly evident– sometimes filtered, aggregated or homogenised—but demonstrably present as distinct voices.

The *World We Want* by 2030 is envisioned as one that leaves no one behind, and this thesis deepens our understanding of the lives of the people who, until now, have been unheard and left behind.

1.3 The Objectives And Structure Of This Thesis

The purpose of my thesis is to explore the perceptions and experiences of marginal communities in Bangladesh and the Philippines, and then examine the way in which their voices have been represented in the research findings of *Go4Health* in agenda-setting for health in the post-2015 debate.

To this end, the specific objectives of my research are:

1. To examine understandings of marginalisation, the factors contributing to that experience, theoretical explanations of marginalisation.
2. To explore the experience of marginalised communities in Bangladesh and the Philippines, with specific reference to their perceptions of health and health needs.
3. To review the representation by *Go4Health* of the voices of the marginalised in Bangladesh and the Philippines in the post-2015 discourse.

Though some of the research for the thesis has been published[2][3][4], the content has been integrated into the text in a traditional monograph structure, organised by chapters. This introduction (Chapter 1) is followed by a review of the literature (Chapter 2) that defines the parameters of the study. I begin the literature review with a description of the structures, problems, and theories relevant to my thesis, in which I describe the "*World We Want*" discourse, and why some people are left

[2] Ooms G et al. Universal Health Coverage anchored in the Right to Health. *Bulletin of the World Health Organization.* 2013; 91:2-2A.
[3] Brolan C, Hussain S et al. Community participation in formulating the post-2015 health and development goal agenda: reflections of a multi-country research collaboration. *International Journal for Equity in Health.* 2014; 13:66
[4] Hussain S et al. From knowing our needs to enacting change: findings from consultations with indigenous communities in Bangladesh. *International Journal for Equity in Health* 2015; 14:126

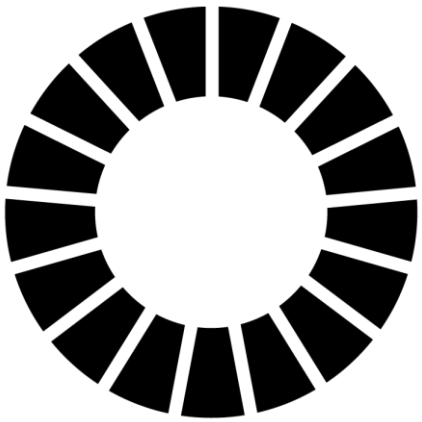
behind. To do this, I explore the processes of social exclusion that cause marginality in varied and overlapping ways. I go on to using components of a conceptual framework that guides this dissertation.

In it, marginality and social exclusion are described in terms of the PROGRESS+ model—useful for identifying categories of marginality—and followed with a review of the ways in which multiple forms of exclusion overlap to produce degrees of marginalisation. In identifying who are the marginalised and the intersecting processes of people are marginalised, I proceed to review why marginal voices matter in global health discourse. Following my review of the literature is an account of the methods I used for this study (Chapter 3). For my primary research, using qualitative techniques, I spoke with lay community people and key informants ranging from service providers, local government representatives, and members of civil society. This process of understanding the perceived needs of marginalised communities, first in Bangladesh, and then in the Philippines, enabled my later examination whether *Go4Health* did what it set out to do—to hear the voices of the marginalised and represent their voices in the discourse leading up to the SDGs. It sought to explore the question: are the *left behind* able to be heard?

My nested case study approach with *Go4Health* is evident in the three subsequent chapters: Chapter 4 is comprised of my findings from my engagement with indigenous communities in the Chittagong Hill Tracts of Bangladesh, where they describe an identity and everyday life shaped by the geography of the region, the very thing that also pushes them to the margins—a geography that is remote and difficult to contend with—a state justification of limited infrastructure provision. But it is also rich in large tracts of forest and arable land, and natural sources of water—sources of sustenance for the communities—and also the cause of militarised violence in the form of confiscation of lands resulting in the loss of their livelihoods. In Chapter 5, I turn to the experience of communities in the Autonomous Region in Muslim Mindanao, where the context of armed violence is brought about by a complex interplay of local, regional, and national conflict. Here, communities live in a typhoon belt, where the only certainty is uncertainty—pervasive poverty and food insecurity in a region known for agricultural production and export; housing that is frequently destroyed or left behind; and peace that is elusive in an environment where change is only possible through local patronage rather than regional or national governance.

Chapter 6 is a thematic review of the concerns of these communities, and those of marginalised communities in 7 other countries—Guatemala, South Africa, Zimbabwe, Uganda, Afghanistan,

Australia, and Vanuatu—as documented in the reports and publications targeted to the post-2015 SDG discourse. These *Go4Health* research outputs document and synthesise the voices of marginalised peoples, which are clearly evident in its products. I further examine how they have been represented in wider global health discourse, finding that although synthesised, the voices of the marginalised *are* heard, and represented in wider global health discourse. In my conclusions (Chapter 7), I discuss the implications of my findings around structural violence and the range of inequities that diminish people's dignity and human rights. I conclude that *representing* the voices of the marginalised in wider discourse is possible, but to truly *speak*, people need resources for critical health literacy and capability enhancement, to gain access to the platforms where change is possible—all of which will need substantial change in social, political, and economic structures. Enabling the marginalised to engage and participate meaningfully in their own communities and states, requires the kind of global change that the SDGs aspire to.



CHAPTER 2

Marginal voices: exploring the literature

2.1 INTRODUCTION

The purpose of this chapter is to firstly mark out the terrain of this thesis, elaborating the context for an Agenda for Sustainable Development that *leaves no one behind*. I begin with the topic of global health inequity, and an exploration of the structures and processes that have contributed to this widening gap, despite the concerted efforts at global development embedded in and embodied by the MDGs. I then turn our focus to the people *left behind*—our understandings of exclusion, the factors contributing to it, including theoretical explanations and responses to exclusion.

I will continue with a definition of marginalisation in reference to a process of exclusion (or viewed inversely, domination) through structural violence by a dominant society with specific economic, political, and social structures built for not only its own benefit, but also for ensuring its preservation. These structures extend from the global to the local, and it is under these conditions that the subaltern classes[5]—the marginalised—must make their voice heard. From the perspective of global health, this literature review is concerned with people's participation in health decision-making—specifically, engagement in the post-2015 development debate—and the possibilities for the marginal in meaningfully doing so.

In further defining the territory of this thesis, Section 2.4 is concerned with community participation in health—its important role in health, followed by a review of community-based priority setting for health. Finally, I explore people's capabilities and capacities for participation in the context of exclusion. I conclude this chapter with my central argument: that constraints to the utilization of participatory mechanisms for exercising voice—and by extension, agency—in local and global processes in the face of rising inequity do point to the imperative for global change.

The second component of my review of the literature is concerned with methods that have been used for consulting with communities with the intent of priority-setting at local, regional, and global

[5] Subaltern classes refer to any "low rank" person or group of people in a particular society under hegemonic domination of a ruling élite class that denies them the basic right of participation in the making of local history and culture as active individuals of the same nation (Gramsci 2010; Louai 2012). In this thesis, the terms "subaltern", "marginal", "marginalized", "socially excluded" and the "left behind" are used interchangeably.

levels. As a team member of *Go4Health*'s WP2 I was active in initial discussions and a literature review, which was a collective process involving all members of the WP2 research group[6]. Appendix C draws largely from my contribution to that exercise to examine earlier community-based priority setting research work to inform the way forward for WP2 consultations. These shaped my Methods for the study, which I have elaborated in Chapter 3. Searches were made on Google, Google Scholar, UQ Library, and through the sharing of literature among *Go4Health* partners and other networks using purposive and snowball methods. Contextual information around study sites and populations can be found in Chapters 4 and 5.

2.2 GLOBAL INEQUITY

A long tradition of scholarly writing, beginning from Aristotle to John Rawls to Amartya Sen and others have shaped modern ideas of justice and fairness in society, linking them to the rights of people (Sen 1985; Rawls 1999; Pogge 2005; Ruger 2012). My starting point will be from the view that human flourishing is a morally central aim shared by all persons by virtue of their humanity, with human dignity at its heart (Ruger 2012). Enshrined by the United Nations Declaration of Human Rights (UDHR) and further elucidated through a number of international covenants and treaties[7] to ensure and protect the rights of people globally, the notion of human rights, fairness, and responsibility served as the basis for the Millennium Declaration and its goals for implementation, the MDGs. The MDGs represent a clear shift in international development assistance from the highly developed countries of the world to the least developed countries,[8] mobilizing global

[6] For further details around *Go4Health*'s Work Package 2, see Section 3.2.2

[7] To date, there are nine core human rights instruments:

1. International Covenant on Civil and Political Rights
2. International Covenant of Economic, Social, and Cultural Rights
3. Convention on the Rights of the Child
4. Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment
5. International Convention on the Elimination of All Forms of Racial Discrimination
6. Convention on the Elimination of All Forms of Discrimination Against Women
7. Convention on the Rights of Persons with Disabilities
8. International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families
9. International Convention for the Protection of All Persons from Enforced Disappearance

[8] It is interesting to note a shift in language in referring to countries—initially in terms of social and economic advances, shifting to economic terms [high income countries (HICs) vs low and middle income countries (LMICs)] to geographic descriptors (global North and global South).

responsibility ostensibly grounded in ethics and distributive justice[9]. The MDGs have resulted in human development gains globally, but as former UN Secretary General Ban Ki-Moon observed, "yet for all the remarkable gains, I am keenly aware that inequalities persist and that progress has been uneven. Progress tends to bypass women and those who are lowest on the economic ladder or are disadvantaged because of their age, disability, or ethnicity. Disparities... remain pronounced". Furthermore, the final report on the MDGs concedes that "despite many successes, the poorest and most vulnerable are being left behind" (UN 2015). Increasing gaps between the rich and poor, within and among countries, are worrisome, with specific groups experiencing some of the worst outcomes in health, and in other areas of the kind of development envisioned by the UN (Wagstaff, Bredenkamp, and Buisman 2014).

This is not news: all societies have hierarchies in which economic and social resources are distributed unequally, and this unequal distribution affects people's freedom to lead lives they have reason to value (Sen 1985; Schuftan 2013). In addition, issues such as climate change and globalization continue to alter how people live, often further increasing the gap. Again, these gaps are not coincidental, and ultimately, the root cause is no single factor, but rather a host of forces that diminish people's agency over their lives.

2.2.1 **Health equity**

The right to health is established in the UN's human rights instruments and is represented in different iterations of the UN's commitments, including the Alma Ata Declaration on Primary Health Care, the Ottawa Charter for Health Promotion, and the Millennium Development Goals (MDGs).

The MDGs were a specific and pragmatic attempt at achieving a minimal level of health outcomes for people living in developing countries. But Ruger (2010) has argued that such approaches cannot effectively address the twin goals of good health and the ability to pursue it, since they typically must favour either a proceduralist (procedure-oriented) or consequentialist (outcome-oriented) perspective. The MDGs essentially prioritised the latter, with the chosen goals, targets and metrics driving resource allocation and development processes: the alternative route—with its focus on process—may have produced greater equity in outcomes, though incrementally, over an extended timeframe.

[9] In many places, colonial legacies continue in the form of bilateral economic and social ties.

Given today's context—a predominantly neoliberal economic order[10]—it is understandable, though inexcusable, that there are large and growing inequalities, with people increasingly being pushed to the margins. That the MDGs made significant gains is undisputed, but academics and development practitioners agree they also did not do what they set out to do. By 2011 it became obvious that the MDGs, while making gains, would not be reached—and many "acceleration programs were underway, heavily funded by the UN and country donors[11]. But in light of the concerns around persisting and increasing inequity in the face of overall development progress, many contemporary scholars (Chan 2008; Lawn et al. 2008; Navarro 2008) have called for a return to basics of the Alma Ata Declaration, which were reiterated by the Ottawa Charter for Health Promotion (Hall and Taylor 2003). In it, several prerequisites for health are identified: peace, shelter, education, food, income, a stable ecosystem, sustainable resources, social justice, and equity, stressing inter-sectoral coordinated action by government, NGOs, local authorities, industries, and the media. This Health for All approach was envisioned to become a reality by 2000; in 2017 it remains an unfulfilled dream. But arguably, the return to the Alma Ata Declaration may be implicit in the multi-sectoral basis of the SDGs, with a concern for equity explicit in SDG10: "Reduce inequality within and among countries", and the commitment to "leave no one behind".

2.3 THE LEFT BEHIND

Who are the *left behind*? In essence, they are the poor (Moszynski 2010; Rippin 2013; Schuftan 2013; IDS 2017; UN 2015). And poverty and ill health are inextricably linked, involved in a vicious downward spiral: diseases of poverty increase poverty, and poverty, in turn, increases the chance of developing the diseases of poverty (Singh and Singh 2008; Labonté, Baum, and Sanders 2015). From a macro level perspective, people's health is determined largely by the distribution of power, both economic and social. Generally understood in economic terms, poverty must be understood not just as an economic condition, but also as an unjust social relation that results in poor health outcomes (Navarro and Shi 2001). This section explores the theoretical explanations for why people are left behind from economic and social gains. I will begin this section with the concepts of class

[10] Neoliberalism is based on a belief that free markets, sovereign individuals, free trade, strong property rights, and minimal government interference is the best means to enhance human well-being In general, the neoliberal view is that governments should avoid poverty reduction as a policy matter and instead rely upon economic growth, tending toward 'welfare minimalism', with benefits or entitlements at a level that prevent the worst forms of deprivation, but that are rarely insufficient for human flourishing (Labonté, Baum, and Sanders 2015).

and hegemony, continuing further with an exploration of the processes of social exclusion and how they interact together to affect people's capabilities to achieve well-being.

2.3.1 **Hegemony and the subaltern**

The relationship between inequality and poverty is established by scholars of many disciplines on all sides of the political spectrum. Inequity, the unfair distribution of resources, has been widely written about, and the most pivotal work that attempts to explain this is the writings of Antonio Gramsci. Drawing largely from twentieth century Marxist thought, he sought to explain inequity as evolving from an exclusively mechanistic and economic argument to one that deeply incorporates a social perspective, originally focused around the power struggle between the landed elites and the common people.

Cultural hegemony, as defined by Antonio Gramsci (2010), is the domination of a diverse society by a ruling class that manipulates the culture of that society so that the ruling class worldview becomes the worldview that is imposed and accepted as the cultural norm. That is, it becomes the universally dominant ideology that justifies the social, political, and economic status quo as "natural and beneficial for everyone", thus maintaining the power and interests of the ruling class through "intellectual and moral leadership". With states run by the elite, Gramsci asserted, hierarchies of inclusion and exclusion are created such that elite interests are served. Elaborating on this theme, Bourdieu's (1986) writings on social class suggest that there are several categories of capital available to individuals, with each individual occupying a multidimensional position in social space. Individuals cannot be defined by their social class membership alone, but also by all the capital that they can articulate through social relations, and which also use or reproduce inequality. The subaltern—referring to any "low rank" person or group of people that suffer under hegemonic domination of a ruling elite class—are those who are denied the basic rights of participation in the making of history and culture as active individuals in a nation or state (Gramsci 2010; Louai 2012). Gramsci's study of the subaltern provided an important starting point for understanding non-landed peoples as social, cultural, and political forces aware of their distinct consciousness of subalternity, particularly in postcolonial studies. The work of the Subaltern Studies Group surmised that the subordination of South Asian society by the British Raj[12] was one of subalternity—one where there was a colonial elite, a (South Asian) nationalist-bourgeois elite produced by British colonialism,

[12] British colonial rulers

and the subaltern, those whose lower status was expressed in terms of class, caste, age, gender, and office (Gramsci 2010; Louai 2012; Tharoor 2017).

Neo-Gramscians continue to describe world hegemony as one that entails a social structure, an economic structure, and a political structure. This hegemony emerges as a result of a widely appreciated sense of supremacy in a global political economy or inter-state system as well as social and ecological systems. Understood in this framework, even international organizations may act as the primary mechanisms through which universal norms of a world hegemony are expressed, with the development "industry" a modern reinterpretation of colonialism (Unay, 2010).

The writings of Gayatri Chakravorty Spivak (1988), however, challenge these representations of the subaltern. She refutes Marx's claim that peasant farmers cannot represent themselves but rather, must be represented through the intellectual who can speak for the proletariat. Spivak points to issues of power and epistemic violence which create Otherness; this is important and relates to issues of domination through the education structure which I will revisit in later in this chapter. Spivak's most important contribution, in my view, is that she considers the people in the margins—the silent, and silenced—"*men and women of the illiterate peasantry, the tribals, the lowest strata of the urban subproletariat"* as part of social and economic structures that suppress meaning as it is constructed by those in the margins, and cannot represent it into the hegemonic systems that are so important to them. In this, she questions philosophers and political theorists—such as Gramsci (2010) and Freire (1972) —before her who suggested that the subaltern are able to know their conditions, and able to speak. For Spivak, the structures that lead to marginalisation may preclude knowing, or where knowledge becomes possible, deny the marginalised the possibility of speech. It is these structures of social exclusion that need to be addressed if the marginalised are to be heard—structures that, for Johan Galtung (1969), impose a form of violence on the populations under their hegemony.

2.3.2 **Cultural violence**

The capacities for the marginal to be heard are a function of agency—and in Spivak's view, the ability to speak—which is constrained dramatically by violence exercised by dominant groups. Galtung (1990) introduced the concept of *cultural violence*[13] as a follow up to his writings on structural violence. Cultural violence illustrates the social nature of hegemony, in that violence is

[13] Aspects of culture exemplified by religion and ideology, language, art, and sciences that are used to legitimize direct or structural violence (Galtung 1990)

present when human beings are impacted on in such a way that their *actual* somatic and mental realizations are below their *potential* realizations. This cultural violence is the cause of the difference between the potential and the actual, as well as that which impedes the decrease of this distance. He illustrates this by using the example of tuberculosis—where if someone still dies from tuberculosis today, despite all of the medical resources that are available in the world, then violence is present. Life expectancy shortened due to war or social injustice, then, are both viewed by Galtung as violence, the first *direct*, and the second, *structural*.

Cultural violence, Galtung (1990) elaborates, is an invariant—a permanence—that remains the same for long periods of time due to the slow transformations of basic culture. Both direct and structural violence use cultural violence to legitimise the use of violence through the use of systems and structures.

2.3.3 **Structures and systems**

Fundamental to Galtung's theory are the ideas of actors, systems, structures, ranks, and levels:

> *Actors seek goals, and are organised in systems in the sense that they interact with each other. But two actors, e.g. two nations, can usually be seen as interacting in more than one system; they not only cooperate politically… but also economically by trading goods, and culturally by trading ideas. The set of all systems of interaction, for a given set of actors, can then be referred to as a structure. And in a structure an actor may have high rank in one system, low in the next, and then high in the third one; or actors may have either consistently high ranks or consistently low ranks.* (Galtung 1969)

Galtung further describes the interplay of different levels of actors in integrated structures, whereby we can view a social order in terms of territorial structures (nations as a set of districts, made up of municipalities), organizational structures (factories can have sub-factories made up of individuals), and associations. These systems all have interactions within them, and can interact with each other. In all of these interactions, value is exchanged, and results in egalitarian or inegalitarian distribution—or violence. Galtung points to feudal structures, arguing that when these structures are

threatened, those who benefit from structural violence (that is, those who are "at the top"), will try to preserve the status quo (and the systems) so well geared to protect their interests[14].

2.3.4 **How violence is enacted**

Cultural violence leaves a mark not only on the human body, but also on the mind and the spirit. These are avoidable assaults to basic human needs, lowering the real level of needs satisfaction below what is potentially possible. Galtung (1990) distinguishes between direct and structural violence with 4 classes of basic needs—with their differing forms of negating these needs expressed directly, as events of aggression, or structurally through processes of domination.

I have attempted to show examples that illustrate this in Table 2-1 below:

1) Survival needs. Negation: death and mortality
2) Well-being needs. Negation: misery and morbidity
3) Identity needs. Negation: alienation
4) Freedom needs. Negation: repression.

TABLE 2-1 GALTUNG'S TYPOLOGY OF VIOLENCE (1990)

Classes of Basic Needs	**Direct Violence** (events of aggression)	**Structural Violence** (processes of domination)
1. Survival needs	Killing	Exploitation A[15]
2. Well-being needs	Maiming (siege, sanctions)	Misery Exploitation B[16]
3. Identity needs	Desocialisation Resocialisation Second class citizenship	Penetration Segmentation
4. Freedom needs	Repression Detention Expulsion	Marginalisation Fragmentation

In order to distinguish between direct and structural violence, these concepts need to be further unpacked.

[14] The 2014 military coup d'état in Thailand, as an example, has been called a military attempt at hegemonic self-preservation of a network of traditional élites (Mérieau 2016).
[15] The subaltern are so disadvantaged that they die of starvation or wasting.
[16] The subaltern are left in a permanent, unwanted state of misery, usually including malnutrition and illness.

2.3.4.1 *Direct violence*

Galtung (1969, 1990) defines violence that is a direct result of the actions of others as an event of aggression. Its most extreme form, killing, can be read as extermination, holocaust, and genocide. Maiming includes an attack on human needs that are brought about by siege, blockage, and sanctions. Historically, this has involved intentional killing of population groups through malnutrition and medical attention, affecting the weakest first—children, older persons, the poor, and women.

Desocialisation, resocialization, and second class citizenship all fall under the category of alienation by a dominant group, where people are desocialised away from their own culture and resocialised into the dominant cultures; for instance, through the prohibition and imposition of language. Finally, repression—a direct form of violence against a group's freedom needs[17]—is characterised by detention (as in imprisonment).

2.3.4.2 *Structural violence*

Central to Galtung's concept of structural violence is that of exploitation, where we can assume the elite get much more out of the interaction in the structure than do the subaltern. In the extreme example, an unequal exchange may be established that creates conditions leading to conditions so disadvantageous that they die of starvation or disease, or are left in a permanent state of malnutrition and illness (Galtung and Höivik 1971; Galtung 1990). To use his examples for health, he describes

> [t]*he way people die differs: in the Third World, from diarrhea* [sic] *and immunity deficiencies; in the 'developed' countries, avoidable and prematurely, from cardiovascular diseases and malignant tumors* [sic] (Galtung 1990).

2.3.5 **Social exclusion as structural violence**

Differences in health occur along axes of social stratification—socioeconomic, political, ethnic, and cultural. Inequity, including inequity in health, is a produce of this stratification, a continuum that leads in its extreme to social exclusion. The dramatic differences in the health profiles of different nations and different groups within the same country reflect the severe global health inequalities between nations and economies (Marmot 2007; London and Schneider 2012).

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[17] Galtung (1990) writes about freedom in reference to the International Bill of Human Rights, which consists of the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, and the International Covenant on Civil and Political Rights.

But inequalities due to unequal distribution are unfair, and that which is unfair is unjust. These inequalities, then, are in fact, inequitable as they now have a moral and ethical dimension: these are differences which are unnecessary and avoidable, and speak to an acceptance of social exclusion as structural violence. (Whitehead 1991; Braveman and Gruskin 2003). The WHO's Commission on Social Determinants of Health's report in 2008 was based on a response to this premise: that no country or region should have to live with levels of ill health that are avoidable (Marmot 2007). As a consequence there is a pressing need to address global—and local—disparities in health. The Commission of Social Determinants of Health set up knowledge networks to inform its work, with one of these focused on social exclusion. The Commission's Social Exclusion Knowledge Network (SEKN), led by Popay and colleagues, emphasised in their report the distinction between the use of 'social exclusion' to describe a *state of being* rather than a *process*. Most policymakers and researchers have used social exclusion or marginalisation to describe a state in which people or groups are assumed to be excluded from social systems and relationships. This results in definitions of exclusion containing indiscriminate lists of excluded groups, what they are excluded from, the resultant problems and the actors and factors responsible for their exclusion. This is reflected, in part, in the work of Evans and Brown (2003), who use the mnemonic PROGRESS+, standing for place of residence, ethnicity, occupation, gender, religion/culture, education, socio-economic position and social capital, as a way to structure the bases of social exclusion, acting as an *aide memoire* for the categories of marginalisation and consequent gradations in health status. The mnemonic was used by *Go4Health* WP2 in its selection of case studies to ensure that the major categories of marginalisation were explored.

However, recognition of the complexity of identity, and the polyvalence of these categories (offering both positive and negative outcomes) and their failure to be exhaustive (disability and sexual orientation are obvious omissions) point to the limitations of the model (O'Neill et al., 2013). One result of being categorised as excluded or marginalised, is that people in this state may carry the label with them for the rest of their lives, further constraining the possibility of change. This way of looking at exclusion hampers our understanding of its nature and causes and fails to recognise the agency of those excluded (Friedman, Akakimpa, et al. 2013). Instead, the social exclusion approach overlaps with the concept of marginality when it is seen as a condition and process of detachment from the institutions and communities of which the society is composed, and from the rights and obligations that they embody (von Braun and Gatzweiler 2014). The SEKN

(2008) elaborates on the social, political, cultural, and economic dimensions of exclusion at household, community, national, and global level, and so does justice to the myriad of exclusionary forces individuals can be subjected to. Importantly, the SEKN (2008) differentiates between active and passive exclusionary processes:

> *Active exclusionary processes are the direct and intended result of policy or discriminatory action including, for example, withholding political, economic and social rights from migrant groups or deliberate discrimination on the basis of gender, caste or age. Passive exclusionary processes, in contrast, arise indirectly, as for example when fiscal or trade policies result in an economic downturn leading to increased unemployment.*

Their description of active exclusionary processes coincides with what is commonly understood by marginalisation—the purposive exclusion of individuals or groups—but the dynamic nature of exclusion means that the complex intersections of active and passive exclusion must be acknowledged.

2.3.6 **Intersectionality, exclusion and health**

The SEKN explicitly adopted this relational perspective, defining social exclusion as a:

> *dynamic, multi-dimensional processes driven by unequal power relationships interacting across four main dimensions—economic, political, social and cultural—and at different levels including individual, household, group, community, country and global levels. It results in a continuum of inclusion/exclusion characterised by unequal access to resources, capabilities and rights which leads to health inequalities.* (Popay et al. 2008)

Marginalisation is complex, and social exclusion in the SEKN definition involves dynamic processes that sometimes overlap: in her postcolonial study, Spivak notes that "*if you are poor, black and female you get it in three ways*", speaking of this compounded triple disadvantage of race, colour and poverty. Crenshaw (1991) holds that conceptualizations that overlap or intersect social identities of class, gender, ethnicity, religion, age, sexual orientation and other axes of identity, also interact on multiple and simultaneous levels. This framework builds on Spivak's work, and helps us understand how systemic injustice and inequality occurs on a multidimensional basis, holding that

racism, sexism, classism, and homophobia do not act independently of one another. Instead, these forms of oppression are interrelated and create a system of oppression that reflects the intersection of multiple forms of discrimination. Language barriers for immigrant women in the United States, for instance, can limit opportunities to take advantage of existing support services. Intersectional subordination does not necessarily have to be intentionally produced: often the consequence of one burden that interacts with pre-existing vulnerabilities to create yet another dimension of disempowerment. If we revisit Evans and Brown's (2003) categories of inequity—place of residence, religion, occupation, gender, ethnicity, education, socioeconomic status, and social capital—it becomes clear that any intersection of two or more of these will compound disadvantage, and that the prejudice that arises from one category can easily "bleed" into another. The current global debate around Muslim asylum seekers provides ready evidence of the intersection of place, religion, ethnicity—but also socio-economic status ("economic refugees") and the exception of certain desirable occupational categories.

Cultural identity and class, then, interact in ways that make services or structures that are formally available to everyone, accessible only to those who are socially, culturally, or economically privileged. History and context determine the utility of identity politics, multiple and otherwise, with internal exclusions and marginalisations—that is, a cultural dominance in addition to the economic rule will lead a particular groups to success and create self-serving structures (Cho, Crenshaw, and McCall 2013). Furthermore, the interaction of social, political, and economic forces at play to diminish subaltern capabilities to flourish. This extends to health as well: the health system—and other infrastructure that determines health—may not be accessible to the marginalised, despite national commitments to Universal Health Coverage, or a global rhetoric that "leaves no one behind".

In recognizing the social determinants of health, Popay and colleagues' work in the Social Exclusion Knowledge Network (2008) elaborates on their theory or multidimensionality of social exclusion:

- "*The* **social dimension** *is constituted by proximal relationships of support and solidarity (e.g. friendship, kinship, family, clan, neighbourhood, community, social movements) that generate a sense of belonging within social systems. Along this dimension social bonds are strengthened or weakened;*
- *The* **political dimension** *is constituted by power dynamics in relationships which generate unequal patterns of both formal rights embedded in legislation,*

constitutions, policies and practices and the conditions in which rights are exercised - including access to safe water, sanitation, shelter, transport, power and services such as health care, education and social protection. Along this dimension, there is an unequal distribution of opportunities to participate in public life, to express desires and interests, to have interests taken into account and to have access to services.

- *The* **cultural dimension** *is constituted by the extent to which diverse values, norms and ways of living are accepted and respected. At one extreme along this dimension diversity is accepted in all its richness and at the other there are extreme situations of stigma and discrimination. The economic dimension is constituted by access to and distribution of material resources necessary to sustain life (e.g., income, employment, housing, land, and working conditions)*"

The assumption is that these processes and their impact on health inequalities operate in the context of predetermined biological determinants (e.g., age, sex, genetic predispositions). Within social systems, interactions between the four relational dimensions of power—social, political, economic and cultural—generate hierarchical systems of social stratification along lines of gender, ethnicity, class, caste, ability and age. These stratification systems, and the unequal access to power and resources embedded in them, lead to differential exposure to health-damaging circumstances whilst at the same time reducing people's capacity (biological, social, psychological and economic) to protect themselves from such circumstances, and restricts their access to health and other services essential to health protection and promotion. These processes create health inequalities which feedback to further increase inequities in exposures and protective capacities and amplify systems of social stratification. Health equity, then, must move to change these dynamics in each of the three dimensions: to reinstate social networks and linkages, to confront the political relationships that justify maldistribution of resources, to reverse these cultural processes that underpin social exclusion, to dismantle the obstacles, empower the marginalised.

Health equity draws from Braveman and Gruskin's (2003) operational definition: it means that everyone has a fair and just opportunity to be as healthy as possible. But this requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education, and housing, safe environments, and health care. Health equity, then, means reducing and ultimately, eliminating disparities in health and its determinants that adversely affect excluded or marginalised groups (Braveman et al. 2017).

And change is possible. Crenshaw (1991) points to the feminist movement to illustrate how the political demands of millions speak more powerfully than "the pleas of a few isolated voices," and emphasises that race, gender, and other identity categories, socially constructed or otherwise, may—through their various interactions—create different experience outcomes. The values attached to categories, she explains, can be subverted—to illustrate, she uses points to the subversion of the category 'Black' and the transformation of 'queer,' noting that identity is a site of resistance for members of different subordinated groups. Importantly, Crenshaw explains that intersectionality provides a basis for reconceptualising identities such that it summons the courage to empower and challenge. A human rights and social justice approach to development will seek to remedy such inequities—as Friel and Baker (2009) note,

> *Having the freedom to live healthy and flourishing lives is synonymous with empowerment—material, psychosocial and political empowerment of individuals, communities, and nations. The three dimensions of empowerment—material, psychosocial, and political—are interconnected. People need the basic material requisites for a decent life, they also need to have control over their lives (psychosocial), and they need voice, engagement and participation in decision-making processes (political).*

2.3.7 **Capabilities for human flourishing**

But if the marginalised are to be heard, if inequity is to be righted, then the marginalised themselves must be able to access the social platforms that allow them to engage—as well as the structural changes asked of the state and civil society. To do this, we need to explore the concept of capability—firstly, capabilities for well-being and agency, health capability, and the capacity to speak and be heard. Sen's capability approach is applied through the lens of health equity—Sen (2002) himself asserts that discussions of social equity and justice, illness and health figure in as a major concern that is concerned with the larger issues of fairness and justice in social arrangements—in addition to health—including economic allocations, paying attention to the role of health in human life and freedom.

Sen's capability approach is a moral framework that proposes that social arrangements be evaluated in terms of the extent people have to achieve the functionings they value. Sen unites the concepts of freedom and valuable beings and doings in the concept of functioning. But to achieve these functionings, people need access to the essential resources that the functionings that depend on, and the capability to transform these. Sen (2002) writes that functionings are 'beings and doings' and

capabilities are a person's real freedoms or opportunities to achieve their functionings. In her interpretation, Alkire uses a graphic organiser to illustrate Sen's example using food and nourishment:

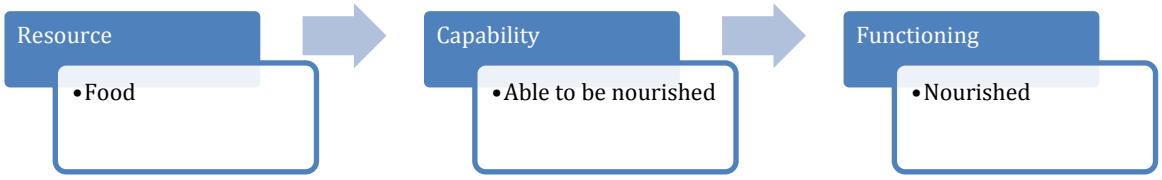


FIGURE 2-1 INTERPRETATION OF SEN'S CAPABILITIES (ALKIRE 2002)

Indicators of functionings may be the technical skills required for employment—but literacy, books and a quality school system are necessary resources; access to that schooling and the capacity to engage the necessary knowledge are the capabilities required. For health, the essentials of shelter and nutrition, safe water and sanitation, and access to health services form the resources; but the complex determinants of health point to the ability to exercise control in one's employment as one of the many capabilities that contribute to health.

The focus on functionings, and the combination of functionings reflects an individual's freedom to lead a particular type of life, that is, the freedom that a person actually has to do this, or be that (Sen 2009). Freedom as "the real opportunity that we have to accomplish what we value" and the ability to shape one's own destiny as a person, and as a member of various communities (Alkire 2002). Freedom is comprised of the ability to act on behalf of matters (*agency*) and the real opportunity to achieve valued functionings (*capability*) (Schuftan 2016). In the context of health, there is a distinction then between health achievement and capability to achieve good health (which may or may not be exercised). The facilities socially offered for health achievement and capability (such as health care) and access to these, may enable or constrain the capability of using these to promote or achieve health. The factors that contribute to health achievements and failures go beyond healthcare and included many influences varying from congenital propensities, individual incomes, food habits, lifestyles, epidemiological environments, and work conditions—clearly these impact on capabilities.

A definition of *health capability* integrates health outcomes and health agency: confidence and the ability to be effective in achieving optimal health given biologic and genetic disposition; the intermediate and the broader social, political, and economic environment; and access to the public health and health care system (Ruger 2010). Health capability is comprised of both health functioning and what Ruger refers to as health agency – that is, the individual's agency to achieve

health goals and act as agents of their own health. Health agency achievement represents what an individual's realised actions are compared with potential actions, with health functioning as the outcome of the action to maintain or improve health. In developing her health capabilities paradigm, Ruger forecasted that study among specific populations would be especially important, in terms of individuals' conditions as well as the socioeconomic barriers to health functioning and health agency. This insight was based on lessons learned from medical outcome assessments that indicate groups we can call marginalised experience some of the worst health outcomes in the world.

Nussbaum (2011) develops Sen's capabilities further, providing tangible and concrete examples of what Sen broadly referred to, and viewing some capabilities as central to minimal human flourishing:

- *Life:* being able to live to the end of a human life of normal length; not dying prematurely, or
- *Bodily health:* being able to have good health, including reproductive health, to be adequately nourished; to have shelter.
- *Bodily integrity:* being able to move freely from place to place; being able to be secure against assault, including sexual assault, having opportunities for sexual satisfaction and for choice in matters of reproduction.
- *Senses, imagination, and thought:* being able to use the senses, to imagine, think, and reason, and to do these things in a way that is informed and cultivated by an adequate education, including but not limited to literacy and basic mathematical and scientific training. This includes being able to use one's mind in ways protected by guarantees by freedom of expression with respect to both political and artistic speech.
- *Emotion:* being able to have attachments to things and people outside ourselves
- *Practical reason:* being able to form a conception of the good and to engage in critical reflection about planning one's life; this entails protection for the liberty of conscience and religious observance
- *Affiliation:* being able to live with and toward others; to engage in various forms of social interaction; having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being including protection against discrimination on the basis of race, gender, sexual orientation, religion, caste, ethnicity, or national origin
- *Other species:* being able to live with concern for and in relationship to the world of nature.
- *Play:* being able to laugh, or play, to enjoy recreational activities.

- *Control over one's environment:* both politically and materially, including having the right to political participation and having property rights on an equal basis with others, having the right to seek employment on an equal basis with others.

In this study, if the marginalised are to engage in the platforms that will impinge on their essential health needs, then their capabilities to use the limited resources that are available to them in both health and local decision making processes will be necessary—but not sufficient—to their achievement the functionalities they seek in health.

2.4 The Imperative for Global Change

But if the Capabilities and Functionalities focuses on the potential for transformation within the marginalised, the imperative for change in the hegemonic structures that they confront remains. The platforms that enable engagement in decision-making around the post-2015 goals will need to be purposively constructed by both the state and civil society. It is in a context of rampant inequity that the global discourse leading up to the SDGs attempted to do this: calling for a post-2015 development agenda to address the need for a positive transformation of the economic and financial systems more comprehensively, setting up almost 100 country consultations, 14 thematic consultations and a web-based forum that allowed individual opinion to be voiced—where individuals had internet access (Bhattacharya, Khan, and Salma 2014). The *Go4Health* initiative—and this research—is an extension of that process.

Beyond this, others have called for a governance that is inclusive of multiple stakeholders in the complex adaptive system that is global health, employing new values and skills (Haffeld 2013). At the crux of all these theories of transformation are the *left* behind—women, men, and children, who every day of their lives are pushed to the margins by powerful social, economic, and political structures, behind which there are also people—those who hold entitlements and privileges that guarantee freedom from want. If what binds us together is our human spirit, then we must draw on that, our sense of social justice, as well as research evidence to bring about the capability of each person to achieve a life that they value.

The values of the 1978 Alma Ata Declaration—comprehensive, universal, equitable, and affordable primary health care (PHC) in all countries, with communities and their leaders involved in the planning and implementation of their own healthcare services through Primary Health Committees—have yet to be systematically applied. While debate around comprehensive PHC and

selective PHC continues, one thing is clear—political commitment was not sustained and the idea of primary health care as per the Alma Ata Declaration, for the most part, became jargon (Hall and Taylor 2003). The next iteration of global health initiatives were in the form of the MDGs, which gained more traction—possibly because they fit neatly into the prevailing neoliberal economic model, without challenging social and political structures in the way that the Alma Ata did. The notion of social interventions governed by communities and citizenry[18] universally was problematic—instead, policies have been put in place such that patients are now viewed as clients, planning has disappeared and has been substituted by competition, and national health services have been dismantled and contracted to the private sector—with all of these contributing to a widening gap of inequity (Navarro 2008).

[18] I am mindful that *citizenry* excludes non-nationals; it should be noted here that for participation to be meaningful, *all* people from *all* communities must be included.

Figure 2-2 encapsulates the WHO listing of the values set forth by the Alma Ata Declaration and incorporated into a framework to promote the right to health:

***Non-discrimination*:** Guarantees that human rights are exercised without discrimination of any kind based on race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status such as disability, age, marital and family status, sexual orientation and gender identity, health status, place of residence, economic and social situation

***Availability*:** A sufficient quantity of functioning public health and health care facilities, goods and services, as well as programs

***Accessibility*:** Health facilities, goods and services accessible to everyone. Accessibility has 4 overlapping dimensions: non-discrimination, physical accessibility, economical accessibility (affordability), and information accessibility

***Acceptability*:** All health facilities, goods and services must be respectful of medical ethics and culturally appropriate as well as sensitive to gender and life-cycle requirements

***Quality*:** Health facilities, goods and services must be scientifically and medically appropriate and of good quality

***Accountability*:** States and other duty-bearers are answerable for the observance of human rights

***Universality*:** Human rights are universal and inalienable. All people everywhere in the world are entitled to them

FIGURE 2-2 RIGHTS BASED APPROACH TO HEALTH (WHO 2017)[19]

Integral to a rights based approach to health is the notion of public participation, and Marlor (2010) asserts that if democracy is a political system that attempts to give voice and power to people, it is premised on the idea of inclusion, including those who are marginalised. Iris Marion Young (1990) wrote "*marginalisation is perhaps the most dangerous form of oppression. A whole category of people is expelled from useful participation in social life and subjected to severe material deprivation*." To the lack of material resources, Young further adds that the lack of capacity to participate politically and culturally, in markets and other institutions, thus linking poverty with participation (Jenson 2000). While Marlor's intentions are to point out that inclusive public participation should harness different forms of knowing, and thus new contributions, through lived experience to decision-making—this view is problematic because it does not acknowledge that alongside voice and power there must also be a critical consciousness, not only around health but also how structures and processes in its periphery (e.g., social determinants) operate. Studies have shown that people's participation have been effective in some contexts, but call to question *how*

[19] The ongoing discourse around universal health coverage is widely considered to be a means to promote the right to health.

participatory they are—that is, to what degree do people feel adequately informed, and able to meaningfully contribute with the expectation that their voice will translate into action? Based on a Freirian[20] understanding of critical consciousness raising, many scholars argue that critical health literacy is ultimately key to building people's capacity and agency for achieving well-being (Arnstein 1969; Rifkin and Bichmann 1988; Bess et al. 2009; Chinn 2011; Rowlands and Nutbeam 2013). While traditional global goal setting forums may capture good evidence and cost-effective interventions, they have shortcomings on community values such as equity, fairness and transparency and have resulted in morally indefensible goals. Ignoring these values also has several drawbacks such as the lack of trust and community buy-in, to poor accountability and a disenfranchisement of populations within their health systems.

The conceptual framework illustrated in Figure 2-3 can be used as a guide for understanding the navigation of community voices to global health discourse for the purposes of this dissertation. At community level, I have begun with Evans and Brown's (2003) PROGRESS+ mnemonic to identify categories by which many groups are marginalised, with the arrows underneath indicating the possibility of intersections between categories of identity—for instance, an indigenous group might be living in a remote rural area and tend to have low literacy rates. These intersections of identity will interact together, in a context of cultural violence, influencing communities' access to resources. It is the utilization of these capabilities that determine whether communities are able to use their voice in forums for public participation. Those forums—or platforms for engagement—will only arise where the state and/or civil society work towards purposively opening up dialogue with the marginalised. In the case studies we examine, we will see occasional examples of these platforms, where governance structures invite participation in decision making that impacts on the lives of the marginalised. More often they are conspicuous by their absence. In a sense, the *Go4Health* research represented the creation of one of these platforms—the transient opening of a space in collaboration with civil society organizations and local leaders to engage marginalised communities around their essential health needs and the incorporation of these into debate on the *World We Want*.

[20] Paolo Freire's notable work *The Pedagogy of the Oppressed* (1972) proposes the transformation of oppressive structures for creating an equitable society through people reflecting on their conditions and taking action, a concept referred to as conscientisation.

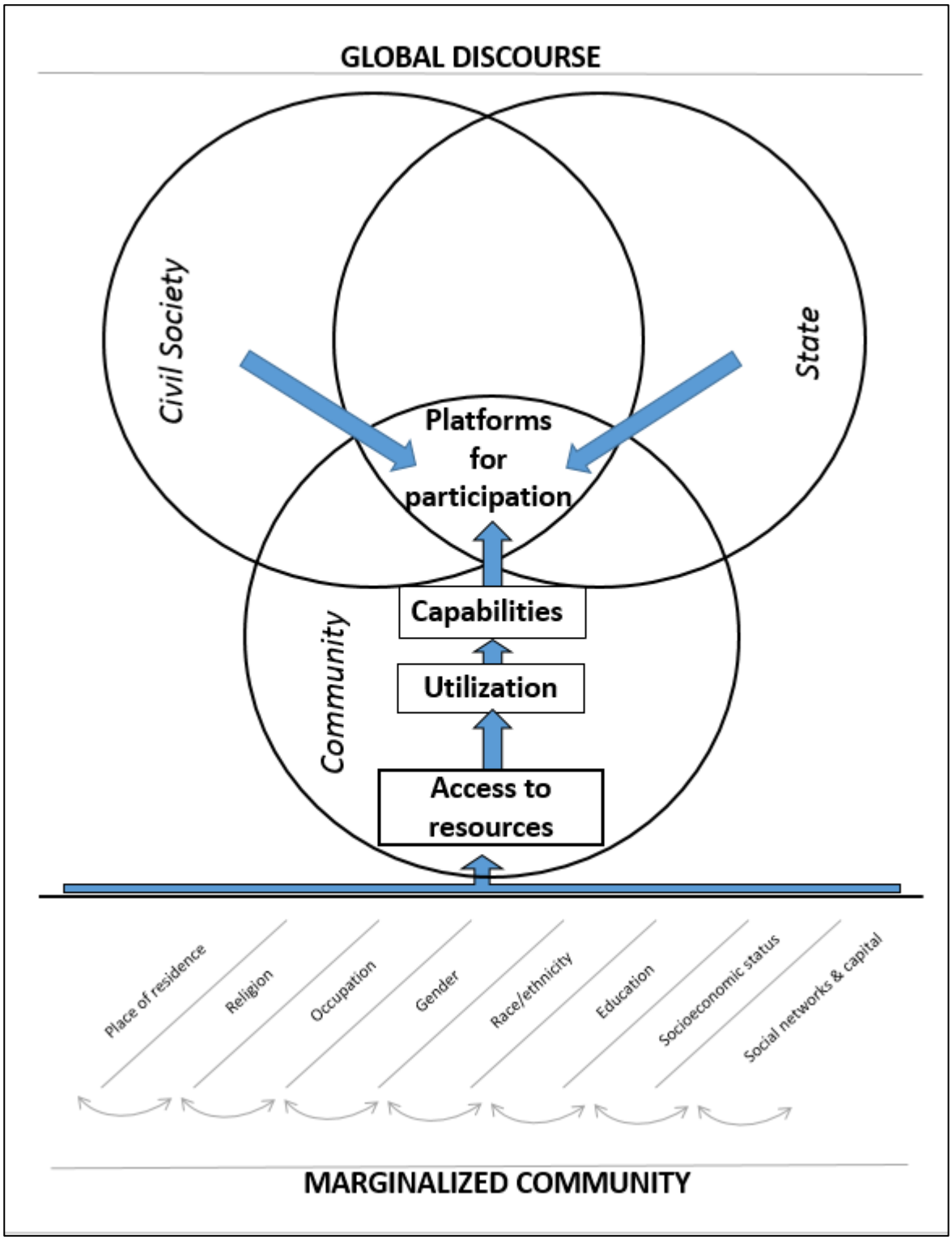
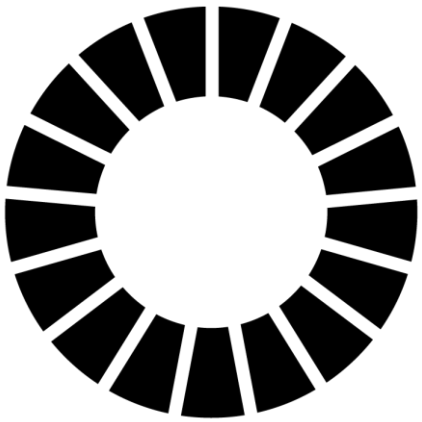


FIGURE 2-3 AUTHOR'S FRAMEWORK FOR INCLUDING THE 'LEFT BEHIND' IN GLOBAL HEALTH DISCOURSE

2.5 SUMMARY

Under former United Nations Secretary-General Ban Ki-moon, Sustainable Development was framed early as a universal agenda, with an imperative to *leave no one behind*. But how do we hear those who have been left behind? This chapter defined the *left behind*—those who did not benefit from the commendable gains of the MDGs due to multidimensional and dynamic exclusionary processes enacted by the dominant culture—that is, domination by the majority—at local, national, and even global levels—whose economic, social, and administrative structures are built to serve the interests of the powerful. The social determinants of health, and people's agency for the freedom to participate in decision-making intended for priority setting for their well-being is jeopardised in numerous and sometimes overlapping ways.

My review of methods used to consult with marginalised groups (as described in Appendix C) revealed that any valid inquiry to elicit their perceptions of health status and experiences must be participatory. Questions of fairness, citizen rights, stakeholder engagement, and community empowerment are raised in many of these studies and demonstrates a need for discourse around community agency in translating their perceptions into action. However, no study to date has aimed to investigate and track the voices of marginal communities into the global discourse for health priority setting. In engaging with marginalised communities to learn of their experiences and perceptions of health, and exploring comprehensively how their voices are heard in global discourse through the international research consortium *Go4Health*, this study will serve as the first of its kind. The conceptual framework I have developed (Figure 2-3) to elucidate the enablers and barriers for community voices to be translated into the global discourse can be used by the reader as an heuristic guide. It points to the possibility of marginalised communities mobilizing their resources and capabilities to achieve the functionalities they are seeking in their essential health needs. But it also points to the need for change within the structures that should enable those functionalities—but which in their experience, continue to constrain and exclude them.



CHAPTER 3
Methods

3.1 INTRODUCTION

This thesis is located in health policy and systems research: it is grounded in the local, with a focus on the marginalised, and reaches the global, seeking to understand how their voice is heard in the policy development of the post-2015 discourse. Health policy and systems research (HPSR) is a broad and interdisciplinary field developed in response to the need for developing sustainable health-care service delivery systems and facilitating interaction between evidence generators and evidence users (Ghaffar 2012). Since the institutionalization of HPSR as a locus for evidence-informed decision-making, the field has expanded to unify diverse disciplines of research and combine platforms of knowledge generation that were once weakly connected in order to improve how societies organise themselves to achieve health goals – that is, it has evolved to bridge the gap between services and systems research and policy (WHO 2012). Mills (2012) documented her frustrations around methods as a neglected area in HPSR and identified priorities for action, which research consortia have attempted to address through learning by doing.

In the previous chapters and in Appendix C, I have established the effective ways that qualitative methods in HPSR have been useful for gaining insight into community perceptions of health systems. My PhD follows a similar path in understanding how communities experience health: through qualitative inquiry I use a nested case study approach and employ established documentary analysis, interview techniques and direct observation to gather data in two study sites in Bangladesh and in the Philippines. Through discourse analysis, I then examine how those community voices, along with those of others in the global South, have found a place in the global health literature as a result the *Go4Health* study.

This PhD is guided by two major works: I draw inspiration from the World Bank's ground-breaking report, *Voices of the Poor: Can Anyone Hear Us?* an earlier global study to engage respondents in a research process using participatory methods with the specific intent of empowering participants into taking action (Narayan-Parker 2000). The second is the medium through which this PhD became possible, the European Union's *Go4Health* study, which applied a human rights approach

to the consultative process, using a public health lens to provide a 'snapshot' of the health needs and priorities of marginalised groups with a view to make tangible policy recommendations for a post-2015 global development agenda. In this chapter, I outline the general methods used for my PhD along with a detailed account of its relationship with the *Go4Health* project. But in doing this, I need to confront my awareness of the short-comings of the research approaches that I have needed to adopt in order to harness the resources available to me through the *Go4Health* project.

To uphold the values that *Go4Health* wishes to champion, and those that previous participatory priority setting initiatives have proposed, it is felt that, to ensure that the methods and processes that our research uses are, above all else, *empowering* and *including marginalised populations*. To have a fair and legitimate survey of community perspectives of their health priority to inform global health priorities, we look to techniques that can employ outsiders as catalysts to stimulate community awareness of their local priorities and how they feed into global priorities (Chambers, 1994, p. 958). *Go4Health* partners are expected to choose research and consultation methods that uphold these values, but apart from that, are given flexibility to choose methods that work best for their particular context. The imperatives of the research, the mandate from the EU to determine essential needs by consultation with the most marginalised communities, and the urgency of the timeframe in which this was needed, has necessitated compromises. Despite our desire to represent marginalised communities, WP2 had resources to only access a dozen communities across four continents; despite our desire to empower communities, this was necessarily researcher—and donor—driven research; despite our search for a deep experiential understanding of marginalisation, this is not an ethnography; despite our recognition of the imperative of participation for community change to occur, this is not participatory action research.

From my BRAC University context, I am acutely aware of some of the landmark studies in participatory approaches. Indeed, the renowned Chhattisgarh study in India allowed five NGOs to develop their own methodology for a pilot phase "to enable a subsequent comparative assessment of the best method and process to capture the elements of human development, and take the process further" (2005). However, we may be able to list some criteria by which we can assess the methods. Apart from generally accepted standards for good, ethical research, methods used for consultations can be assessed on these participatory criteria.

The researchers should allow local "people to undertake and share their own investigations and analysis" of the results (Chambers 1994). To be sufficiently participatory, the methods should not

only seek to "elicit and extract" knowledge by outsiders (Chambers 1994)but engage the community as equal, empowered partners. An ideal process would be "dynamic, open, discussion-oriented and determined by the people, rather than being pre-determined by the methodology itself" ("Human Development Report: Chhattisgarh. New Concept Information Systems" 2005). This would also enhance the acceptability of the method. One more aspect comes into play here. Abelson et al. conducted a series of consultations on public involvement processes for health system decision-making (Abelson et al, 2004). Citizen participants felt that the partnership between them and researchers was most meaningful when the consultation process prioritised information sharing and communication principles above all other principles.

Chambers (1994) argued that consulting a community to elicit their opinions and priorities cannot produce legitimate results. He noted that outsiders-led techniques had several inherent sampling biases that "hide the worst poverty and deprivation," and excluded the experience of the most under-privileged, weak and marginalised. In order to incorporate the values and opinions of marginalised communities at global priority setting forums, it is important to learn about their most urgent healthcare priorities "from, with and by" the communities themselves (Chambers 1994). He encouraged participatory research methods that create confidence in a community of the richness and validity of their own knowledge and abilities and using this indigenous technical knowledge (ITK) to conduct their own appraisal and analyse their own conditions.

In these participatory methods, outsiders are relegated to a role of convening, catalysing and facilitating this process. Instead of traditional extractive-elicitive approach "where the main objective is data collection by outsiders," they are required to use a sharing-empowering approach "where the main objectives are variously investigation, analysis, learning, planning, action, monitoring and evaluation by insiders". This implies a radical personal and institutional change for outsiders who should focus on establishing the community's ownership of plans, actions and projects. Methods are largely shared, usually more visual than verbal and the local people are more active than the outsiders.

Chambers called such approaches that enabled "rural people to share, enhance, and analyse their knowledge of life and conditions, to plan and to act" Participatory Rural Appraisals (PRA). Chambers noted that participatory methods that tapped into ITK gained better insights and were more acceptable, timely, cost effective, valid and reliable than more conventional methods. Some of the methods involved in PRA are listed here. The methods outlined may be used in sequence, for

example participatory social mapping leading to the identification of key informants or analysts, or well-being ranking leading to focus groups, matrix scoring and preference ranking.

Participatory action research uses "dialogue and participatory research to enhance people's awareness and confidence, and empowers them to action". Techniques such as "collective research through meetings and socio-dramas, critical recovery of history, valuing and applying 'folk culture,' and the production and diffusion of new knowledges through written, oral and visual forms" uses the capacities and creativity of poor and powerless people and allow them to do their own investigation, analysis and planning. What I have done, in meeting the requirements of *Go4Health* to secure responses to the five domains of questioning that their research demanded, is to apply as many of these principles as possible to my engagement to the communities in Bangladesh and the Philippines, and to represent their voices as comprehensively as I have been able to in this thesis, and into the *Go4Health* reports and publications.

3.2 Study Design

The research question central to my PhD came about as consequence of my employment at BRAC University (BRACU) in Dhaka, Bangladesh. As a research coordinator at BRACU, I coordinated community case studies in 3 countries in Asia—Afghanistan, Bangladesh and the Philippines. Two of those case studies—Bangladesh and the Philippines—form the substance of this thesis. I took an active role in planning and designing the *Go4Health* study as part of WP2, delegated the task of conducting research with marginalised communities in the global South, in order to ensure their voice was heard in a rights-based and inclusive discourse shaping global health goals in a post-2015 development agenda (Brolan et al. 2014).

My involvement with this unique project, that brings the health priorities of communities to the fore in recommending goals for health, was timely. I began work in the project in 2012, at a moment when negotiations were underway at the world stage for what evolved to become the post-2015 Agenda for Sustainable Development, more popularly known as the Sustainable Development Goals (SDGs). The purpose of my work in *Go4Health* was to fulfil the European Union's deliverable to make evidence-informed recommendations for new health development goals in the post-2015 context, committed to raise the voices of communities and bring them to the larger post-2015 global health discourse.

This PhD is nested within *Go4Health*, and in doing my work with the project, questions around its processes and positions begged to be asked. I have repeatedly discussed these issues in my interactions with other academics during project meetings, and these led me to crafting a PhD proposal: to learn about communities' priorities in their own words, and to examine how their voices are both represented and filtered in a wider discourse through *Go4Health*'s products.

My dissertation is guided by the conceptual framework that uses the mnemonic PROGRESS+, developed by Evans and Brown (2003), to identify the dimensions of marginalisation: place of residence, religion, occupation, gender, race/ethnicity, education, socioeconomic status, social capita, sexual orientation, and disability. It recognises the intersection of individual identities of the marginalised as utilised in contributing to capabilities, in turn developing functionalities that enable participation in a platform for participation that enables citizen engagement with civil society, the state, and ultimately global governance (Evans and Brown, 2003; O'Neill, 2014; Sen 1999).

3.2.1 **Post-2015 agenda setting: a global study for global health goals**

The *Go4Health* research consortium is a multi-centre research collaboration funded by the European Union through its FP7 research program from 2012 to 2016. '*Go4Health*' stands for 'goals for global health' and for 'governance for global health.' From the perspective of this interdisciplinary and global consortium, goals and governance are elements of a social contract between citizens and governments where citizens agree on a set of goals and accept an authority empowered to take the necessary measures to achieve those goals [www.*Go4Health*.eu]. The central objective of the *Go4Health* project was to advance and improve on the concept of a global social contract as articulated in the Millennium Declaration; proposing goals and a governance structure centred on a framework of shared but differentiated responsibilities for a post-MDGs agenda.

Go4Health responded to a call for "setting health-related development goals beyond 2015," that aimed to "ensure that the health-related development objectives for the period after the expiration of the MDGs are based on the best scientific evidence available and address the main shortcomings of the current MDGs," with a view that New Health-related Developments Goals (NHDGs) should:

- strike a balance between horizontal and vertical approaches to healthcare
- indicate an improved system for global health innovation; and
- be measurable, achievable and sustainable, while

- effectively accounting for the constraints of developing countries for improving health outcomes themselves.

A consortium of researchers robust in both our quality and quantity rose to the challenge. Consisting of 13 institutions from academia and civil society, the breadth of expertise in our group reflects the interdisciplinary nature of our research: public health, human rights law, economics, and political sciences. I turn, the project has been located at the intersection of health, human rights advocacy, and research. The institutions, under the coordination of the Institute of Tropical Medicine in Antwerp, Belgium, were divided into working groups, each with specific set of tasks that would inform a set of NHDGs.

FIGURE 3-1 *GO4HEALTH*'S WORKING GROUP COORDINATION

In terms of its theoretical framing, the *Go4Health* project, fundamentally, was grounded in the principles of the Universal Declaration of Human Rights and International Covenant on Economic, Social and Cultural Rights, specifically the right to the highest attainable standard of health (Ooms et al. 2013). This normative positioning distinguishes *Go4Health* from other research initiatives that attempt to maintain an 'objective' neutrality within their research: *Go4Health* sees itself as a policy actor, as well as analyst. With a human rights approach, the consortium as a whole has been, from its inception, keen on promoting Universal Health Coverage (UHC), widely held to be the most significant concept in the field of global public health (Chan 2013). The component titled "Essential Health Needs Formulation," where regional research hubs were expected to explore the needs of communities, was expected to support this claim. From the first *Go4Health* consortium meeting in September 2012, it was expected that the outcome of Work Package 2 (WP2) of *Go4Health* would support the normative stance taken by the project. When I discussed these tensions with Dr. Peter

Hill, who later became my principal supervisor, we agreed that I should put a proposal forward for consideration as a Research Higher Degree at the University of Queensland. Following necessary admissions processes and administrative procedures, I enrolled as a PhD student in July 2013.

TABLE 3-1 *GO4HEALTH* WORKING GROUPS, OBJECTIVES, AND INSTITUTIONAL MEMBERS

Work Package	Group title	Objectives	Members
1	MDG Innovation and Analysis	To critically analyse the MDG approach, its achievements and shortcomings, including the present incentive systems for MDG-related health innovation.	Institute of Tropical Medicine (Belgium) London School of Hygiene and Tropical Medicine (UK) University of Heidelberg (Germany)
2	Essential Health Needs Formulation	To formulate a set of goods and services that corresponds with Essential Health Needs (EHNs), which should be guaranteed to every human being as entitlements under the human right to health.	Georgetown University (USA) Centre for Health, Human Rights, and Development (Uganda) BRAC University (Bangladesh) Centre for the Study of Equity and Governance in Health Systems (Guatemala) University of Queensland (Australia) Medico International (Germany)
3	National and International Responsibilities Allocation	To affirm and elucidate national responsibility for providing health goods and services, and to clarify the international responsibility in relation to the national responsibility.	University of Nairobi (Kenya) University of Queensland (Australia) University of Toronto (Canada) Georgetown University (USA)
4	Global Governance of Health Analysis and Dialogue with Multilateral Actors	Propose changes to global governance of health such that it holds governments and others accountable for their responsibilities, enhancing the likelihood that NHDGs will be achieved	University of Edinburgh (UK) Norwegian Centre for Human Rights (Norway) University of Queensland (Australia)

Source: Go4Health Final Proposal 2012

3.2.2 **Work Package 2 (WP2) of *Go4Health***

My PhD is nested in the work of WP2 as part of the Asia regional hub for conducting community research for fulfilling the objective of "Essential Health Needs (EHNs) Formulation." WP2 consisted of 2 NGOs and 3 academic institutions, under the coordination of Georgetown University, members were tasked with conducting community based research in 3 countries within their geographic region. With my BRAC University team, I consulted with communities in Bangladesh, Afghanistan, and the Philippines. Other institutions and sites of community research are indicated below:

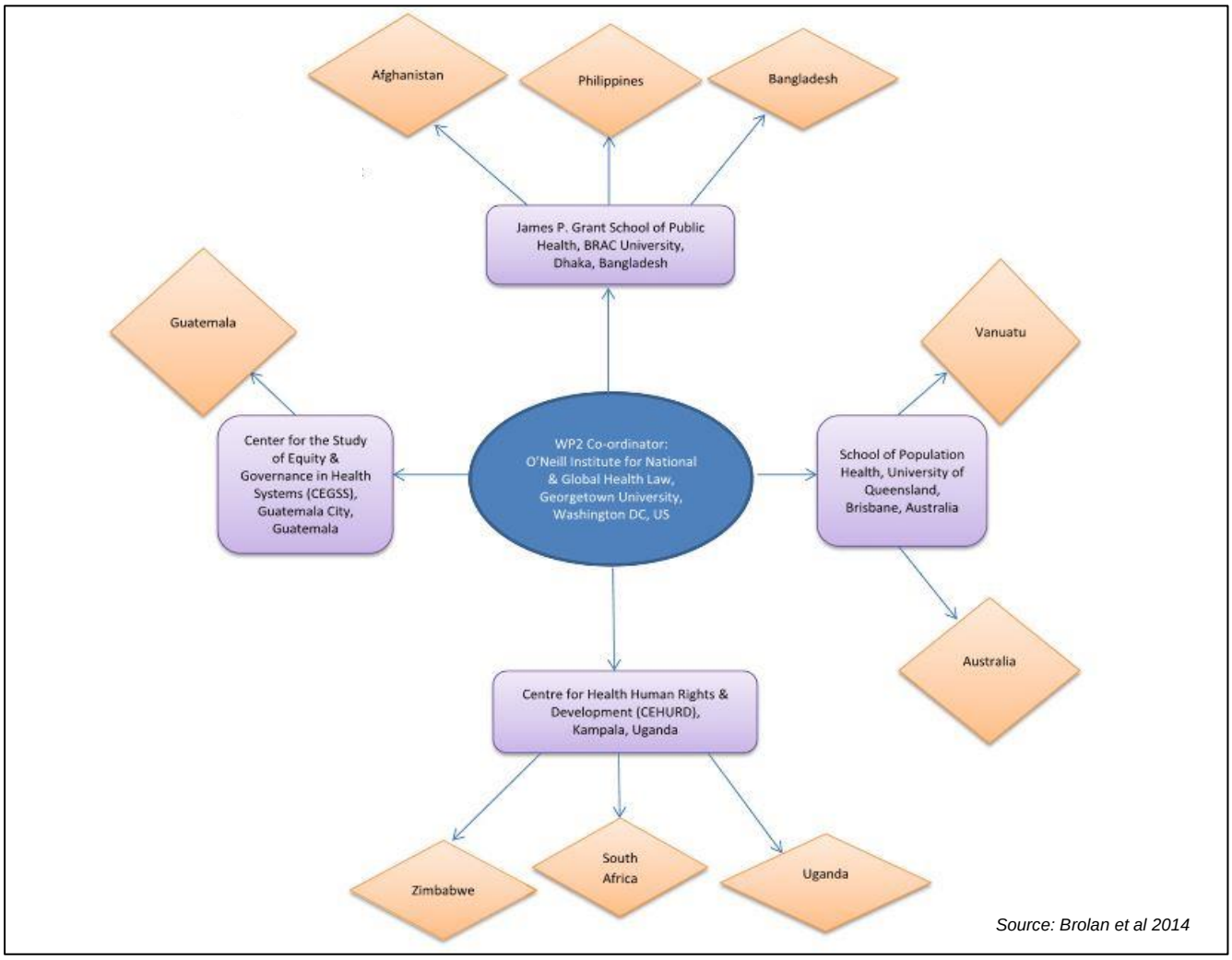


FIGURE 3-2 *GO4HEALTH*'S WORK PACKAGE 2 COORDINATION AND COUNTRY CONSULTATIONS

FIGURE 3-3 *GO4HEALTH* WP2 STUDY SITES[21]

(FROM WEST TO EAST: GUATEMALA, SOUTH AFRICA, ZIMBABWE, UGANDA, AFGHANISTAN, BANGLADESH, PHILIPPINES, AUSTRALIA, VANUATU

[21] Countries of study indicated with a red star.

3.2.2.1 *WP2 Methods*

The WP2 research formed a vehicle for data collection for my own PhD. As the two processes are interdependent, but distinct, the WP2 research process needs careful description, and can be visualised below. My engagement began in September 2012 at a workshop in Entebbe, Uganda, when the WP2 team and the *Go4Health* consortium met. Table 3-2 sets out the structure of collaborative meetings between members of the WP2 team, and the milestones determined by that research agenda.

TABLE 3-2 WP2 ENGAGEMENT FROM SEPTEMBER 2012—AUGUST 2013

Timeline	Mode of engagement	Activities
September 2012	Face to face meetings	Understanding the project: definitions and deliverables
October – November 2012	Skype, Webex, and email correspondence	Formative research, internal decisions around site selection, population sample
December 2012	Face to face meetings/workshop	Agreement on domains of inquiry, interview guides
January – June 2013	Data collection	Community consultations, translation (where necessary), transcription
February – August 2013	Data analysis and reporting	Coding and thematic analysis, report writing for submission to WP2 coordinator

3.2.2.2 *Collaborative research protocol and study design*

Several months of deliberations over in-person meetings, extensive e-mail correspondence, web-based online meetings, and a common literature review were necessary prior to embarking on WP2 consultations. The crucial areas we had to agree on were definitions of community and marginality before we could identify and select marginalised communities in our regions to consult with.

We discussed and agreed on definitions of community and marginality. As indicated in Chapter 2, "community" is a term I will be using throughout this dissertation to refer to a cluster of people held together by commonalities, such as shared issues and relationships. In addition to shared characteristics, they also share a common bond such as shared resources or

shared social interactions (Campbell and Jovchelovitch 2000; Howarth 2001). Marginality is more difficult to define, and although many of us "knew" which groups in our regions are "marginalised" through our contextualised practical knowledge and experience – articulating its meaning was more difficult, and required discussion around dominant groups and processes of social exclusion, led by a sociologist within the WP2 team.

The WHO's Social Exclusion Knowledge Network define "marginality" as a state of being, and a result of active processes of social exclusion or "marginalisation" by dominant groups (Popay et al. 2008). With these established and agreed upon, WP2 aimed to ensure a broad sampling of marginalised communities to capture a diversity of perspectives of a wide range of communities, to provide a snapshot of diverse community priorities and concerns in several regions of the world in order to inform the NHDGs.

Regional hubs dispersed to their respective institutions and proceeded to form internal reference groups to inform specific methodologies for undertaking community consultations. WP2 concurrently conducted a literature review around how to include community members as stakeholders in priority-setting research, how to engage meaningfully with communities that are marginalised, and strategies for determining community priorities. Each partner engaged in ongoing WP2 discussions through electronic means (correspondence, Skype, and Webex calls) to identify themes to guide our inquiry.

At institutional level, each WP2 member mobilised preparatory processes that included selecting tools, analysing national and community contexts, further refining questions and tools, preparing informed consent forms, securing ethical clearance, and developing plans for interpretation, recording, transcription, translation, and other areas related to methodology. The final phase of planning took place during a meeting in December 2012 when we narrowed our thematic focus into 5 conceptual areas, or domains of inquiry, which corresponded to our task of Essential Health Needs Formulation.

These domains of inquiry are:

1. Community understandings of health
2. Essential health needs of the community
3. Social determinants of health
4. Roles and responsibilities of relevant leaders
5. Community participation in decision-making

TABLE 3-3 *GO4HEALTH*'S GLOBAL, BUT NOT REPRESENTATIVE REACH WITH MARGINAL COMMUNITIES

Research hub	Country	District/municipality	Communities
BRACU	Afghanistan	Paghman Qarabagh Kalakan	Conflict area, rural
UQ	Australia	Queensland	Rohingya refugees Karen refugees Urban (Indigenous) Migrant (Samoan)
BRACU	Bangladesh	Bandarban Habiganj	Tripura (indigenous) Mro (indigenous) Wetland
CEGSS	Guatemala	Santa Maria Nebaj Tecitán	Indigenous, rural High rates of poverty (non-indigenous)
BRACU	Philippines	Maguindanao	Conflict area, high incidence of poverty
CEHURD	South Africa	Eastern Cape	Rural, with high rates of poverty, HIV, adolescent pregnancy.
CEHURD	Uganda	Gulu Buikwe	Conflict-affected HIV-affected people LGBTQI[22] Older persons
UQ	Vanuatu	Efate Tanna Espiritu Santo	Small Island State, vulnerable to climate change consequences.
CEHURD	Zimbabwe	Goromonzi Chitungwiza	Poverty High rates of HIV

Our thematic approach and decision to use a qualitative research methodology is increasingly popular in HPSR and especially appropriate for multi-disciplinary health research teams,

[22] Lesbian, gay, bisexual, transgender, queer, intersex persons

referred to by Gale and colleagues as the Framework Method. This is a flexible tool that can be adapted for use with qualitative approaches aiming to generate themes—in this case, the 5 domains of inquiry acted as our analytical framework, providing a structure for collecting large amounts of data from a variety of contexts. The Framework Method is similarly useful in summarizing and reducing the data in a manner that could provide answers to our inquiry and subsequently meet our work objectives.

Flexibility was permitted, necessary, and key in carrying out consultations successfully. The study design allowed for contextualization—as mentioned above, for each regional hub to use its own methodology while maintaining the systematic approach of the Framework Method. This entailed specific procedures for analysis that included: 1) transcription, 2) familiarization, 3) coding, 4) developing a working thematic framework, 5) applying the framework, 6) charting the data into a framework, and 7) interpreting the data. As part of WP2, each partner delivered reports to the coordinating institution[23] organised thematically, based on the initial study design.

The uniqueness of each of WP2's community consultations lent an extraordinary diversity to *Go4Health*'s output, which informed the mandate for global health while also making important contributions to wider policy discourse around the SDGs (Ibell et al. 2015; Hussain 2014; Brolan et al. 2014; Ruano et al. 2014; Sheridan et al. 2014; Baba, Brolan, and Hill 2014; Mulumba et al. 2014). The flexibility of WP2's research protocol and study design allowed my team at BRACU to use our experience and knowledge of the Asian region to carry out consultations in an effective and meaningful way.

Led by a Principal Investigator, Dr. Timothy Evans, later succeeded by Dr. Sabina Faiz Rashid, our core research team was based at the James P Grant School of Public Health, BRAC University. I worked closely with our NGO partner, BRAC, gaining from the research expertise of their Research and Education Division through research associate Atiya Rahman (whose background is anthropology) and Dr. Hashima E Nasreen, who has extensive experience conducting household-level health surveys. For each country consultation, we were supported by a team of 10 research assistants with qualitative research experience.

[23] Georgetown University, please see Figure 3-1 for WP2 institutional relationships.

Together with my team, I received senior oversight by the PIs and a reference group made up of public health experts and academics with significant field experience in Bangladesh and throughout the global South. The members of the group were the PIs of the project along with, Dr. Alayne Adams, Dr. Malabika Sarker, and Dr. Syed Masud Ahmed. As coordinator of the BRACU team, I undertook a substantive role in the WP2 study protocol and design, and under the supportive supervision of BRACU's reference group, led the study from its inception until December 2014.

I led, conducted, and managed data collection and analysis from January 2013 until December 2014. Both BRACU and the *Go4Health* coordinating institution, ITM approved my use of data collected from the Asia region's community consultations, which I conducted in three countries: Afghanistan, Bangladesh, and the Philippines. Upon ending my work contract with BRACU in December 2014, I continued my involvement with the work of WP2 through the University of Toronto until the *Go4Health* project ended in February 2016. From my enrolment as a PhD candidate at the University of Queensland, I had another layer of academic supervision,that bridged the interface between the *Go4Health* research and my own research agenda.

3.2.3 **Population sample**

I conducted research in communities in 3 countries on behalf of BRACU: Afghanistan, Bangladesh, and the Philippines. My site selections were based on the guidance of both the *Go4Health* protocol as well as those of my BRACU supervisory reference group. First, the communities we would select must meet the definitions of marginality and community to satisfy WP2 research protocol I helped develop. Because BRACU is situated in the global South, where many communities are marginalised as a result of multiple processes of exclusion, and because we were constrained by resources and time to ensure the most marginalised people would be heard, we utilised a conceptual framework for further refining our selection of a population sample.

As discussed in Chapter 2, PROGRESS+ is an acronym for place of residence, religion, occupation, gender, 'race'/ethnicity, education, socioeconomic status, and social networks and capital, a framework for examining gradations in health in populations, and has been used successfully for targeted public health interventions (Evans and Brown 2003; O'Neill et

al. 2014). My BRACU reference group directed me to utilise this framework to consider populations in BRAC's program areas within Asia. This would help us examine the different categories by which communities are marginalised, and subsequently identify which of those communities are excluded by dominant society through more than one category. In doing so, we could identify communities that are marginal, but just as importantly, those with whom we had existing relationships. This would provide us with practical access and entry into communities that may otherwise be mistrustful of outsiders, and also have a respectful and meaningful consultation because our partners' presence is acceptable to them. The final definition we arrived at:

> *"Those whose voices are typically not heard locally or globally, and/or whose health was most threatened, and/or who are at risk of premature death, and/or who do not have any fixed places for living, and/or who were living in a place where natural calamities occur frequently (which in turn results in a higher rate of mortality) and/or accelerates the vicious cycle of poverty"* (Hussain et al. 2013)

In the matrix below, based on the literature and on previous institutional contact, I have outlined the characteristics of the communities that contributed to the BRACU selection as marginalised communities. While strongly supported within BRACU, the limitations of the PROGRESS framework were challenged in discussions within WP2, and its failure to accommodate disability and sexual identity were issues of particular concern. We recognised the limitations of attempting to represent marginalisation across four continents—we were unable to engage European experience—and ensured that all the dimensions of marginalisation that we had identified, including disability and sexual identity—were accounted for in the total set of case studies undertaken by the WP2 partners. Over 10 case studies undertaken globally, this allowed WP2 to represent insights into the full spectrum of marginalisation, but with the each specific case study revealing the complexity of its own experience.

TABLE 3-4 PROGRESS AND COMMUNITIES FOR THE BRACU CONSULTATIONS

Place of Residence	Kabul province, Afghanistan	Chittagong Hill Tracts, Bangladesh	Autonomous Region in Muslim Mindanao, Philippines
Religion	Muslim	Krama Christian Animist	Muslim/Moro Episcopalian
Occupation	Farmers Teachers Midwives Unemployed Students	Farmers Weavers Traditional healers Day labourers Students	Day labourers Unemployed Traditional healers
Gender	Women have little/no education, worst MMR in the world	Women share in agricultural work, also responsible for care of children and older persons	Women responsible for child care
Race/ethnicity	Pashtun	(Indigenous) Tripura Mro Marma	Moro Indigenous groups Settlers from north
Education	No or little education for most; particularly women	Some people are literate, have high school education	Some people literate
Socioeconomic status	Poverty widespread	Poverty widespread Militarization has caused displacement	Widespread poverty Low social status
Social networks and capital	Strong family networks, relations with local leaders important	Traditional community networks are very strong; weak links with national systems	Links with national systems are choppy, local networks are clan-based

3.3 A Study Within A Study: Methods For This PhD

3.3.1 **Paradigms and tensions**

Methodology scholars agree that research is best conducted by identifying the researcher's stance toward the nature of social reality (Grix 2004, Creswell 2007). My view of reality is that it is constructed, and is contingent on perception and social experience. Charmaz (2003) argues that reality is constructed by individuals as they assign meaning to the world around them. That is, reality is subjective, and individuals and groups make sense of situations based upon their individual experience, memories, and expectations. Here, the researcher is a transformative intellectual who is an advocate and an activist (Guba and Lincon 1994, Mills et al 2006).

Understanding people's perceptions is the crux of this study, and in order to do so, I employed a qualitative approach. In contrast with the *Go4Health* study, which applied a Framework Method to answer its research questions, I used their framework to provide an initial platform for a structured approach, but then pursued a naturalistic inquiry and employed a grounded approach in exploring my own research.

3.3.2 **Country case studies**

My PhD focuses on the experiences of communities in Bangladesh and in the Philippines. I employed a case study approach for each country, and used the same methodology for the two. Some allowances for contextualization became necessary due to the unique social, economic, environmental, and historical contexts in each study and these have been documented. Though I had the option of including the research from Afghanistan for this PhD, issues of security and access to community constrained the extent to which that study was suitable for the purposes of this thesis. In Mindanao and the Chittagong Hill Tracts, there were visible parallels from the outset: both regions have some autonomy from their national governments, both are largely populated by indigenous peoples, both have had and continue to be sites of internal conflict and a heavy state military presence.

3.3.3 **Research teams**

I led a core research team comprised of three people: myself, Atiya Rahman, a Research Associate and co-Research Investigator, and a Research Assistant, Arifonnessa Jany. We

received further support from Research Assistants who did active field research in Bangladesh and in the Philippines. Further detail on members of the in-country research teams and their positionality (including ethnic and linguistic abilities) is available in the case studies.

3.4 METHODOLOGY

I employed a qualitative methodology to fulfil the objectives for this PhD, outlined in Table 5 below. A more detailed description of the sites and methodological approaches to each case study is included in each of the chapters dealing with the country case studies. In this chapter I present the broad methodological approach that underpins the thesis as a whole

The essential methods employed in this study are:

- Literature review and documentary analysis;
- Interviews;
- In-depth interviews with key informants;
- Informal interviews;
- Focus group discussions;
- Participant field observation;
- Reflexive analysis;
- Systematic review of the products of *Go4Health* research.

TABLE 3-5 METHODS EMPLOYED FOR FULFILLING STUDY OBJECTIVES

Objective	Method
1(a) Examine understandings of marginality	• Literature review
1(b) Examine the factors contributing to marginalisation	• Literature review
1(c) Examine theoretical explanations and responses to marginalisation	• Literature review
2(a) To explore the experience of marginalised communities in **Bangladesh**, with specific reference to their perceptions of health and health needs.	• In depth interviews • Focus group discussions • Key informant interviews • Informal interviews • Field observation
2(b) To explore the experience of marginalised communities in **the Philippines**, with specific reference to their perceptions of health and health needs.	• In depth interviews • Focus group discussions • Key informant interviews • Informal interviews • Field observation
3. To review the representation by G4H of the voices of the marginalised in Bangladesh and the Philippines in the post-2015 discourse	• Systematic review of *Go4Health* products from WP2

3.4.1 **Review of the literature**

To guide my search for the literature, I identified concepts that first need clarification, then proceeded to search for English language articles from academic literature as well as non-conventional or grey literature. In addition, I drew from my work with *Go4Health*'s WP2 literature review of a selection of research methods for community consultations. I continued literature review throughout the course of this thesis project. Articles, books, and grey literature were important for triangulating my observations and findings throughout my studies, and I have used these in the chapters as references and supporting materials.

3.4.2 **Interviews**

The research used a range of interview techniques: key-informant in-depth interviews and focus group discussions adopted a more structured approach, building on the prescriptive question lines developed in conjunction with the WP2 researchers, but allowing for further extension of enquiry depending on the context. In addition I sought opportunities for informal

discussions, that clarified points made in the semi-structured interviews, documenting these in my field notes.

3.4.3 **Interview tools**

My research team and I developed interview guides in accordance to the WP2 protocol (see Appendix C). Questions in the guides corresponded to 5 domains of inquiry prescribed by the *Go4Health* project: community understandings of health; the essential health needs of communities; community perceptions around social determinants of health; the roles and responsibilities of relevant actors in ensuring community health; and community participation in decision-making processes. I developed the initial interview guides as part of a *Go4Health* working group.

A common methodology in qualitative data collection, semi-structured interview guides, allow interviewers the ability to ask open-ended questions, and to follow topical trajectories. I employed this technique to allow for probing into issues to enrich the data collected for the *Go4Health* project, satisfying project requirements and adding nuance with locally based knowledge. These semi-structured interview guides were at the core of all In-Depth Interviews (IDIs), Focus Group Discussions (FGDs), and Key Informant Interviews (KIIs) in this study.

My colleagues and I tested the interview guides by conducting FGDs, IDIs, and one KII. We tested the tools in an urban slum close to our office. Following a team debrief during which we discussed in detail the appropriateness of the questions to which we sought answers, we refined and re-designed the interview guides to pointedly remind interviewers to ask probing questions, particularly around understandings of health, and roles and responsibilities of relevant stakeholders.

3.4.4 **Population sample and interview techniques**

Four types of respondents participated in this study. The first, whom I refer to as “community people” throughout this work, are the general community, or lay people. This respondent group forms the majority of study participants: in total, we conducted 17 focus group discussions (FGDs) with community people. Each FGD consisted of 5-8 people in homogenous groups separated by age and gender.

For the second respondent group, I use the term “local leaders” to refer to community members who hold or adopt leadership roles. This includes leadership in both formal and informal institutions, where one might be considered a leader in a traditional hierarchy by their community, but may not be recognised as such by the rule of law in their country. We consulted local leaders through the use of in-depth interviews (IDIs).

Finally, the third respondent group consists of “health providers” who hold knowledge or expertise around community health that is not easily found among (lay) community people. These are a wide range of people who work in health provision and health services in both the informal and formal sector, such as community-based health workers, nurses, midwives, doctors, and staff at service delivery organizations. We conducted in-depth interviews (IDIs) with key informants from the provider category to gain insights into the community’s health needs, priorities and their understanding of their health entitlements.

A fourth group of respondents consisted of those working with the communities, but not part of the communities—NGO staff and government officials whose perspectives were useful in triangulating the data offered by the community respondents but clearly differentiated from community perspectives for the purposes of this study.

3.4.5 **Interpretation**

Interviews with lay community members were conducted in the language of their choice. This was necessary because many respondents’ first language was not the dominant one in their country. This meant that many interviews required research team members to speak the local language. In cases where interviewers were not able to speak the language, interpreters were recruited, with the assistance of local institutional partners. Interviews with key informants were conducted in a language familiar to the interviewer and did not require the assistance of interpreters.

3.4.6 **Modifications**

Due to externalities, modifications were sometimes made throughout the course of this study. Some examples are: delays in the commencing of field research due to medical reasons, militant activity, and political unrest at study sites that caused risk to the personal safety of researchers. These are discussed further in the context of the country case studies in Chapters 4 and 5.

3.4.7 **Participant field observation**

In both Bangladesh and in the Philippines, I participated in all field research. When I did not conduct interviews, I participated as an observer, taking note of my surroundings, social interactions between people (and their interactions with me and my research team).

3.5 SYSTEMATIC REVIEW OF *GO4HEALTH* LITERATURE

For this component, I identified *Go4Health* products in open access literature to conduct an analysis of the voices of marginalised voices from WP2 that entered into the larger literature accessible to the global public. These include peer-reviewed literature around *Go4Health*'s community consultations, *Go4Health*'s public reports, and the consortium's contributions in the UN post-2015 consultations. Further detail is provided in Chapter 6.

3.6 ETHICS

3.6.1 **Approval**

This study was approved by the ethical review committee of James P Grant School of Public Health at BRAC University prior to consultations with communities (see Appendix A). Since my enrolment at the University of Queensland in July 2013, I obtained expedited ethics clearance from the School of Public Health Research Ethics Committee after UQ authorities received confirmation that I had permission from BRACU to use data collected from the *Go4Health* project (see Appendix B).

3.6.2 **Informed consent**

My team and I provided detailed information about the study to community leaders and all study participants verbally. The conduct of interviews took place only after obtaining verbal informed consent, which we sought in such a manner due to the low literacy rate in the communities. To ensure that each individual was fully informed, we described the nature, duration, purpose and methods involved in the research. All individuals who participated in this study gave their voluntary and autonomous consent to participate. The details we provided to study participants included:

- The title of the project
- The purpose of the study
- The expected duration of their participation in the study
- A clear and precise description of procedures for their involvement

- The name and contact details of an appropriate person to answer further questions concerning their involvement in the project

3.6.3 **Compensation**

No participant was offered or received compensation for their participation in the study. It is customary throughout Asia to provide light refreshment during group discussions and meetings, and accordingly, this was done.

3.7 LIMITATIONS

With the global discussion on the post-2015 agenda on a trajectory mapped out by the UN, I was constrained by project deadlines to complete and report to *Go4Health* on the consultations so as to make contributions of significance to the larger discourse. Ideally, engaging with and consulting with communities is a time-intensive undertaking where a relationship of mutual respect and trust must be established first. The role of intermediaries is an important one in this dissertation: first, BRAC's wide reach enabled the conduct of this research, allowing my team access and entry to marginalised communities. The work of interpreters and translators have been crucial in providing me access to community members' views in a language I can understand. However, translation may bring with it a loss of information and translator biases due interpretation and assumption (Temple and Young 2004; Easton *et al.* 200; Oliver *et al.*, 2005). Finally, researcher bias is a consideration that could be a limitation in this work.

My use of a case study format to present findings from research in each community is intended to provide a sense of how communities perceive health and the extent to which they feel their health needs are being heard and met. The case studies bring to the fore community narratives around health in their own voices. While these case studies do not purport to be comprehensive ethnographies, the layering of data from multiple methods and informants, the relationships established through BRAC support, and the triangulation with diverse available sources does provide a "thick study" of the experience of these communities, and their imaginings for the "*World We Want*" to be articulated in the post-2015 agenda.

3.8 Access And Brokers

My affiliation with BRACU and BRAC enabled me to gain access to the communities I consulted with for this study. For the Bangladesh case study, I had strong links with a local NGO that I worked with previously with, and because of its positioning, is highly regarded and trusted by communities in the Chittagong Hill Tracts, the region of Bangladesh where indigenous communities make up the majority of the population. The partners were happy to work with me again and helped my team build rapport with community leaders through face-to-face introductions, who in turn allowed us to enter their communities and speak to the women and men among them.

In addition to issues of power where the presence of multiple brokers in the process of consultation—community enablers, interpreters, interviewers, transcribers, and translators—raises questions around how community voice can be truly heard.

3.8.1 **Researcher positionality**

Hill and colleagues (2010) examined the ways in which researchers examine their own identities in relation to the research and commonalities and differences in researchers' own cultural backgrounds and migration histories, identifying its engagement with the research process itself and the insights provided. Cross-cultural research brings with it both challenges and opportunities for learning for my role as researcher with a third culture identity. Researchers of social science posit that visible markers like gender and 'race', as well as other ones that become apparent through interaction—such as socio-economic and education status—result in a dynamic that can influence both the research process and its outcome (Weiner-Levy 2009). With my research nested with the *Go4Health* project, my identity was multidimensional—as a Bangladeshi researcher based in Dhaka, representing a large and well-known NGO, but also as an internationally educated Canadian[24] of a visible minority. My identities as a Bangladeshi-born Canadian, cisgender woman, and secular Muslim, all became significant in rapport building with study participants at different stages of the research process.

As a daughter in an expatriate Bangladeshi family, I have experienced racism in both places where I spent my formative years—the United Arab Emirates and in Canada. In Abu Dhabi,

[24] My formative years were spent in Montreal and Ottawa.

people of South Asian origin are referred to by the dominant majority as *miskeen* or poor, an allusion to the minimal pay of Bangladeshi, Indian, and Pakistani migrant workers in the construction[25] and domestic services industry. This is a term I became very familiar with in my interactions with local children. As a new immigrant in Canada, I experienced racism in numerous ways: being treated disrespectfully at a doctor's office, treated rudely by and also experiencing direct violence within the public education system, in the form of verbal abuse around my cultural identity by other students, with my house in a predominantly White neighbourhood on several occasions vandalised with eggs. In a society dominated by people of European ancestry, my experience with racism and discrimination was in tension with my cultural and religious identity as a Bangladeshi Bengali Muslim—as a result, my experience within my minority cultural group in Canada was one where I was expected to conform to the gender norms prescribed by the Bangladeshi and Muslim diaspora. On one hand I was victim to discrimination as a middle class immigrant, and on the other, where my family's efforts to preserve my cultural and religious identity led to an arranged marriage to a member of my socioeconomic group in Bangladesh, conforming to Bengali Muslim social norms and structures. These tensions of identity and difference have resulted in my interest in ethnicity, marginal groups, issues around agency, and structural violence—that identity is temporally and spatially fluid, and that stereotypes influence "othering".

My positionality as a researcher "others" me due to relationships of power among researchers and the "researched". During field research for this study, at different times, my gender, ethnic identity, religious identity—however representations of my identity were not always within my control—some are obvious due to my appearance and in my manner of speech. People often expressed their curiosity, both subtly, and more often, asking me about my religion or accent. Identified as a Muslim, a shared identity with the study participants in the Philippines allowed me to temporarily and partially inhabit the space of an insider (however I did not seek to promote that aspect of my identity). In the Philippines, where Muslims are a minority, I was warmly welcomed by community members in the Autonomous Region in Muslim Mindanao (ARMM) when I responded to their questions around my religious beliefs. In Bangladesh, the case was slightly different—my identity as an ethnic Bengali allowed me access into a militarised zone controlled by state forces who are largely Bengali Muslims. But being clearly identified as a Bengali, identifies me with the dominant culture, which may be

[25] A construction boom in the 1970s and 1980s brought my father, a civil engineer, to the United Arab Emirates.

reflected in the limited responsiveness of study participants, who, as recorded in Chapter 4, were largely silent around issues of racism and discrimination, which are well documented in the larger literature.

In both areas of study, my identity as a mother was important in building rapport with midwives and other mothers. As someone who is sensitive to issues of identity, my journey as a researcher has been transformative through introspection, both professionally and viscerally. My employment with BRACU may sometimes have confused study participants to think that because of the apparent links with BRAC, a large international NGO, may have led them to believe that some benefit could be gained for their communities (even though it was articulated otherwise, in the informed consent component prior to interviews and consultations). In the Philippines, where BRAC did not have any health interventions, some respondents asked me whether we would consider implementing a health program.

Finally, at both professional and personal level, my trajectory as a researcher from September 2012, when I became involved with this work until present, has been a transformative one. By no means have I experienced the unjust and violent conditions that participants in this study have been subjected to, but at some level, I am familiar with the experience of racism and a sense of limited agency within structures that are intended for the preservation of the powerful. This is something that I have noted throughout my research journal writing as well as personal correspondence and informal discussions with other researchers, and, in addition to being addressed in this chapter, is also mentioned in Chapters 4 and 5. My intermediary role in raising the voices of the marginalised enabled me, in many respects, to raise my own.

3.9 Data Handling

The data for this PhD were generated through the use of interview tools that I designed and tested with my team. I recorded my personal field observations and maintained a research journal for the duration of this work, which I consulted for triangulation.

3.10 Transcription

Transcription, the transference of spoken language, with its particular set of rules, is an integral chore in qualitative data collection (Oliver et al., 2005). Transcripts represent the data base on which researchers rely, to then examine, evaluate, sort, copy, and quote and is a

process of representation, and consists of complexities that require attention (Mero-Jaffe, 2011, Davidson, 2009).

Many scholars describe the constraints and opportunities in transcription (Poland and Pederson 1998; Sandelowski 2000; Davidson 2009), and all agree that naturalised transcription, that is, transcription that pays attention to the conversation—noting any silences, interruptions, laughter, must be marked and analysed carefully. This is especially important for this study because its purpose is to study—the communities in focus are already marginalised, and great care is needed to avoid gaps in raising their voices.

Traditionally, the most up-to-date technology is used for transcription, and accordingly, I ensured that all interviews were recorded on MP3 devices. We divided into research teams of 2 people for each interview, with one person asking questions while the other acted as a note-taker and looked after the audio recording. Each interview was transcribed within 24 hours of its conduct. These were then triangulated with research notes taken at the time of the interview by each researcher pair. I received all hard copies upon their completion and photocopied them for backup purposes.

3.11 TRANSLATION

Qualified professionals translated interviews conducted in a language other than English. For the Bangladesh study, interviews with community people were conducted and transcribed in Bengali. The original interview transcripts were then translated into English for analysis purposes.

For the Philippines study, interviewers translated and transcribed the content of interviews directly into the English. Their working language proficiency and previous research experience allowed them to produce translation and transcription of high quality. I checked every interview. In the event of gaps in understanding the work, I returned transcripts to translators for clarification.

3.12 Data Management

Upon the submission of each interview transcript, photocopies were made to ensure a back-up copy would be available in the event of a loss of the original. Only original transcripts were provided for translation into English, and copies were retained as back-up.

I prepared and maintained a spreadsheet to track every transcript, documenting the following information:

- interview/transcript identification code
- date and site of interview
- names of interview team (interviewer and note-taker)
- language of interview
- date of transcript submission
- date of transcript sent to translator
- name of translator
- date of translated transcript received

3.13 Data Analysis

I conducted data analysis for this dissertation in 2015, after the fieldwork for the *Go4Health* project had ended. I returned to the data and read through each transcript carefully to obtain a sense of its whole. For each constellation of words or statements that relate to the same central meaning in each transcript, I considered as a unit of analysis, which I refer to as codes (Graneheim and Lundman 2003). I then entered the codes into a Word document, which I manually divided into categories, considering the context of the study sites and population sample while doing so. Upon completion of that step, I proceeded to enter information into a table, organizing the categories and codes for careful review. I shared and discussed these categories with my advisors, Dr. Labonté and Dr. Hill, who examined my categorizing for reliability. Finally, I identified the emergent themes in each country data set. The final findings presented in this dissertation are my own interpretation, distinct from those of the *Go4Health* project.

3.14 Research Quality

Rigour in research – that is, its trustworthiness – is a literature unto itself, and some of the important quality criteria that scholars agree on as the gold standard include those outlined in

the table below. Khayatzadeh (2009) illustrated this using a table based on Lincoln and Guba's (1985) ground-breaking work on qualitative research. Several categories have been agreed by scholars, but as some argue, "getting it all right" is an unrealistic aim, rather research conclusions should avoid "getting it all wrong". To ensure rigour, I used five categories, noted in the table below (Braun and Clarke's work well with Miles and Huberman's discussion on standards for the quality of conclusions).

TABLE 3-6 MEASURING THE QUALITY OF THE RESEARCH

Category	Purpose	Recommended techniques	Application for this study
Objectivity	Refers to the explicitness about the inevitable biases that exist; that is, ensuring that conclusions are drawn from the subjects and conditions of inquiry.	Reflexivity External audit	Paradigmatic information and researcher positionality articulated at outset.
			One case study was published by an international peer-reviewed journal.
Reliability	Deals with consistency of the study over time, methods, and researchers. This focuses on methodology and the possibility of generating the same results when the same measures are administered by different researchers to a different participant group. The intention here is to minimise bias but qualitative researchers acknowledge their influence on the research process and knowledge produced.	Detailed documentation Data checks External audit	Detailed information around methods provided, based on initial study design and research notes, indicating any modifications.
			Study successfully replicated among 3 population groups with modifications for context[26].
			Engagement and feedback with *Go4Health* and thesis advisors to ensure reliability.
Internal validity	Refers to the credibility of the findings, of whether there is an authentic portrait through a process of checking, questioning, and theorising that is internally correct and rings true to the people studied as well as to the reader.	Prolonged engagement Fact-finding visits Peer debriefing	Lived experience in Bangladesh and work with BRACU enabled me to become familiar with the health system and research context.
			My network partners in both countries of study had longer term engagement with study

[26] This research design was applied to gather data from marginalized communities in Afghanistan, Bangladesh, and the Philippines.

Category	Purpose	Recommended techniques	Application for this study
	Also refers to whether the research demonstrates what it claims to demonstrate.	Triangulation Member checks	participants through development programs.
			Formative research was completed prior to fieldwork.
			Each day of fieldwork was concluded with team debriefs to check, question, discuss, and address concerns with the research.
			Triangulation was completed through interviews with key informants, reviewing existing literature, and field observations.
			Member checking was completed following data analysis to confirm accurate representation of findings.
External validity	Also termed as generalization, which scholars postulate can refer to three levels – first, sample to population, analytic, and case-to-case transfer – and entails careful interpretations for broader applicability as well as comparison.	Purposive sampling Thick descriptions	Selection of communities with similar contexts.
			Detailed account of experience, noting social and cultural phenomena are present in the findings. The analysis locates the similar, different, and transferable.

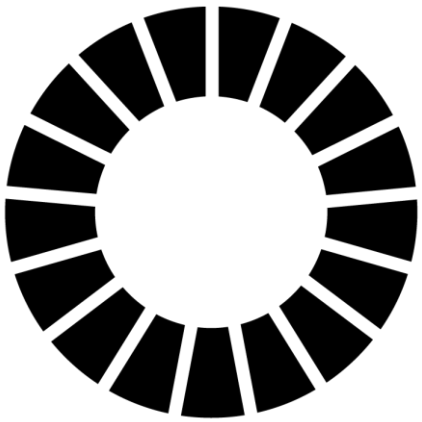
Category	Purpose	Recommended techniques	Application for this study
Utilization	Refers to the usefulness or value added of the research, for instance, what it does for the researched, the researchers and for its consumers.	Knowledge-driven dissemination Action-oriented dissemination Policy-driven dissemination	Portions of this work has contributed to the field of global public health in the form of journal articles and invited workshop and conference presentations.
			Partner NGO BRAC intends to use information from this study to refine their development programs to better suit the work with marginalised communities.
			This work is tactical in that the timely research has contributed to the global political discourse on human development.

Sources: Miles and Huberman, Creswell, Lincoln and Guba (1985), Braun and Clarke, Sandelowski, Weiss, Khayatzadeh

3.15 SUMMARY

The study that I designed and developed employing methods in this chapter was nested within an international multidisciplinary project. One component of the project was to gather the voices of marginalised communities, and my own positioning within the consortium (as a partner) and outside of it (as a PhD student) provided me with a unique opportunity to access marginalised communities, to hear what communities have to say about their lives and health conditions, and also to learn about how they are heard at a global level. My epistemological stance for this work is unapologetically post-constructivist; my values are as inextricably tied to the research as my personal identity, and the methods deployed for these case studies are reflected as such.

An overview of the countries of the study sites provides the reader the context within which each of the communities that participated in the study are subjected to processes of exclusion. In the forthcoming chapters, these phenomena are described in the study participants' own words in the forthcoming chapters, followed by an examination of the intermediaries' role that answer the research question "How can the marginalised be heard in a global health agenda?"



CHAPTER 4

Bangladesh case study

4.1 INTRODUCTION

This chapter presents the findings of my research with marginalised communities from the Chittagong Hill Tracts of Bangladesh. In their own words, they share their sense of their own identity and history, their understandings of health and wholeness, and a desire for change that is both meaningful and respectful of their unique identity. These three themes are further supported by the people who serve the community, with knowledge and expertise around the communities' health and well-being. This chapter is the product of two distinct processes: its primary function was to meet the project requirements for *Go4Health*—providing a base for formulating Essential Health Needs into global health discourse. But undertaking that task provided a space for open questioning that allowed me to satisfy one of the core objectives of my PhD: to engage with communities to explore their experience of marginality and the perceptions on health. In this chapter, communities in Bangladesh place emphasis on identity and how it shapes their life and everyday experience, including health, the health system and its responsiveness to their needs, and finally, the communities' perceptions on the way forward for a healthier and fairer life.

This research is a case study nested within *Go4Health*, with a prescribed framework for managing and analysing data to create consistency across the multi-country study. The *Go4Health* framework consisted of five overarching domains, developed collaboratively in Work Package 2 (WP2) meetings to ensure consistency between case studies: understandings of health, essential health needs, determinants of health, roles and responsibilities of relevant stakeholders, and community participation in decision-making processes. These have been critical in bringing to light how communities define health, the kind of care and services they access, and who they perceive as responsible for addressing and ensuring their health needs. This chapter presents new and additional information from indigenous communities of Bangladesh, for whom, as discussed in Chapter 6, *Go4Health* acted as an intermediary in bringing their voices to global health discourse. The complexity of these people, and the host of social and structural issues that contribute to public health become clear in the passages that follow. Rich detail becomes available to us when we search deeper into the data, the evidence that they have volunteered beyond the circumscribed responses to the *Go4Health* questions, and we discover the interconnectedness of different aspects of daily life,

which affects experience of the health system. My own analysis includes my own field observations as an outsider, looking in. It takes into account what is said by the community members and their service providers, but also what they do not say—particularly their resonant silences around well-documented human rights abuses that have shaped these communities.

4.2 METHODS

4.2.1 **Setting**

Bangladesh is a lower middle-income country with a total land area of 130,170 km^2, and a population of 159 million (BBS 2015). A small minority, indigenous groups, account for 1.1% of the population with most of them settled in the Chittagong Hill Tracts. Located in the extensive hills of the southeast region, the CHT cover 10% of national land, or 13,294 km^2, and consists of three districts: Bandarban, Khagrachuri, and Rangamati (D. Roy 2012). This is an area with mountainous terrain and dense jungles with limited arable land and downstream sources of water. The CHT region was ceded to the British colonial rulers of Bangladesh (then known as Bengal) and officially annexed the CHT in 1900. Its status as an excluded area persists today in the form of a semi-autonomous government. The CHT Regulation of 1900 is the basis of the legal and administrative system of the region, despite significant political change in the country (R. C. K. Roy 2000).

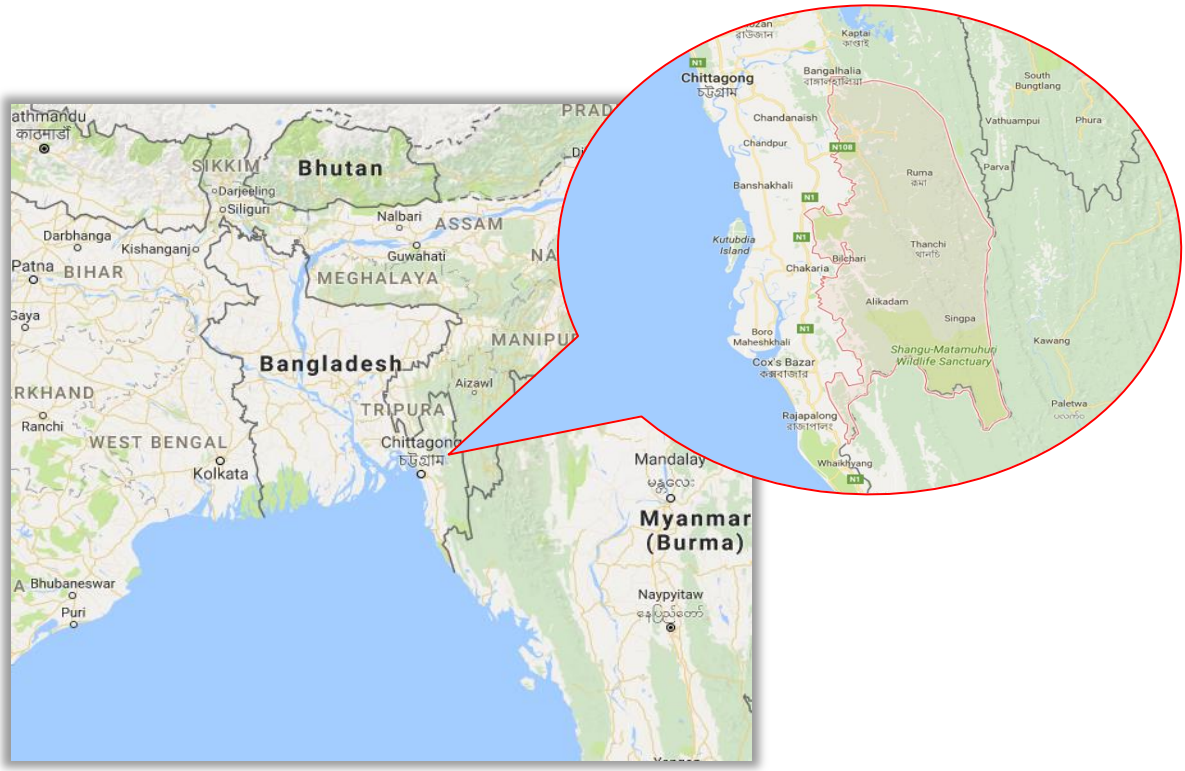


FIGURE 4-1 MAP OF BANDARBAN, CHITTAGONG HILL TRACTS, BANGLADESH

The CHT are home to around 11 indigenous groups, each with unique ethnic, linguistic, and cultural attributes. All three of the districts are post-conflict areas that were ravaged by over 25 years of civil unrest, which ended with the 1997 CHT Accord, sometimes also known as the Peace Accord. In it, the CHT are further recognised as a separate area—the term *separate* gives rise to the local word *para* to describe clusters of indigenous communities—that has its own acknowledged cultural and land rights that specifically target the indigenous groups. Locally, traditional governance structures are recognised and the area has been given greater autonomy, and a regional council. However, the Peace Accord has been largely unimplemented and indigenous communities continue to be subject to ongoing militarization and human rights abuses (R. C. K. Roy 2000; D. Roy 2012; Chakma and Dhana 2015).

Out of all three districts, Bandarban is the most remote and least populated district, not only of districts in the CHT but also in the country. Of the total population of 400,000 inhabitants, over half belong to one of the local 8 ethnic groups: Marma, Tanchangya, Chakma, Tripura, Khyang, Bawm, Rakhaine, and Mro (D. Roy 2012). The remaining population is made up of Bengali settlers, who arrived as part of transmigration programs in the 1960s and 1970s that promised land grants, cash, and rations endorsed by the government to encourage nationalization with the purpose of diluting

and displacing the diverse ethnic identities of the district (Chakma and Dhana 2015). Studies have shown that the Bengali people of Bandarban have regular access to public services and utilities, and routinely have better outcomes in terms of social, economic, educational, and health indicators when compared to non-Bengalis. In regards to government organization in Bandarban, this district has a semi-autonomous government that co-exists with local traditional systems. The rest of the country has a centralised national system of governance. There are 7 *upazilas* or sub-districts in Bandarban, within which there are 30 unions, the smallest administrative units in the national governance structure. In addition, the traditional governance system of the CHT is recognised: within that system, Bandarban has 98 *mouzas* or revenue units and a total of 1554 *paras* or villages (Barkat et al. 2009).

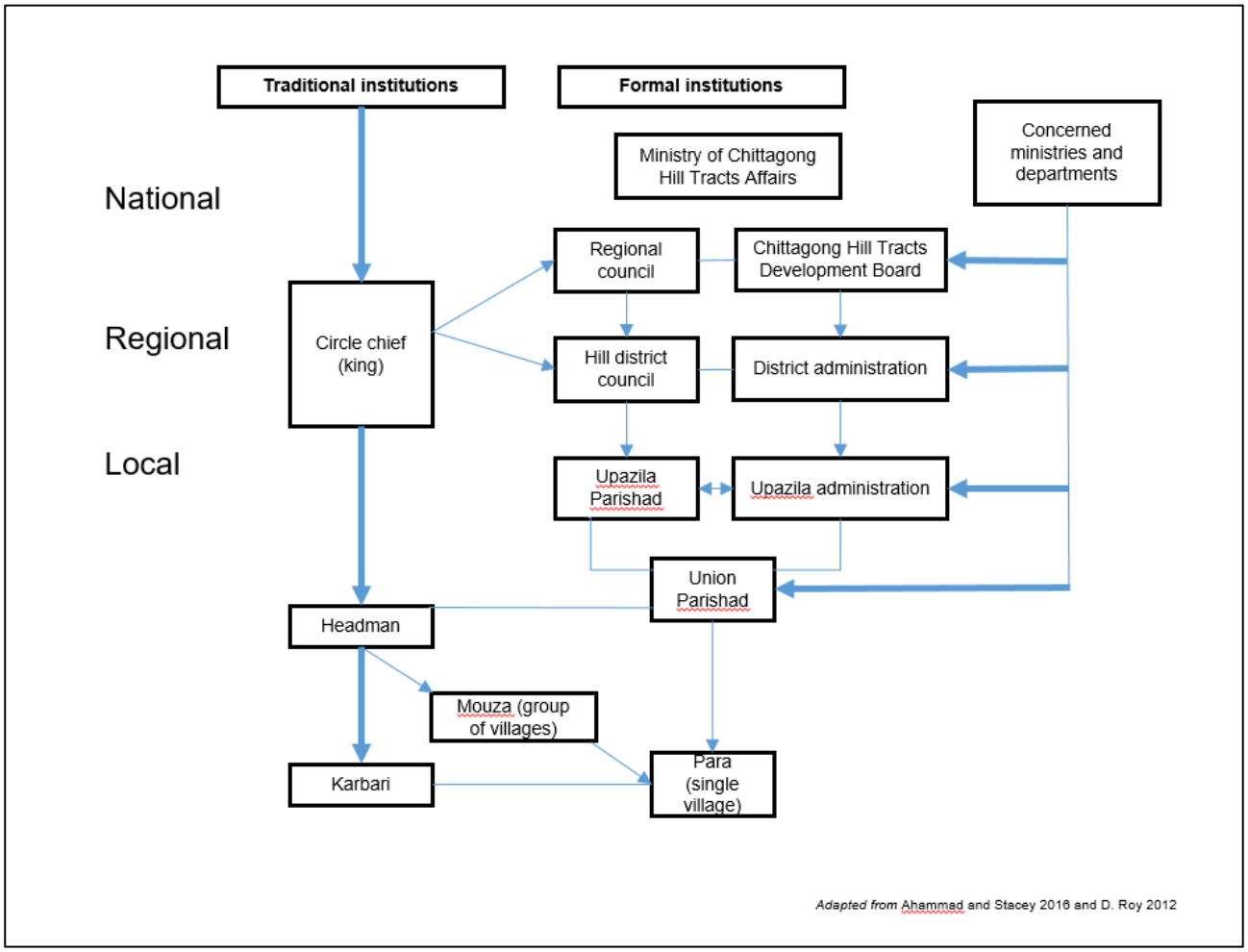


FIGURE 4-2 TRADITIONAL AND STATE INSTITUTIONAL STRUCTURES IN THE CHITTAGONG HILL TRACTS

The CHTDB, responsible for the infrastructure and socioeconomic development of the region, is comprised of government officials and representatives. Linkages with communities are maintained through consultative committees that include the Circle Chiefs, executive officers of the Bandarban, Rangamati, and Khagrachuri Hill District Councils.

Religious missions have operated in the area for many years, providing limited services, and continue to do so today. Following the CHT agreement in 1997, a number of NGOs began to deliver development services in Bandarban. These NGOs are highly regulated by the government and operate in partnership with the national government and international donors in efforts to develop the region (Barkat et al. 2009; R. C. K. Roy 2000).

The public health system in Bandarban is governed and operated as in the rest of Bangladesh. Services are delivered through facility-based and community-based services. There is a vibrant private sector that consists of services delivered through non-government organizations (NGOs), faith-based organizations; individual drug sellers, homeopaths, traditional healers, and traditional birth attendants (TBAs) are also available in town and sometimes within the communities. Public health service outreach is organised by the Ministry of Health and Family Welfare (MoHFW), which follows the nationalised standard for service delivery, but is often of limited quality and lacking in accountability (Mahmud 2009). The district hospital is located in Bandarban's single urban centre, the town of Bandarban. There are also 7 sub-district health complexes located in each upazila, and 27 community clinics that provide public health services. The community clinics are the first point of contact in the health system where community members can meet with health personnel who are trained to provide basic services such as routine immunizations, pregnancy and tuberculosis (TB) identification, antenatal and postnatal care, and TB and oral rehydration treatment. The personnel who work at the community clinics are accountable for providing doorstep services 2-3 days per week through household visits within their catchment area. Bangladesh's health system is widely lauded for this aspect of health service provision (Chowdhury et al. 2013). This is especially important for rural communities as facilities are difficult to reach and are routinely short of resources and healthcare providers are often absent. The MoHFW has had limited reach in service provision to the communities via satellite clinics or doorstep services, and attribute this to the absence of roads (Hussain et al. 2015).

FIGURE 4-3 COMMUNITY CLINIC, BANDARBAN

4.2.2 **Study Population**

I undertook research with two indigenous groups, the Tripura and the Mro. Each community resides in clusters of households, referred to as *paras,* that are ethnically, linguistically, and culturally homogenous. Under the leadership of village headmen and karbaris, traditional leaders whose jurisdictions cover several *para*s, community members observe traditional social hierarchies. Inhabitants of this district also have some limited participation in nationalised administrative processes. Both communities have their unique languages. The Tripura language is also known as Kok-Borok, which has its own script. The language is considered to be vulnerable[27]. The Mro language is a spoken language, lacking a written form, and is known to be critically endangered[28] (Mosley 2010). Few people speak Bengali, the official language of Bangladesh. Some people, mostly men, carry out commerce in the main urban centre, and also speak Marma, which acts as a local lingua franca and is the language of the ethnic majority in Bandarban.

The first community selected for this study, Haatibhanga, belongs to the Tripura ethno-linguistic group and is located about a 2 hour walk from the nearest paved road. All homes and the *para*

[27] UNESCO definition: most children speak the language, but that it is restricted to certain domains, like the home.
[28] UNESCO definition: the youngest speakers are grandparents and older, and they speak the language partially and infrequently. In our field observations, children appeared to be speaking in the same language as their parents.

centre, which doubles as a schoolhouse, are built out of straw and bamboo. There is no electricity, piped water, or sanitation, and residents rely on natural sources of water for drinking and washing. The community is largely self-sufficient: they are subsistence farmers who weave their own clothes, and who have small-scale businesses. The primary source of food and livelihood is shifting cultivation of communal lands.

The second community belongs to the indigenous Mro community, who live in Tonkabati which is also referred to as Brickfield. The settlement in Brickfield has a *para* centre, again doubling as a schoolhouse, a small teashop, and a brick-and-mortar church. Homes in both communities are made of straw and bamboo and are built on stilts. Most families are nuclear.

Neither village has a public health facility but receive intermittent doorstep public health services from a Health Assistant (HA), Family Welfare Visitor (FWV), or Community Health Care Provider (a new position that combines the tasks of the HA and FWV. Two private NGOs also provide doorstep services in the communities through volunteer Community Health Workers (CHWs). Both communities had at least one traditional healer and a midwife living among them.

4.2.3 **Researchers**

I coordinated a research team that was a group of 12, led by a female Research Associate (Atiya Rahman). The members of the team consisted of 10 research assistants experienced in social science research. Half are female: (Rahima Akter, Arifonnessa Jany, Masuma Chowdhury, Sayema Akter) and the other 5 male (Sukanta Paul, Bijoy, Faizul Shuvo, Rayhan Rana). All of the research assistants and I were employed by BRAC University, and Atiya continues to work at the Research and Evaluation Division (RED) of BRAC.

Our team debriefed after each day of interviews, focus group discussions, either in person or by phone. During debriefs, we discussed challenges and ways of mitigating them. For instance, in cases when community members were unable to come together to make up the accepted number of people for a focus group discussion (5-8 people), we decided to do in-depth interviews to ensure the different age and gender groups are included. This will be evident in Table 4-1: when we were unable to consult with older men in the community as a focus group, we sought out individual older men for in-depth interviews.

4.2.4 **Reflexivity**

This component of the findings required reflexivity—a deep inward gaze into my personal and professional positioning (Ryan, 2005). The "otherness" of researchers in these case studies is discussed in Chapter 3. In this specific context, for me, it is largely to do with my appearance and cultural attributes that point to my being a member of Bangladesh's hegemony—that of the Bengali Muslim majority. My colleagues on the research team were also all Bengali, most of them Muslim, though some Hindu—though again, these identities, for indigenous communities, meant that again we were the "other." Naturally, in a context where one of the contributing factors to the marginalisation of the participants of this study is their identity, and their relationship to the dominantly Bengali state, the situation of the researcher as representative of the hegemonic other may carry significance (Weiner-Levy, 2009; Weiner-Levy and Queder, 2012).

To the study participants, despite our apparent links to NGOs working with their communities, we were short term intrusions into their lives, potentially representing that ethno-linguistic hegemony of the state, and we anticipated that their comfort in sharing their views openly was possibly limited. We did not speak local languages, and were dependent on translators to accurately represent our questions, and not censor or embroider the responses. In several interview transcripts, there is a sense among the responses of many study participants of things not being said, specifically issues relating to the larger socio-political context. This gap is discussed toward the end of the chapter, where I triangulate the responses of study participants with my own field observations and the prevailing literature.

My institutional links with BRACU, too, carry meaning: first, my employment as a research coordinator put me in a privileged position in relation to the rest of the research team, and Research Assistants on the team followed the Bengali cultural norm of calling me 'apu,' meaning older sister in Bengali, but also a term used for indicating respect for senior female colleagues. With our partners at BRAC and with a local NGO partner, I was the liaison for making all arrangements for gaining access and entry into communities. Finally, at the community level, my interactions were brokered by intermediaries: our local partner introduced me to the *karbari*, or local headman, with whom I could have an audience to explain my purpose; as well as an interpreter.

4.2.5 **Data Collection**

The first step in data collection was to carry out a desk review of secondary data around the topics of health equity, MDG progress in Bangladesh, and the health situation of indigenous groups living in the Chittagong Hill Tracts in general, and Bandarban in particular.

Data collection for this study occurred in two phases, for one week each, from January-February 2013 and again in May 2014 in the two unions in Bandarban: Haatibhanga, located within the administrative area of Bandarban Sadar, and Tonkaboti.

In identifying participants we used purposive sampling, prioritizing informants most likely to be able to provide rich insights into community, their health and health services, with respondents for community consultations selected using the expertise of local partner organizations. This included a community-based organization in the area, a nationally based organization, and local leaders, seeking a range of perspectives (Crowe, Inder, and Porter 2015). Our aim was to ensure the participation of different groups within the community, and not just of local elites. This helped to gather a larger diversity of responses and information about local needs across socio-economic, age and gender divisions.

During the first phase of data collection, the research team was composed of 10 people, myself included. Over the course of 2 days of orientation and training, we shared with our research team information around the *Go4Health* project, its objectives, and the interview tools. All members of the local research team had previous experience of engaging in qualitative research and participated in a tools training sessions conducted by myself, AR and two qualitative health research experts. For fieldwork, we divided ourselves into 5 teams of 2 researchers and had the help of one interpreter in each team to conduct each interview.

Interview tools were based on the *Go4Health* study: inquiries relating to community understandings of health, essential health needs, the determinants of health, the roles of relevant actors within and outside of the communities, and community participation in health decision-making (see Appendix E) were used to elicit answers from respondents from both community members and civil society organizations. Interview guides were translated into Bengali by experienced translators (Sandelowski 2000). Many indigenous languages do not have a script, and as such, Bengali interview questions posed by the researchers were then interpreted into local languages by locally recruited people. Interviews with lay community members were conducted in the language of their

choice. All of the interviews were recorded in MP3 with respondents' consent. Recordings were transcribed in Bengali by the interview team and then translated into English by professional translators.

As outsiders who are unable to speak any of the local languages, our research team could only ask questions and act as observers when interviewing lay community people. My role as observer allowed me to take note of the surroundings and interactions among and between people during my time in the field. In cases where interviewees were comfortable speaking in Bengali, I took the role of interviewer with support from another member of the research team as well as a locally recruited interpreter.

Respondents were categorised into 4 groups as follows: lay community, community leaders, community health providers, and civil society. I interviewed health providers from both the informal and formal health sector. Respondents from the informal health sector include herbalists, locally referred to as *boddo* and *kobiraj* or healer, and from the health sector included a physician, a nurse, community health workers (CHWs), and a traditional midwife. For focus group discussions consisting of gender-segregated community members, we ensured that the sex of the interviewers was the same. Likewise, we used this approach for interviewing midwives and faith healers in the community. Manderson (2006) views this as an appropriate way to mitigate any discomfort an individual may have in discussing gender-specific health issues. In all other cases, the gender identity of the interviewer was treated as irrelevant.

In total we conducted 38 interviews. During the first round of data collection, we consulted with 87 respondents. A breakdown of these interviews can be found on Table 1. All interviews and discussions with community members were conducted in the respondents' preferred language with the assistance of locally recruited interpreters.

TABLE 4-1 DATA COLLECTION METHOD AND SAMPLE BY RESPONDENT CATEGORY (N=87)

Method	Lay community (n=60)		Health providers (n=15)	Local leaders/community representatives (n=5)	Service delivery organizations/civil society (n=6)
	Female	Male			
FGD[29]	4 groups	4 groups	-	-	-
IDI[30]	4	4	15	5	2
Member checking[31]				1 (FGD n=10)	4 (IDI)

Focus groups were an accessible way for community members to participate in this case study. Because the *karbari*, or headman—the traditional leaders of the community—gave us permission to speak to the people of his *para*, or village, community members were happy to participate. Focus groups are an effective means to include a larger sample of a population of similar categories of people, with an enabling environment for them to speak out. This provides rich interactive data, though it has been noted in some studies, that some people are circumspect in a group situation. This is mitigated by our research team's constant observation, encouraging quieter participants to respond, and asking probing questions are all strategies to hold inclusive focus groups.

Following *Go4Health* protocols, I completed an initial data analysis with colleagues at BRAC University in Dhaka over the course of several months during and following the fieldwork. Over a one year later, our research team returned to Bandarban to do further *Go4Health* work. During this period, I engaged in member checking to enhance the rigor of the findings—meeting with a further subset of key informants after the initial analysis of data to corroborate and nuance findings—a qualitative technique that Guba and Lincoln (1994) posit is the most crucial technique for establishing credibility of data. This consisted of a round table discussion with community leaders, followed by in-depth interviews with members of civil society.

4.3 FINDINGS

This section offers the descriptions and insights of community members and civil society people living and working in the Chittagong Hill Tracts, in their own voices. In presenting the data I have prioritised the voices of community members and their perspectives, then considering the input of those working closely with the communities, then my own observations, supplemented only where

[29] Focus Group Discussion
[30] In Depth Interview
[31] Member checking involves returning to the field after initial analysis of findings to test these preliminary findings with key informants (Guba and Lincoln, 1994)

appropriate with evidence from the literature. The findings begin with the community's representation of what daily life is like in the district of Bandarban, with descriptions of how its geography is tied to community identity, followed by their insights to health—where, how, and why community members seek care. Community members described aspects of their daily life that directly affect their health outcomes. The community members unpack those components of life experienced in the margins of Bangladeshi society, describing them in detail in their own voices. Representatives of service delivery organizations provide further information about the communities, and I add to these voices my own observations to offer insight on what was said and exploring what may have been omitted by community members.

In describing their local context, participants discussed their everyday life as being essentially shaped by the geography of the region: "*Our hilly environment itself is a problem, and then there are logistic problems…"* [Ban_ FGD_AdolM_3] These are communities that identify with the hills, whose agricultural practices are defined by the constraints of difficult terrain and limited access to water, but who have been progressively displaced within their own environment. With many aspects of daily life interconnected and described in detail by community members, the complexities and underlying issues that result in health inequity do become apparent as their narratives unfold. Their references to related tensions are subtle, and community members stopped short of articulating the tensions between their communities and the dominant majority in the country. Respondents from civil society did shed some light on many of the structural issues that prevent community members from enjoying improved outcomes, and a more detailed discussions of these barriers—and the possibilities for overcoming them—are explored in Section 4.3.3.

4.3.1 **Everyday life**

In my synthesis of individual interviews and group discussions, as well as informal conversations, it became evident that as people described their daily life, every respondent referred to their surroundings—their natural environment. In my observations as a field researcher, it was clear that the land—and water—hold importance for the Tripura and Mro communities in a way that the rest of the country does not. Indigenous communities in Bandarban have a deep affinity with their land, and this is evident in their very identity—they describe themselves as *Pahari*, or "of the hills." Specific ethnic identities are a determining factor in how they are socially organised: each *para* or village is homogenous in ethnicity, faith, and language. Though there is a local governance structure based on the nationalised system, community members favour their traditional leaders to the local government. The *karbari*, or headman (in both communities, they are male), is revered by

the community and acts as their main decision-maker. He is in charge of communal lands, and for ensuring the well-being of *para* members.

The hilly terrain of Bandarban is rich in forests, which play a significant part in people's lives. Daily life in the sloping *para*s rich in forest land is centred around '*jum'*—shifting or fire-fallow cultivation of the land. *Jum* cultivation is a common practice among the majority of indigenous communities in the hilly terrain of Chittagong Hill Tracts. This practice is so central and deeply ingrained in their identity that the communities of Bandarban (and many others in the Chittagong Hill Tracts) self-identify as *Jumma* peoples. In my interviews as well as field observations, these geographic and lifestyle identities cut across every aspect of their lives: all *para* members in Haatibhanga, and in Tonkaboti, where the Tripura and Mro reside respectively, describe their everyday life as shaped by the land, particularly in regards to how they deal with the bounty and the limitations it presents. In their narratives, the Tripura and Mro speak of life wholly, and in it, there is an overarching sense of subsistence, self-reliance, and ultimately, resilience among their highly socially cohesive communities. The Mro and Tripura peoples, in describing their identity and way of living explain how these extend into their experience of health. The traditional ways of the communities are highly valued by all respondents, but negotiating traditional knowledge and lifestyles with modernity in a country dominated by a majority that is ethnically, linguistically, and culturally different brings with it tensions.

For respondents, health is a component of the wholeness of life. It is intertwined with the everyday. This is clearly demonstrated in communities' responses to *Go4Health*'s prescriptive inquiry: in answering questions about health, what emerged was a continuum of responses that ranged from topics about everyday life to the health care system in the Chittagong Hill Tracts—all with overlapping and compounded problems—together with the solutions for overcoming them. This section begins with the Tripura and Mro communities of Bandarban district, as they describe life in their *para*s, beginning with descriptions of their land, and its omnipresence in daily activities.

4.3.1.1 ***Land, life, and agriculture***

Study participants from the indigenous Mro and Tripura communities identify closely with the physical environment of Bandarban. They all describe themselves as being *Pahari—of the hills* or *from the hills.* This is because physical geography dictates the way in which they have always lived, and respondents continue a tradition of relying on the land and water to serve their daily needs. Respondents describe their dependency as a necessity: communities do not have basic modern

infrastructure, and this means they must rely on nature and fend for themselves. Running water, electricity, sanitation, solid waste disposal, and paved roads do not exist in any of the villages included in this study, and these are all issues community members address in terms of the terrain and their implications on everyday life. Many say they are aware that people outside the Chittagong Hill Tracts do have these amenities, in later passages, some describe trying to secure these, but they have accepted the continuation of traditional ways of living as a norm.

The land in Bandarban is rugged, with steep hills and valleys that consist of expansive forests and limited arable land. Sources of water in the area include springs, waterfalls, creeks, and streams. Settlements, or *paras*, are made up of clusters of households in the hills, and are situated within walking distance of a water source. People build their homes from bamboo and other materials that are available in the forests. Community members report relying on the forests to collect food. However this can sometimes be problematic, as people are allowed limited access to the forests as forest reserves are under the control of the national army. But our respondents did not expand their discussions around forest access, reluctant to provide more detail despite our awareness of written accounts of state enterprises and large companies from other parts of the country utilizing these restricted lands, documented in the grey literature and in some national newspapers.

Communities in the Chittagong Hill Tracts describe using arable land to produce food for consumption, and at the time of this study, turmeric was being harvested. The adult men and women from the Tripura communities who had left for work spent their daylight hours engaged in agricultural work. For the remainder—some women were weaving or caring for infants, older women were drying harvested turmeric, and older children, both girls and boys, were away in the *para* centre, at school. From my formal and informal conversations with respondents, I learned that all members of the communities are expected to participate in various agricultural activities, even if they have other commitments such as school or fetching water. These directions come from the village headman or *karbari* whose leadership role is a traditional one, and recognised by the national government as part of the semi-autonomous identity of the Hill Tracts communities. According to interviewees from service delivery organizations based in the Hill Tracts, a communal approach to land allocation and food production is typical to the Tripura and Mro. This high level of social unity, valued by all members of the two communities, begins in the family and translates into the community as a whole and as an important component of survival and well-being:

> *All the family members must live in harmony. The children in the family should do as their parents tell them—the things that are needed to lead a good life in the*

community. Not having any problem in the community is a healthy community. [Ban_IDI_ComL _9]

Daily life in the Chittagong Hill Tracts brings with it a collective focus on survival in that specific geographic setting, and an absence of modern infrastructure, means that it is only in nature that people living in remoter areas such as Haatibhanga and Tonkaboti can find sustenance. Community members spend the majority of their time collecting water and securing food. Everyone participates in food production in some capacity: women and men both work in the fields. Children, particularly girls, collect water. Women weave clothes for themselves and their families. Securing these basic needs mean that people are reliant on the elements—work can only be done during daylight hours, and seasons impress upon the availability of different kinds of food. These all make life busy, with timing a key factor in accomplishing tasks, and respondents report being exhausted at the end of each day from these daily labours. This traditional way of life is highly valued among respondents, and both the Mro and Tripura communities are tightly knit under the leadership of their *para* headman.

Study participants who live in *para*s report that they do not often go into the urban centre of Bandarban (locally referred to as "town" or simply "Bandarban"). They usually only do so for participating in the local market—primarily to buy and sell food—and for accessing services such as health care and secondary education. Going into town from the Mro and Tripura villages takes up to 2 hours, beginning with traversing the hilly terrain along walking trails to the nearest paved road. As one resident explained,

There are no proper roads in any of the neighbourhoods here. Even to go the main road we need about half an hour, and we cannot always find transportation to go to the market. It is 16 kilometres or maybe more to go to the town. [Ban_IDI_InfHP_28]

Within Haatibhanga, there are some trails between homes, and a brick path into the main part of village, which I learned from community health workers had been only recently built by a foreign NGO. Once *para* residents leave their village to reach the nearest paved road, they are able to access vehicle pick up points: for Haatibhanga, the stop is outside a small teashop, located at a hilltop that is a 30 to 45-minute walk from the settlement. For Brickfield residents, the pickup point is unmarked, and a 60-minute walk from the *para*. Utility vehicles, which act as local public transportation, are the mode of transport most residents use to go into town, at a small cost. Other

vehicles used for transportation to include motorcycles and auto-rickshaws and are usually used by those travelling from town to go into the *para* for visits. Service delivery workers report using motorcycles to access remote *para*s. Auto-rickshaws are rarely used, unless a large load of produce must be transported, or for emergencies, as they are considered expensive and difficult to find. *Para* members use mobile phones to call an auto-rickshaw service from town. Because few people in the *paras* own mobile phones, summoning an auto-rickshaw often requires going to a neighbour's home (which can be up to a one hour walk away) to make a call. My observations confirmed participants' information that networks do not cover most of Bandarban's remote regions, and those making phone calls must seek out areas where network coverage is available.

Para members are accustomed to using the trails within the hills, however, over a third of all respondents cited a need for improved roads, communications, and transportation. One interviewee, a community leader, echoed his *para* constituents in indicating that this would lead to increased access to essential services like education and health care. However, he indicated frustration with efforts to secure roads for his community:

> *Roads are needed for our communication, for going to the health centres, for the children's education…. During the election the chairman said, 'we will build roads for you', 'we will arrange anything you need, be sure to give me a vote'. And after the election they don't take the trouble to come here.* [Ban_IDI_ComL _9]

Having no roads leading in or out of the villages not only means difficulty accessing services—but it presents other limitations for community members as well:

> *There is no high school for those who are supposed to get admitted in Class 6 after completing primary school. Those students are compelled to stay at home after completing primary school. They can't continue their education. For example, there are 2 high schools: at Thanchi and Bandarban [town]. There are only two schools in the entire district. But there are some communities where children are sent to town for joining high school. But in a community it is not [financially] possible for every parent to send their children to [boarding schools in] the city. That is why there is no scope to attend class 6 after they finish primary education.* [Ban_FGD_CC2_R1]

In these two remote communities there are few opportunities for education: the majority of respondents among the Tripura and Mro report that they are unable to read or write, either in their own language or in Bengali. Those who are able to read and write only have a few years of primary

level education. This is because education provided in *para* centres is not always consistent, as teachers, who are usually from outside the communities, are unable to easily enter and leave the villages:

> *During the monsoon weather, the condition of the roads is worse. The roads become wet and muddy. There are no vehicles, so transport becomes a huge problem.* [Ban_IDI_EM_15]

Road conditions in the steep hills and valley during monsoon and rainy weather are treacherous and prevent those from outside the community to enter the villages. This further isolates the people, leaving them to rely on their own resources during long periods of inclement weather. Older respondents from the Tripura community reported that paved roads throughout the Chittagong Hill Tracts have only been built in the last 20 years, explaining that not much has changed for them, as the arterial roads are only helpful if there are roads leading to them.

Despite the isolation and limited road networks some informants indicated that the government was aware of this local priority: a different view emerged from a discussion with a Bengali health provider based in Bandarban town, also an active member in the district's health and social welfare committees. He reported that *"the government has worked for the development of roads,"* and pointedly mentioned that "*the Minister did not keep any other commitments, yet he has done work for the development of the roads.*" But there is a level of ambiguity underlying even this concession to development. The Mro community confirmed the Bengali health provider's information, in a slightly different way, reporting a drastic change in the distribution of lands and access in the last decade, the result of policies implemented by the Bangladesh armed forces. In addition to my formative research, I was aware from previous research experience that the Chittagong Hill Tracts are an area highly monitored by the national government, with infrastructure development and policing entrusted to the Bangladeshi national army. This has been the case since a Peace Treaty was signed in 1997 to end indigenous uprisings for autonomy. Cases of extrajudicial violence, rape, and missing persons are attributed to the army presence, and are documented in reports by human rights groups. However, these are issues that did not explicitly arise from any of the interviews in this study.

But two respondents from Tonkaboti *para* shared important information about their relocation—a community leader and a community health worker were the only respondents who made any

mention of the forced relocation of the Mro community—despite its impact of this repeated relocation, and the current uncertainty, on the whole community:

> *Everyone here has been evicted [from their land]. They were sent to those hills for two years [pointing], and now they have come here. Everyone lives very close to each other. It has been hardly two years since I came to live here. That is a military firing zone—that is why we couldn't stay there. This is bad because the place for living is not set, there is no farm or house, it's like we are homeless. We have no land or wealth here. The arrangement is a brick field, the army wants us to stay here. I mean this place is even called Brick Field. There is [just] plain land here. The army tells us to stay here. We can stay here however we want, [but] there is no other place [for us]*. [Ban_IDI_EM_14]

This double relocation, I learned from informal conversations with other health workers, is a result of the militarization of the Chittagong Hill Tracts with a view to contain potential uprisings among indigenous communities, ostensibly to build a military camp for the national army. This was followed by building a firing range for training exercises, resulting in a second relocation for the Mro community. As the respondent shares, a brick factory was built, the clay soil suited only for making bricks, and some members of the community are employed there as day labourers. In this account, there is a sense of dysphoria: the Mro identity is closely linked with land, and living on plain and unproductive land, with being given no options for relocating to more suitable land, is an assault on an entire community.

That the national government delegates a special mandate to the national army for the development of the Chittagong Hill Tracts is a commonly known and documented fact in Bangladesh, and community members alluded to road construction in the Hill Tracts as one of several activities entrusted to the army by the national government. While this development has improved mobility and access to and from *para*s like Tonkaboti and Haatibhanga, and has enabled *para* residents to gain access to markets and modern services available in town, the services promised to the communities as part of national development—and the services *para* residents say they need in their communities—such as electricity, water, and sanitation, remain elusive. In building roads leading to valuable land as part of a national development strategy in the Chittagong Hill Tracts, the national government has not only displaced people from their ancestral lands but has also removed communities' means of subsistence.

Communal ways of living on and working in the land, so central to both Tripura and Mro identity, means that food production is a collective endeavour. In the remote Chittagong Hill Tracts, the primary reason for farming and food production is for the subsistence of the community. Traditional knowledge is applied to farming practices, and with *jum* (shifting cultivation) as the norm in the Hill Tracts, communities, under the direction of their *para* headman, grow different crops on both plain and sloping lands. Surplus produce, a rarity, is sold at town markets. *Jum* agriculture is so much part of survival and the social fabric for both the Mro and Tripura that their identity *Jumma* peoples (people who practice jum) and collective action in securing (semi) autonomous governance is an important one.

4.3.1.2 ***Food, livelihoods, and poverty***

In responding to questions around the essential factors that contribute to health, participants spoke about the challenges to their food security, and the difficulty of having a balanced diet that provides them with enough nutrients. They linked this with challenges of growing enough food for their consumption during lean seasons, describing shorter fallow periods than in the past. With fallow periods reducing over time and the limited amount of land that community members are granted access by the government, many community members spoke about food and nutrition shortage.

> *[whoever] does not eat healthy food from their childhood it is difficult to grow up in a healthy manner, rather they remain small. For example if you compare your people with our tribe, you will… see that you people have eaten all kinds of nutritious food since you were very young and you have access to all kinds of health needs, whereas the tribal people lie in remote villages where they are deprived of a healthy life.* [Ban_ FGD_AdolM _3]

During our discussions, the Mro community spoke at length about the drastic change in the distribution of lands in the last decade, the result of policies implemented by the Bangladesh armed forces. Their forced displacement means that access to natural sources of water and arable land has become limited, adding to the already difficult task of producing enough food, another problem for the indigenous people of Bandarban.

> *We were told to leave. We are [now] facing difficulties… we cannot find enough bamboo or trees to cut; the army comes and cuts all the bamboo. We do not have enough food to eat.* [Ban_IDI_ComL_35]

The loss of land and their livelihood creates an environment of insecurity. In addition, there is a direct effect on their daily eating habits. It is not only about growing or being able to buy sufficient amounts of the right food; storing supplies in the sub-tropical monsoon climate presents complex challenges for the villagers. The *para*s do not have electricity, and community members spoke about having to cook before every meal in earthen stoves that require firewood in order to avoid gastric problems as a result of eating spoiled food.

> *We need to have healthy food that is safe to eat. We cannot eat rotten food. We need to eat food cooked on the same day, or else we suffer from gastric problems. Any food that was cooked earlier—it has to be thrown away.* [Ban_IDI_ComL_21]

> *When it is extremely hot we become sick. If we cook and keep the food, the food becomes stale in the hot weather, so we have to cook three times a day.* [FGD_AdulF_27]

4.3.1.3 ***Water and sanitation***

In the remote areas of the Chittagong Hill Tracts, water is of utmost importance. Healers in the communities use the words for "water" and "life" synonymously. Community participants all speak about relying on natural sources of water like streams and waterfalls for drinking, cooking, cleaning, and bathing. Streams and rivers run through the large tracts of forest land, and waterfalls are intermittent throughout the Hill Tracts. Villages are located near sources of water as there are is no infrastructure for running water in the steep hills and valleys.

There is no water source within Haatibhanga *para*, however I observed that there was a stream and small waterfall on my way to a neighbouring village, about a 2 hour walk away. Community members report that water is not easily accessible, and as they shared in an earlier section, water collection is a chore delegated to girls in the *para*. The villages, share their access to natural sources of water, and this, I understood through discussions with community members, is common practice. Once again, social unity is an important factor for survival: water is a scarce resource throughout Bandarban:

> *[The] water problem doesn't exist at Hatibhaanga only. It exists in entire Bandarban zila [district]. Water is available here but it is not safe. There is no pure water here.* [Ban_FGD_CC2_R1]

For the Mro community, the scenario is different. As a consequence of their displacement by the national army, living on plain land makes it possible for them to access water sources more easily than in the highlands.

Community members describe "pure" water as water that they perceive as safe to drink. The majority of respondents drink water from streams and waterfalls—without treating or boiling. But as I observed as I walked to the village of Haatibhanga, villagers also go to the waterfall to bathe. These waterfalls are few and far between in the hills.

Some felt that easier access to water could be secured through community fundraising money for a tubewell. But this also presents a problem:

> *We know that we need this water, but we cannot run our family if we don't buy rice and other food. That is why we cannot get the water. It is not possible even if everyone contributes. If it was Dhaka [the capital] we could have used a motor from the generator to get water from the ground and use it and enjoy good health.* [Ban_FGD_AdulM_19]

Tubewells can be found all over Bangladesh, but are uncommon in Bandarban and the rest of the CHT. In my formative research, I found literature describing the topography of the area is not as problematic for reaching aquifers.

> *Sometimes while working our water supply runs out (during jhum farming), and the drinking water that we carry also runs out, in such a situation we have to drink any water that is available. If that water is not safe then we get diarrhoea, this is why we need pure water.* [FGD_AdulF_27]

Community members say that health is closely related with hygiene and sanitation, areas on which they place great importance. Cleanliness is of great concern, particularly in the context of Bandarban, where water is scarce.

> *For instance when we are using the toilet, we cannot use it properly when water is unavailable. Even if there is no water in the toilet, we could take water ourselves and use it properly, but the water is far away. Hence the problem is water.* [Ban_FGD_AdulM_19]

Exposed latrines are common, and there are signs of open defecation in the villages. In Haatibhanga, only a single covered pit latrine was visible, and it was situated near the home of the headman.

> *….here the fact is that due to scarcity of water, a proper sanitation system is never followed here. No matter if the water is clean or unclean, it is not available. Because a huge amount of water is required for sanitary latrine, that is why people leave stools under the open sky and in the jungle. Now the water source is far away. Here World Vision provided some materials to build latrines. But those are stored in the yard. They can't be used due to scarcity of water. Though poor people got these for free they couldn't use it and left them in the yard. Just collecting drinking water for oneself is really painstaking. It is such a laborious job.* [Ban_FGD_CC2_R1]

Participants said that it is very difficult to put their knowledge around hygiene and sanitation into practice; water is very scarce, and other resources that could be useful in improving the health status of the *para* are far away from homes. This means that although washing, bathing, and cleaning are highly valued in discussions with the community, they are of secondary importance in the remote hills of the region, where there is hardly enough water to drink. As with hygiene, sanitation has also taken a back seat to more pressing needs. My observations during fieldwork confirmed this--supplies to build sanitary latrines that still remained packed and unused were visible near the home of the Tripura *karbari*. Severe water shortages negate putting hygiene practices to use[32], and effectively render the latrines unusable. Instead, as one young man reports, "*people defecate in open spaces, eat without washing their hands, also diseases spread*." [Ban_FGD_AdolM_12]

This creates a tension for those who spend greater lengths of time outside the community with opportunities to live with basic water and sanitation services. Describing a life left behind, and communities of other indigenous groups, one young woman, herself indigenous, studying at a residential school in Bandarban town said:

> *Most of them are from the hills. They do not have a lot of facilities. Even their crockeries are very dirty - they don't clean them*[33]. [Ban_FGD_AdolF_8]

[32] It is common practice to use a *lota* filled with water for cleansing

[33] The young woman has perhaps, in leaving village life and adopting modern urban life, is assimilating the value laden assumptions of the rural indigenous "other"

The majority of respondents living in Haatibhanga and Tonkaboti described hygiene and sanitation as a priority but faced difficulty keeping clean in the absence of water. This dissonance is most acute among recipients of health promotion messages, who understand the imperatives of hygiene and the responses expected of them, but are faced with the pragmatic constraints of their environment. This is particularly evident among adolescents, who receive secondary education outside their *para*, and adults who frequently go to town and beyond, or those who have relatives in other parts of the country and beyond. The health promotion messages are well received and arguably implemented in townships, but when repeated in contexts where it is difficult to implement these changes this translates into apparent disdain for the indigenous community.

In summing up the lifestyle and overall living conditions in Tonkaboti and Haatibhanga, a staff member of a local service delivery organization belonging to the Marma ethnic group describes the *para* members who participated in this study as "left behind" in the overall development of Bandarban. The remoteness of the *para*s, he says, makes it especially difficult to extend public services, and as a result describes Haatibhanga as "backward". This is the dilemma for these communities: their geography is integral to their identity—they are "of the hills" —yet the constraints of that geography and its limited water supply, even where they have not been subjected to forced relocations, compromises their agriculture, their economies, their nutrition, their hygiene and sanitation. For communities where health and water are used interchangeably, the lack of water equates to compromised health. The lack of road access limits access to markets, to schools, to emergency care. And the failure to provide services to these marginalised communities compounds that disadvantage.

4.3.2 **Health in our context: holistic understandings in a discrete system**

Having explored identity and health, the specific questions posed by the *Go4Health* domain on essential needs for health allowed us to rank the issues that they saw as critical in the new social contract being proposed in the post-2015 debate. The findings from focus groups largely corroborated the priorities articulated in individual key informant interviews. Community members shared their clear sense of their priorities for health: the table below outlines their ranking of the different structures required to support improved community health, followed by needs that directly relate to the health system. As we discovered in an earlier section, there sense of urgency in securing enough water and food in *para* members' rankings of health needs. Every member of the lay community identified water as their single most important health need.

TABLE 4-2 RANKED ESSENTIAL HEALTH NEEDS BY RESPONDENT CATEGORIES (N=80)

Essential Health Need	Community people (n=60)	Health providers (n=15)	Community leaders (n=5)
Infrastructure for health			
Safe drinking water	60	12	4
Sanitary latrine	51	11	4
Roads and transportation	19	5	1
Clean/hygienic environment	17	2	-
Nutritious food	17	1	-
Income opportunities	10	1	1
Educational institutions	8	2	-
Mosquito nets	7	-	-
Proper housing	1	-	-
Community centre	1	-	-
Electricity	-	-	1
Health systems change			
Community health centre	45	12	3
Physician	43	8	3
Medicine	32	5	-
Health literacy/behaviour change	31	4	1
Community-based health care worker	20	2	-
Training for TBAs	1	-	-

During our discussions and interviews, participants expressed their understanding of health as a holistic concept that included basic sanitation, access to food and water and to a social environment that allowed for personal growth. The essential health needs identified can be found in Table 4-2, which also shows how many times each was mentioned during the course of the fieldwork. When asked about their priorities, study participants stated that they know what they need for improved health: water and sanitation are of utmost importance, and road access could make these public

utilities and other services a reality. Community members in Bandarban suffer through long days that involve hard agricultural work and long treks to water sources. Water, food, and lifestyle are all related to health—not only do respondents see them as determinants of health, they argued at each of the needs expressed are all components of health, and life as a whole. However, knowing and prioritizing needs is not enough to improve local situations.

But the response to being asked, "what does good health mean to you?" was not limited to that holistic representation of health as positively linked directly to their context. There were other responses that pointed to the direct expression of ill health as a result of the constraints they faced in that same environment: community members also spoke of visual cues like body weight, pallor, and the ability to work, but most also recognised that health involves both physical and mental well-being, as well as a sense of unity within the community.

During a group discussion with my team, male adolescents said:

> *For example if you compare your people with our tribe, you will see that you people have eaten all kinds of nutritious food since you were very young and you have access to all kinds of health needs, whereas the tribal people live in remote villages where we are deprived of a healthy life.* [Ban_FGD_AdolM _3]

Fever due to jaundice, typhoid, and diarrhoea occur frequently, according to respondents as well as those who provide them with health services. They are acutely aware of the cause of these water-borne diseases. Community members report being aware that these illness are linked to drinking untreated water, but because this is something they report needing to do habitually, it is in part normalised—they feel they must accept these temporary conditions as part of everyday life. In some cases, children in the community have died as a result of untreated diarrhoea:

> *Environment has to be good to stay healthy. It is very difficult to live in a remote village. You are more vulnerable to diseases.* [Ban_FGD_AdolF_8]

The role of the natural environment for health is ever present in the way community members and their local service providers speak. Referring the displacement of the Mro community, one interviewee explained,

> *The Mros use the water from the waterfall since a long time ago. lf you want the proper amount of water then you will need a big forest, then the water from the waterfall will come and gather there. And this is their only water source. There is no tubewell [in the village], so if they cut off the trees in the forest too, then the*

waterfall will dry up. There will be no water left. Then the people will have to move to those parts [of Bandarban] where there is water. Their survival depends 80% on the forest, gathering wild fruits and gathering timber for livelihood. Cutting down the trees will have two effects: one of them is that they are deprived of the forest resources and second is that the natural wildlife will be lost gradually, as a result the people will have a lack of nutrition… The government has a responsibility of preserving the forest but they are not doing their duty properly. Rather they are clearing out the forest. The government can control everything, since they do not do that; the others are taking advantage of the situation. But it is everyone's loss. Everyone has to deal with the adverse effects. [Ban_IDI_32]

4.3.2.1 ***Health care in a pluralistic system***

The provision of services offered by the state is limited: the geography further compromises its delivery. The state led health system that community members and key informants from service delivery organizations describe is intermittent at best, and is regarded as tokenistic. The perceptions of those in the communities is that they are treated as an inconvenience, that service providers resent the inconvenience that they face in working in these remote communities. NGOs appear to be more reliable in their delivery, but with resources heavily dependent on donor funding, services to the community are not sustainable.

The uneven service provision is a reflection of the deeper underlying social, political, and economic forces at work in this environment, with the interests of the military given priority, and the residents lacking security for their future. A key informant points out:

lf we see this in political terms, they [communities] always want to live in an area which is near a water supply. But sometimes the army forces them to leave the area; and as a result they cannot get enough water. And when they are evacuated from their homes, politically they become isolated. And as a result, they become more helpless and often lose the social help that they could have gotten otherwise from neighbours. They face economic crisis when they move to a new area. When they do not have enough money—definitely, that has an impact on their health, because they cannot avail the required services and healthcare facilities. There was a village called Kramadpara. The army pushed them even further from that village. So it took them very long to settle there. [Ban_IDI_32]

Study participants have limited access to health services. In their own communities, public health extension workers like Family Welfare Visitors, Health Assistants, and Community Health Care Providers provide doorstep services. Respondents affiliated with service delivery organizations reported a service delivery focus on maternal and child health programs. According to one key informant, this was the result of a national and international commitment to accelerate progress toward meeting MDGs—offering some hope for an expanded commitment if more comprehensive services were highlighted in the post-2015 goals.

There are no satellite clinics in the villages. Due to the difficulty in travelling through terrain which does not support vehicles, community members who are unwell cannot seek out facility-based services which often requires at least a 2 hour journey. Respondents discussed their health-seeking practices in a context where there is neither facility nor formally-trained health care workers living among them. In the absence of facilities or reliable health services within their communities, respondents seek the help of traditional healers and lay midwives for their immediate health care needs. Respondents report that common reasons for which they seek care within the community include wounds, pain, fever, diarrhoea, pregnancy, and childbirth. Some seek out homeopaths on the main street in the nearby town of Bandarban, although these are not people from the communities.

Among the Mro, there is a clinic with limited hours, and medication like paracetamol is sometimes available. Aside from this, villagers in both the Tripura and Mro communities regularly rely on home remedies or seek the care of traditional healers and TBAs:

> *There are 3 dhatri (midwives). There is no one else in this area.* [Ban_IDI_EF_2]

> *The healer provides herbal medicine for body pain, severe hand and leg pain, skin disease etc.* [Ban_FGD_AdulM_11]

Respondents reported that vaccines for children under 5 are a component of doorstep services, which they use.

> *If we get sick we cannot get medicines or see doctors easily. My younger sister died due to diarrhoea.* [Ban_FGD_AdolF_8]

> *We are also deprived of healthcare providers; they do not provide healthcare service or medicines. When we are sick we have to get to the doctors somehow [without ambulance services]. The health workers do not come to us.* [Ban_ FGD_AdolM _3]

Facility-based care is important to respondents, particularly in the absence of the famous doorstep services available to most of Bangladesh's rural communities. But for residents, the local informal health provider is the first point of entry into seeking health care, as one of these informal providers concedes:

> *At first they come to me. When they don't get well, they go to hospital.* [Ban_IDI_THP2 _23]

All community members participating in the study confirmed this. Many were emphatic about the healing powers of their local informal providers, but also noted that seeking them out also serves the practical purpose of accessing health care easily, sometimes even within their own community. Another health provider, a trained community health worker, said

> *If they are slightly ill they go the pharmacy, or private doctors. If it is a serious illness, they go to the hospital.* [Ban_IDI_SS_7]

Traditional cultural practices are also significant, and have been significantly preserved for pregnancy, childbirth, and the postpartum period. Traditional health care practices are widespread here, particularly in pregnancy and childbirth, and do not always make positive contributions to health. In the postpartum period, women face dietary restrictions, eating only rice with salt, sitting by the fire, making offerings of colostrum—crucial to early baby nutrition and immune protection—to the gods. Faith healing, using protective talismans and sacrifices to the gods, were discussed by some respondents, and reflect the importance of traditional belief in a context where public health services are not adequate, and the risks to health—around pregnancy and childbirth and early childhood—are particularly high. Few women report seeking modern medical care, however, some have been provided counselling and care during ante- and post-natal period by community health workers from local NGOs. The majority of women report receiving care from a traditional midwife based in their own community, typically an elder. She becomes responsible for care, counselling, and ultimately the delivery.

There are no physicians or clinics within reasonable walking distance, and there are few options for medical care that are available in the community. Doorstep health services are popular for other communities in Bangladesh, but respondents reported that their experience has been different:

> *We are also deprived of healthcare providers; they do not provide healthcare service or medicines. When we are sick we have to go to the doctors by ourselves. Health workers do not come to us.* [Ban_ FGD_AdolM _3]

Other community members mentioned that they do receive some doorstep services but these are limited to ante- and post-natal care, and health promotion that was provided by the MoHFW and NGOs. Services are not regularly rendered and the communities cannot rely on care being readily available.

Patients who are seriously ill are taken to town, where they can seek care at either private clinics or at the (public) district hospital. The reception for indigenous community members may be unsympathetic, with staff—even when they are from the same ethnic groups—sometimes viewing other indigenous communities negatively, for example, making value judgements about hygiene practices. The care in district hospitals is expensive and can create a cycle of debt. Out of pocket payments like having to purchase medical supplies that are out of stock in the hospital is a common problem. Another cost incurred by patients and their families is the expectation of small gifts of cash to care workers at hospitals. This facility is located 4.5 hours walking distance away. Delays in seeking medical care often result in patients growing sicker or even in patient death. Participants reported that it is a two-hour walk to the nearest paved road, the first place where vehicles can finally be accessed. When patients are extremely sick or weak, the walk to the road is impossible and so community members help to transport the sick using homemade bamboo cages.

Doorstep health care services in the remote areas of Bandarban are rare, and intermittent. According to respondents, doorstep services to the communities in the study included pregnancy and TB identification, DOTS, malaria prevention and control, oral rehydration therapy (ORT), antenatal care (ANC), perinatal care (PNC), under-5 child immunization, and under-5 child nutrition. For appropriate and timely care, respondents report that they go to the tertiary level public health facility in Bandarban town where they know they can be seen by a physician. An alternative to this is seeking care at a private facility, and these are also available in town. Facility-based care is predictable, and respondents report this to be the surest way of receiving reliable care. The people they need—nurses and doctors—are available, as are necessary medicines and supplies.

4.3.2.2 ***Health Workers in our community***

Bandarban has a serious shortage in health workforce that is a source of anxiety for respondents. There are few clinics in Bandarban district, and these are only intermittently staffed and have a limited stock of medicines.

> *We are also deprived of healthcare providers; they do not provide healthcare service or medicines. When we are sick we have to get to the doctors somehow [without ambulance services]. The health workers do not come to us.* [Ban_FGD_AdolM_3]

There was no clinic near the Tripura villages, and only one person had been employed as a CHW. She worked for a local NGO that had UNICEF funding for maternal, neonatal, and child health services as part of the mandate for achieving MDGs 4 and 5. The program was reputed to be helpful for women and children:

> *Here, at first there was GRAUS's MNCS, which means Maternal, Neonatal and Child Survival project. They worked for the mothers and neonatal children's protection.* [Ban_FGD_AdolM_12]

Community health workers in Bandarban, particularly in its remote areas, are few and far between. This is unusual for Bangladesh, where doorstep services from GOs and NGOs are widely available through programmatic health interventions.

Absenteeism is a result of the remoteness of the villages. A mid-level staff member of a service delivery organization, himself native to Bandarban, expressed his frustration:

> *There should be a doctor in the clinic, and at the very least, there should be a health assistant physically present at the clinic. But even the health assistants are absent. They tell us that there is a logic to this: "if we have to pay for transportation and go daily from Bandarban [town] to that place then our monthly salary will be over soon. lf we have to commute everyday, then the whole month's salary used up on transportation costs, how can we then afford anything else?" As a result, they do not stay in the workstation. They want to live here in Bandarban, and get only the monthly salary, no extra fringe benefits like transport cost etc. So, they are a bit negligent. Even so, [the doctor] is supposed to be there. But he does not want to be there.* [Ban_IDI_KII_32]

In response to absenteeism and for the convenience of having accessible health care, community members see value in local recruitment of health workers. Trust is an important component of health care service for users, and having someone from their own community providing advice and care is one way to ensure that people act on health promotion messages.

It was evident that there are few community-based health workers, and there was no evidence of the government cadre of community health workers, Health Assistants (HAs) or Family Welfare Visitors (FWVs):

> *There are no health workers in my village, so first we need health workers in my village to keep it healthy. Health workers are the most important thing we need in my area…ones who will give us medicines and also give us health awareness advice.* [Ban_FGD_AdolF_8]

When asking about the health workforce in the communities, the NGO services appear to have stronger and more consistent representation—in one community we learned "there are two health workers—one is from GRAUS and one is from BRAC." Another respondent who self-identifies as Mro and provides services in Brickfield, the Mro community in this study, said *"there is no one else like me".* In another community, BRAC was also the sole trained provider:

> *Now BRAC is also doing it. [BRAC health worker] tells us especially about malaria. She does blood tests and gives medicine.* [Ban_FGD_AdolM_12]

Visits from representatives of church missions are also appreciated by community leaders, who report that these occur infrequently:

> *Once in four months, a missionary doctor or nurse comes and tests everyone's health. They hold meetings at night and give us [health] advice.* [Ban_IDI_ComL_9]

Community members see value in local recruitment of health workers. Trust is an important component of health care service for users, and having someone from their own community providing advice and care is one way to ensure that people act on health promotion messages.

> *They want a kormi (Health Service Provider) for general diseases from whom they can get medicines. They are talking about a particular Sastho Kormi (Health Service Provider) who will be known to them. I mean who will visit every para (Small part of an area), every house and who will have communication with hospitals. So that whenever they will go to receive service from any NGO, they will get it easily. That*

means, when village people will go to receive treatment, they will take help from that known person and will get the service very quickly. [Ban_IDI_EF_2]

Representatives from service delivery NGOs describe problems in recruiting and retaining a health workforce that could adequately serve the needs of the communities, in part the result of local constraints on access to education.

Education is also required but local people don't have that. The government has a requirement that the health workers must pass their SSC and HSC in order to qualify. But you will not be able to find a single woman like this in this area. The recruitment process is not right at all - there are no people like this in the local community. [Ban_IDI_KII_32]

4.3.2.3 ***Health literacy***

But there was also a clear connection between knowledge and health—particularly among younger informants or those with an exposure to the world beyond the Chittagong Hill Tracts. Here the influence of education and NGO activities were clear—the resigned acceptance of the futility of hygiene and sanitation messages in the absence of water and basic sanitation replaced by a level of confidence that change was not only possible, but imperative.

But there is a strong sense in responses that this is located outside the community, not yet strongly part of local practice. The majority of community members declare that they are not knowledgeable enough about health. Service providers affirm this view:

They do not have the knowledge regarding nutrition to help them eat the nutritious food that they get naturally from the environment. As a result they do not eat the food that is required for them, rather they eat whatever they want to eat; food that might be lacking in nutrition. [Ban_IDI_KII_32]

But the government should work on these. If these are done then many things will be developed. But the government doesn't do these. It comes and gives vaccination only. It doesn't work for people's wellbeing. It is only in the system to give vaccination on a day and come for visit on the next day. But they take it so casually that sometimes they don't even bother to come. [Ban_FGD_CC2_R1]

Some villagers, however, have more knowledge than others. This is partly the result of the formal education system integrating health promotion, and is reflected among the younger members of the communities who have had some schooling. They appeared to understand health promotion messages, and conveyed these to their communities in their villages to encourage behaviour change.

> *If we are motivated enough then we will get to know. And if not then we have to be motivated [by someone]. At first I have to know. There are many people who neither know nor understand. Few people who learn better can be made trainer. And among 100 people under him/her if at least 10 people become aware then the number will gradually increase.* [Ban_FGD_CC2_R5]

The first indications of critical health literacy are also evident in the voices of young male participants in the study. They often returned to discussing the issue of poverty and food security when they were asked questions about health and health services, and reminded me that livelihood programs are an essential health need for their communities. Community members revere those among them who they consider to be part of the "aware" community. To them, these "aware" people include health workers, teachers, traditional leaders, and elected local representatives. This was evident when respondents were asked about who should participate in public life. Most felt they were provided too little information to participate in a meaningful way.

Health promotion programs are widespread in Bangladesh, and community members report learning about health from different media. These include community health workers from government and non-government agencies, teachers, and villagers who have exposure to life outside the community. Such villagers include children in residential schools located in Bandarban town, as well as others who have built a life outside the district, elsewhere in Bangladesh or overseas.

Health promotion programs create health literacy, and respondents feel that this is an important step toward better health outcomes. Awareness-raising is a key component of service delivery in Bandarban, and community members confirm this. Knowing what to do to keep healthy and prevent disease is important to these communities who cannot easily access a primary health care provider or facility. The importance of this is emphasised by one young man who said; "*if someone has signs of diarrhoea, we must know how to prepare the saline and give primary treatment*" [Ban_FGD_AdulM_19]

Even one traditional healer expressed his appreciation for such programs:

> *Health is a very important matter for a person. For me, health means awareness and other pros and cons. For example, before if any children had fever or anyone was ill then their parents would sit at home and not do anything [about it]. Now we can say that parents have awareness.* [Ban_IDI_InfHP_28]

Community members sometimes use the words for education, enlightenment, and information interchangeably, and these may be a result of limitations in translation: to be "uneducated" refers not only to the lack of formal education but also a gap in "understanding" important information. Lay community members look to community health workers, teachers, religious leaders, and other members of their community who have links outside of the community like educational institutions. Community members place high value on formal education. This in turn, according to an older woman, results in a community that is "aware" and able to take charge of their own health:

> *If people are educated then they will be more conscious about their health, then they will know the difference between healthy and unhealthy practices. This will help them to remain healthy.* [Ban_IDI_EF_13]

One young woman, a student at a residential high school in town, spoke about sanitation problems in her home community, linking their behaviours with ignorance:

> *An uneducated person doesn't know about these things, how to stay clean or where to excrete? An uneducated person would excrete anywhere… but we [students] are educated now… when we go to the village we try to make the uneducated people understand the do's and don'ts. We can see slight changes now. As I am educated when I go home I try to make my parents understand that if you stay dirty your health can deteriorate*[34]*.* [Ban_FGD_AdolF_8]

Young men expressed their appreciation for information, which they feel must come from outside their community. Links to external sources are of value for the communities:

> *Community people's awareness is the most important requirement. If they develop awareness, they can find out what they need for themselves. Before 1997, no NGO other than the missionaries could work here. World Vision and Caritas did some*

[34] For her, education is a way forward, bringing with it all the changes of social development and values associated with urbanity and assimilation into dominant culture.

work. Besides them no other local NGO could work here, and as a result health awareness did not develop here. [Ban_FGD_AdolM_12]

Health awareness is raised mainly through doorstep services. Health information is also conveyed through mass media, and adolescent respondents made particular mention of this:

It is related with toilet in various ways, apart from that we have seen in the Meena cartoon how people are defecating in the river, then the river is carrying the faeces around and people are bathing in that same water and taking the water from the river home, this is a problem. Everyone is suffering due to one person's mistake. This is how diseases are spreading. This is how the toilet is related to health. [Ban_FGD_AdolF_8]

The Meena cartoon mentioned by adolescent girls seemed to resonate with many people, and this was developed as and advocacy tool by UNICEF's Regional Office in South Asia (ROSA). The cartoon aimed at changing behaviours and perceptions around the development and protection of girls. Topics included education, health, gender equity, and freedom from exploitation and abuse.

While programming from the MoHFW and other sources are informative, some community members feel that it has little relevance for their context:

They [health workers] are talking about what are the characteristics that a person should have in order to be called healthy, such as his physical structure. They are saying that those who are healthy play regularly. But they do not have to do hard labour work like us. They don't have to collect bamboo and wood from the jungle and sell them in the market. They are also financially stronger. If they want they can have any vitamin foods they like. Even if they fall sick, they can see a doctor and fix their health. That is all they are talking about. [Ban_FGD_AdulM_19]

The difference of approach between government services was also remarked on. NGOs are perceived as being closer to the community, and as agents for the community, with a deeper sense of what the community's needs are:

The various information that I am giving you as a NGO worker, they could not provide even that information. They never conduct meetings. They cannot say what problems are present in the village. [Ban_IDI_KII_32]

4.3.3 **How to enact change**

While the *Go4Health* questions around identifying essential needs elicited detailed and considered responses, the follow up questions around governance and accountability for the provision of those essential needs were met with uncertainty. There was some understanding of local governance mechanisms, but little detail around needs were processed beyond the local into national systems, and certainly no clear conceptualisation of global governance or international solidarity beyond what they experienced in their exposure to NGOs and faith based organizations.

Though they had a limited understanding of rights, lay community members have do have a sense of human dignity that emerges from their discussions. When asked about rights, a community health worker replied:

> *For me, a right is something that I deserve. For example, as a human being I have some human rights. I have to know what my rights are and what aren't. And becoming aware of that I have to speak up.* [Ban_FGD_CC2_R7]

Participants expressed knowing the importance of being part of decision-making processes, and stated that this is a way to enact change within their *para*s and districts. Knowledge about the existence of mechanisms for public participation is widespread, and it was mentioned in our interviews and FGDs that there are mechanisms to raise issues so local authorities can push them forward. However, there is little movement after communities use these participation spaces and there are few efforts to include local voices in any decision-making. The villagers felt like Bangladeshi government shows little interest in the situation, and routinely ignores them. Instead, they report looking to other structures that they feel are responsive to their needs.

4.3.3.1 ***Decision-making mechanisms***

The questions on governance posed by the *Go4Health* guidelines were met with uncertainty, and an unfamiliarity with processes of government beyond the very immediate local level. When asked about who should provide for the list of the essential needs that they had articulate, the answers were generic—usually "the government" or "NGOs" but without any sense of how that might be achieved or how those agencies might be held accountable. Lay community members have an awareness of existing mechanisms but few were familiar with information about how even local governance processes operate. Only those who themselves held positions representing the community could elaborate on how decisions pertinent to their communities are made. Those involved with these processes spoke of their unsuccessful attempts at securing electricity and water

tanks for their communities. Frustrations with higher level decision-makers who pay little or no attention to their needs were voiced, and the perception that the state would prioritise only the interests of those in higher political office was spoken of by every community leader. Instead of investing time and efforts in institutional machinery that systematically mutes their voices, communities, under the stewardship of their traditional leaders, shift their focus to local and international NGOs to bring about change.

> *They do not try to find out what is happening here. They do not perform their duties. They told us earlier that they would be there for us. But they do not concern themselves with us.* [Ban_IDI_ComL_35]

Because of this feeling of being ignored, the villagers in both communities consulted for this study feel more comfortable going through NGOs for voicing their needs and concerns. Meetings where villagers are invited to participate are routinely initiated by NGOs, and not the local government or community. However, little information is disseminated around policy processes through these spaces, and not everyone has a voice that is counted: gender is clearly an issue in traditional and state governance structures. An elderly woman described the meetings and noted that only some opinions are considered:

> *Men participate [at meetings]. If women are invited, they participate. If the meeting is arranged by outsiders [NGOs], women are invited. Everyone's opinion is heard [then]. But in the end they only consider the opinions of those who they think are worthy.* [Ban_IDI_EF_2]

4.3.3.2 ***Traditional leaders and NGOs***

Community members generally see NGOs as the only institutions that are capable of delivering tangible results, and they reported overall improvements in health and education. Traditional leaders also pointed out the importance of NGOs for their communities' health and wellbeing because they bring with them funding and, although they cannot always deliver the services promised, they are more reliable than the government. However, some participants are cautious about relying solely on them for care. Many of the health and development interventions are project-based, and because they are financed through donors, their presence in the area is only temporal. For the villagers, relying on these stakeholders also takes away from the need to pressure local authorities and the state, and that contributes to their current isolation. Things do not change easily, because it takes education, awareness and working together as a community to make demands:

> *The government has a responsibility to create an educated society and informed constituency with health literacy and awareness. But the effort from the government*

> *is not sufficient; if the educated people of the community, community representatives and NGOs take initiative and begin working for change then I don't think it's a hard thing to achieve…. The root of everything is unity. If we are united and stand together to raise these issues, they [the government] will have to fulfil our demands.* [Ban_IDI_InfHP_28]

That trust remains an issue for the marginalised indigenous communities of Bandarban is clear:

> *When government will impose any rule, it will have to consider international policy. If it is done at international level, the government will be under pressure and it will not be able to violate international law.* [Ban_FGD_CC2_R1]

4.4 Chapter Synthesis

This case study is based on research interviews, focus group discussions and observation with some of the Bangladesh's most geographically isolated communities. Few research studies can be implemented without constraints on time and financial resources, and so too was this study—despite links through local NGOs, and a research team of 12, the initial interview period was little more than a week, with interviews mediated by local language interpreters. What was essentially a rapidly performed rural appraisal can be viewed as problematic, particularly in a scenario where there is no immediate or clear benefit to the community in question. Yet, shaped by *Go4Health*'s mandate to hear the voices of the marginalised in relation to their specific topics, this research delivered all of the elements of the five domains, working with a marginalised community to determine their understandings of health, essential health needs, the determinants of their health, the roles and responsibilities of relevant actors, and their participation in decision-making. Certainly it has fulfilled of its contribution to that important global imperative—ensuring that a global agenda for health is inclusive of the voices of those who are typically excluded in priority-setting in our way forward, for the *World We Want*.

But beyond this, beyond the prescriptive questions required for *Go4Health*, we have been witness to much more than community understandings and perceptions of the health systems—in engagement and direct dialogues with communities of the Chittagong Hill Tracts of Bangladesh, a narrative around a life that is rich and complex, presents itself organically.

The Tripura and Mro communities of the Chittagong Hill Tracts live in isolation from the rest of Bangladesh, and in telling us about their health needs, they tell much more about lives lived in the

margins of a dominant society. The Hill Tracts, their home along the Bangladesh and Myanmar border, are at the core of their identity as *Pahari* (hill) peoples. The topography of their ancestral lands, communally tended, is different from the alluvial plains of the rest of the country, requiring different farming methods and an affinity with natural resources. The *Pahari* communities have unique ethnolinguistic identities, and practise traditional ancestral religions, with a small number of Christians—a consequence of colonial history Hill Tracts of the region—all, again, that of which separate their identity from that of the ethnically Bengali Muslim majority. These identities all overlap for the diverse and distinct *Pahari* who make up the majority of Bangladesh's extreme poor. In their accounts of everyday life they tell us about the challenge of food security and food safety, and limited access to basic social services such as health, education, as well as justice, and public life. Yet, while the accounts of these communities are rich in their experience of marginalisation, their lack of access to markets and economic centres, to higher health care, to education, their lack of secure settlement, of the water and food that they clearly see as essential to health and life, the Tripura and Mro are not cognisant of the national, the regional, the geo-political factors that contribute significantly to this marginalisation. They are silent around the detail of their relocation and vulnerability to the military, but unaware of the political realities beyond that which impinge on their lives.

Nationalization policies have jeopardised the lifestyle of local communities that lived according to their own traditions and customs and undermined their basic human rights. Facilitated by its armed forces, the state encouraged Bengalis, particularly the landless poor, to re-settle in CHT, with offers of cash and land. Indigenous peoples, already marginalised, have been pushed further into the interior of the Hill Tracts, with productive lands grabbed by the state, denying communities access to forests, arable lands, and water sources for people whose identities are inextricably tied to their natural environment.

The Ministry of CHT Affairs and other government agencies and departments in Bangladesh regulate and execute activities in CHT, and despite commitments outlined in the Peace Accord to include indigenous people in state bodies, they have yet to do so (Chakma and Dhana 2015). Allegations of closed door decision-making and a lack of coordination between state and local bodies concerning the CHT are rife within and outside the government (R. C. K. Roy 2000; D. Roy 2012), and this is supported in the responses of community leaders. To date, the Accord has been implemented favourably toward the state but issues around indigenous people's land rights remain unresolved (Amnesty International 2013; Jamil and Panday 2008). Customary usufruct rights to

ownership of land under traditional and common property are not recognised by the state, and large quantities of forests and fertile lands confiscated by settlers and state authorities remain inaccessible to indigenous landowners. For indigenous peoples, this has resulted in displacement, food insecurity, loss of livelihoods, and lack of access to water sources (Hussain et al. 2015). In contrast, towns and their nearby villages occupied by Bengali settlers are developing, with electricity, running water, sanitation, health and education services, and economic opportunities available to residents.

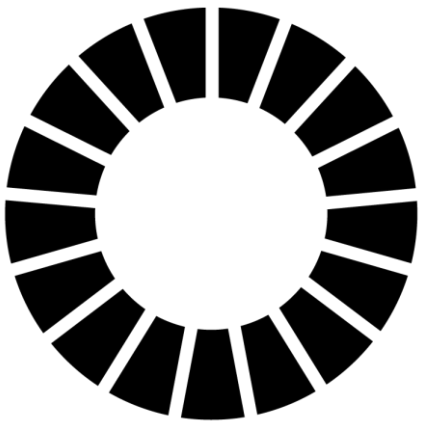
But one of the critical issues is the lack of reliable data. There is an acute shortage of reliable data and statistics and differences of opinion regarding the reliability of the scant data that are available about the population size of the different indigenous peoples in Bangladesh. Most documents contain the population figures based on ethnicity, but it contains no further ethnically disaggregated data on socio-economic variables. Demographic and other information are regularly recorded by the government of Bangladesh and are publicly available, however information on the CHT is inadequate. The population census reveals little about the number of ethnolinguistic groups in CHT, their populations, and how and where people live (Barkat et al. 2009). Some scholars agree that under-enumeration is a deliberate act to underplay the importance of the indigenous population. Indigenous peoples in the country have emphasised the importance of having ethnically disaggregated data to help initiate appropriate legislative and administrative measures, including affirmative action, and to ensure adequate development allocation (Roy, 2010).

The issues that the health system faces are common across Bangladesh. Primary health services are delivered throughout the MoHFW and the DGHS. Strategies have been developed within the health sector to strengthen delivery, improve quality of health inputs, and to develop strategies to build capacity for service delivery. But the progress seen across Bangladesh, in concert with the support of the NGO and international sectors, is not being seen in the CHT. Challenges remain in human resources, procurement, and data collection. Too few doctors are available for the adequate coverage of the whole population. Updated data is a major constraint in assessing progress. Large amounts of vacancies persist in hard-to-reach areas. Cross-cutting issues affect the overall delivery and quality of human development services: governance issues, financing, training. Accountability is a difficult challenge and requires continuous effort. Centralised administration hinders its performance: programming decisions are taken by ministries when instead they could be handled more effectively at local level. Policies and programs are planned at the top level with little involvement from stakeholders, resulting in projects and policies that do not reflect the needs of

communities. Local stakeholders therefore tend to take little ownership in the implementation of these programs and their participation is likely to be weak. Fiscal patterns indicate that actual expenditure falls short of both budgeted and revised budget expenditures. Outreach programs need to be strengthened, and partnership with international institutions such as UNICEF and with NGOs can provide greater push and visibility to this effort (IMF, 2015).

Mahmud (2009) in her analysis of Bangladesh points out that 35% of the population is provided services directly from NGOs—including microcredit, education, health, or sanitation. NGOs have flourished due to weak state provision, low levels of private foreign investment, and high levels of readily available bilateral and multilateral donor funding as the principal factors that created the political and economic space for such organizations. The end result, she asserts, is a 'franchise state' where essential public services are run by NGOs funded by donors or the state, reinforcing communities' perception that NGOs follow through on important human development work while the government takes a back seat. NGOs and the international community may have more of an impact if there is pressure on the Bangladeshi government to include indigenous populations in its socioeconomic development efforts.

In their everyday experience of food insecurity, their lack of access to water, sanitation, and essential health services in the context of an absent and unresponsive state government, these two indigenous group are literally "left behind" by the rest of Bangladesh. They are only acknowledged in discourse directly related to CHT matters: the representation and participation of indigenous communities in any national policy discourse is limited or non-existent. Their mistrust of the state, because of its exclusionary systems, and structural and at times, physical, violence is evident in their accounts of displacement, and having to do without the basic development that they need. What the communities of the Chittagong Hill Tracts are asking for is the most basic of needs—food security and water security, and the right to live on their ancestral lands—demands that are consistent with their human rights—and though their awareness around rights, and the avenues for ensuring they are met are limited, their sense of human dignity is very clear. This research seeks to make that clear, and to give voice to their essential demands.



CHAPTER 5

Philippines case study

5.1 INTRODUCTION

This chapter presents the findings of my research with marginalised communities from the Autonomous Region in Muslim Mindanao (ARMM) in the Philippines. In their own words, people share a sense of their unique religious identity, their struggle for autonomy and stability in a fragile setting, their understandings of health and wholeness, and their desire for critical understandings required in order to bring about change. These themes are further supported by the people who serve a range of different communities in Mindanao, with knowledge and expertise around their health and well-being, and finally, the unique challenges they face in a context of ongoing conflict. As in the Bangladesh case study in Chapter 4, the contents of this chapter are the product of two distinct processes: the first that shared question guides to meet the project requirements for *Go4Health,* and the second that satisfies one of the core objectives of this dissertation: to explore the experience of marginalised communities, with an emphasis on their perceptions of identity, health and the responsiveness of the health system to their needs.

This case study is again nested within *Go4Health*, with its prescriptive framework for fieldwork and the managing and analysing of data to create consistency across the multi-country study. *Go4Health*'s framework consists of five domains: understandings of health, essential health needs, determinants of health, roles and responsibilities of relevant stakeholders, and community participation in decision-making processes. These have been critical in bringing to light how communities define health, the kind of care and services they access, and who they perceive as responsible for addressing and ensuring their health needs. Though the short and intense engagement with communities was intended to get responses for very specific areas, community members and their service providers give us much more—they tell us about their everyday life—how they live, how they fare, and the overlapping and intersecting ways in which their outcomes for well-being are affected.

This section begins with an introduction to the communities—the country in which they live, its social and political context, and a description of the health system available to them. Their identity separates them from the dominant majority of the country, ethnically, linguistically, spatially, and

spiritually, and all of these are known to result in inequitable access to social services and protections (Abanes, Scheepers, and Sterkens 2014). A description of methods that demanded contextualization is covered briefly, noting language abilities and safety concerns in field sites.

These findings provide information about the perceptions of communities in Mindanao around their health. The complex circumstances that study participants endure impacts on their experience of health, as evident in their descriptions of pervasive poverty, armed conflict, and desire for change. They provide rich detail around barriers to accessing their country's reputable public health system, informing us of what they think needs to be changed for the system to be responsive to their needs. In addition to the voices of communities in Mindanao, my analysis considers the statements of service delivery organizations as well as my own field observations—though the voices of the community are always given priority.

5.2 METHODS

5.2.1 **Setting**

Philippines is a middle-income country in south-east Asia with a total land area of 298,170 km^2. An archipelago made up of over 7,100 islands between the Philippine and South China Seas, it has a tropical marine climate and is susceptible to several cyclones and typhoons every year. Its population of 102 million is primarily concentrated in the northern and central archipelagos, Luzon and Visayas, where farmlands are ideal for agriculture. Mindanao, the southernmost archipelago, accounts for about 43 million people, and is known as the country's food basket, producing 60% of the country's food and the largest amount of corn, coconut, coffee, bananas, pineapple, and cassava for export (Lockie, Travero, and Tennent 2015).

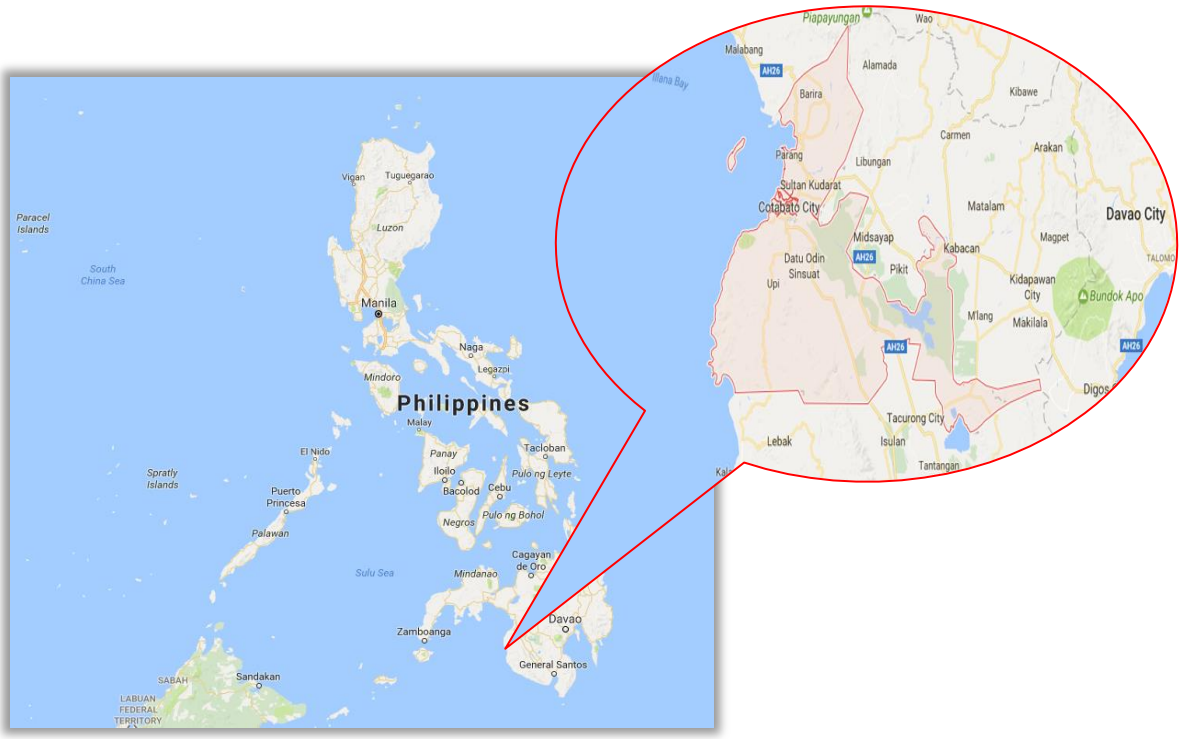


FIGURE 5-1MAGUINDANAO PROVINCE, AUTONOMOUS REGION IN MUSLIM MINDANAO, PHILIPPINES

In demographic terms, the Philippines is composed of various religious and ethnic groups that are heavily concentrated in specific geographic areas. Over 90% of the population belong to various Christian denominations, with Roman Catholics comprising the majority. The Christian majority live in Luzon, the Visayas, as well as in Mindanao. Nationally, Muslims are a small minority and are concentrated in Mindanao. Ethnicity and religion are fused together: the six largest ethno-linguistic groups—the Tagalogs, Cebuanos, Ilocanos, Bisayas, Illongos, and Bicoloanos—are commonly identified as Christians, and live all over the country (Abanes, Scheepers, and Sterkens 2014). The terms Muslim and *Moro* (Spanish for 'Moorish,' a historically slang term for Muslims and the preferred term in the Philippines) are used interchangeably to describe Filipino Muslims, and refer to 13 ethnolinguistic groups—the Maranaons, Maguindanaons, Tausungs, Yakan, Sama, Badjaw, Kalagan, Sangil, Iranun, Palawani, Melebugnon, Kalibogan, and Jama Mapaun (Noble 2009). This ethno-religious stratification is attributed to the country's colonial history: Arab traders from the 10th century onward introduced Islam in the southern regions, Spanish conquerors arrived in the Philippines in the 16th century, bringing Christianity and an 'othering' of the *Moros,* and later, an American presence in the mid-20th century contributed to settlement programs whereby people from Luzon and Visayas were encouraged to populate the sparse Mindanao archipelago. In addition, there is an indigenous population known as the Lumad that identify as neither Moro nor Christian and also live in Mindanao (Paredes 2015).

An influx of settlers from the north, land laws that dispossessed people of their lands, and distinct ethno-religious identity led to decades of conflict—with Moros and Lumads forming an alliance as the Bangsamoro Liberation Front—with the national government. Tentative agreements led to the formation of the Autonomous Region in Muslim Mindanao (ARMM), consisting of 5 provinces: Maguinadano and Lanao del Sur on the mainland, and the 3 island provinces of Basilan, Sulu, and Tawi Tawi. Mindanao continues to be well known for its decades of armed conflict and its separatist movement. During the course of this research, peace talks were underway between the Philippine national government and the Moro Islamic Liberation Front, a separatist organization representing the Moros and Lumads, to end armed conflict in ARMM. The Comprehensive Agreement on *Bangsamoro* (literally "Moro nation") was signed in March 2014, however armed conflict within the region continues: small militia groups such as the Abu Sayyaf group, the New People's Army, among others, are actively seeking greater autonomy. As a result, the region continues to be considered a conflict zone. As of May 2017, Philippine president Rodrigo Duterte has declared martial law on the archipelago of Mindanao, and at the time of writing this dissertation, small militia groups have taken Marawi City in the province of Lanao del Sur under siege (*BBC News* 2017a, *BBC News* 2017b).

FIGURE 5-2 PROMOTING PEACE IN A FRAGILE SETTING – MINDANAO, PHILIPPINES

The governance structure in the ARMM, illustrated in the figure below, varies slightly from that of the rest of the Philippines. There are 116 municipalities, with only 3 urban centres—Lamitan City and Isabela City in Basilan and Marawi City in Lanao del Sur. ARMM consists of 2,490 *barangays*, the smallest administrative unit in the Philippines ("Local Government Units" 2017). In rural areas,

barangay is used as a term for village or ward. The ARMM government works and the national government work closely together in the area of development, particularly with regard to the implementation of education, health, and social welfare services. Inequality between the Muslim minority in southern Philippines and the majority in Luzon and Visayas is pronounced, with low socioeconomic conditions along ethno-religious lines. Landlessness, poverty, and inequality are considered to be the root cause of conflict, though state formation is another interpretive framework (Abanes, Scheepers, and Sterkens 2014).

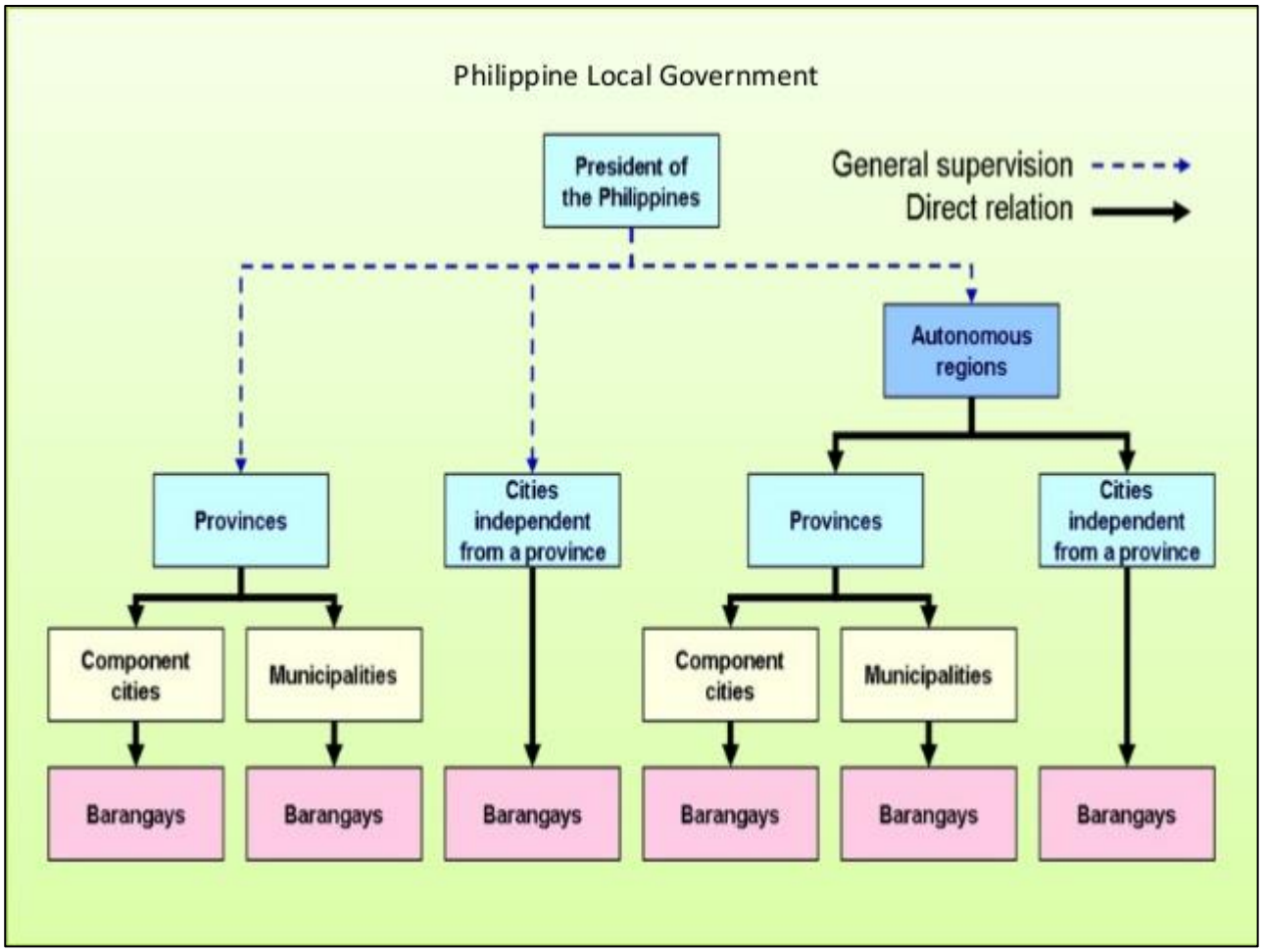


FIGURE 5-3 GOVERNANCE STRUCTURE, PHILIPPINES

The Department of Health (DOH) is the principal health agency in the Philippines and is responsible for ensuring access to health services throughout the country with a mandate for universal health care, known as Kalusugan Pangkalabatan (KP). The public health system is managed by the DOH and Local Government Units (LGUs) and includes program packages for health promotion and the prevention, management, and control of disease from primary to tertiary level facilities. The system is decentralised, meaning that each Local Government Unit LGU or

barangay has an internal revenue allotment at its disposal to allocate resources based on local priorities, and primary services are delivered at rural health units and barangay health stations by barangay health workers, public nurses, and doctors.

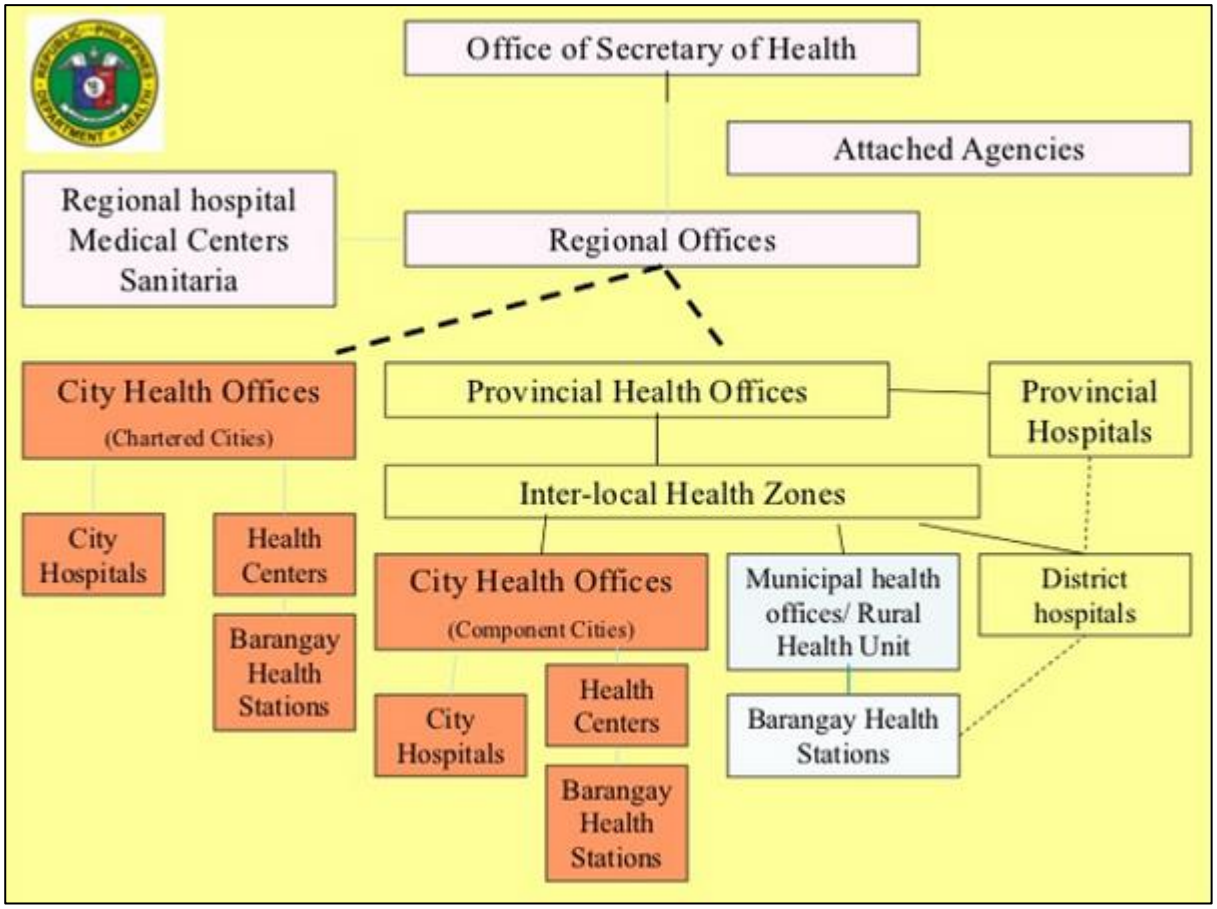


FIGURE 5-4 HEALTH SYSTEM STRUCTURE, PHILIPPINES

Health care is intended to be available to everyone through PhilHealth, a government-owned corporation for health insurance coverage. It is comprised of different membership categories, including people working in the informal economy as well as indigent members—persons who have no visible means of income, or whose income is deemed insufficient for family subsistence by the Department of Social Welfare and Development (DSWD) (Romualdez et al. 2011). Despite these policies, the Philippine health system has been criticised as highly unfair due to fragmentation, limitations in population coverage, people's access to services, and regional disparities. Health equity is a particular concern, with the worst health coverage indicators in regions with the worst economic and social development—that is, in Mindanao, and especially in the Autonomous Region in Muslim Mindanao (ARMM) (Friedrich Ebert Stiftung 2015).

5.2.2 **Study Population**

We engaged with 3 communities in the province of Maguindanao, in ARMM, two Muslim communities and one Christian: the first community live in Datu Odin Sinsuat. In ethno-linguistic terms, community members belong to the Maguindanaon group, and are Muslim.

The second community lives in Upi, and people in the area belong to the Bisaya, Ilonggo, and Tedurai ethno-linguistic groups while others belong to unspecified indigenous groups. All respondents self-identified in various denominations of Christianity in the evangelical spectrum, including Episcopalian, Baptist, and Good News Christian. Their experience appears to parallel the experience of the Muslim majority, with the claims for autonomy and the fractured local politics estranging them from mainstream Philippines infrastructure.

The third community resides in Parang, and all study participants identified as Muslim and belonging to the Iranun ethno-linguistic group.

Households are scattered, yet within walking distance of each other. There are water pumps in each of the communities, as well as public latrines. In Datu Odin Sinsuat, Upi, residents have access to a rural health unit, and Parang shares a rural health until with an adjacent barangay.

Participants for the second round of community interviews were selected and consulted in two roundtable discussions—similar to focus groups but with more inclusive membership and greater flexibility in participation. The first consisted of community members who participated in the earlier phase of the study as well as new participants, and included community leaders, local government leaders, community health workers, and service delivery organizations. This way we could ensure that we could get feedback on our findings from the same communities during the first round but also get a broader perspective. The second roundtable discussion was carried out as a dialogue with members of civil society organizations (CSOs) in Mindanao.

5.2.3 **Researchers**

My research team in Mindanao consisted of 11 people, including myself as research coordinator, a female colleague from BRACU (Atiya Rahman, AR), and Abubakar Balabagan (AB), our research focal person in Mindanao. Together, AR and I, trained and led a team of 8 Research Assistants (RAs), all recruited by colleagues from the Mindanao BRAC office and AB. Prior to the

recruitment I worked closely with contacts in Mindanao to ensure that research assistants hired in the team all have prior experience using qualitative methods in social science research.

Every member of the locally recruited research team had previous experience in qualitative research with the local BRAC office, which regularly conducts evaluation research for its locally implemented education program. Half of the locally recruited research assistants were male: John Henry, Muhammed Hussein Maulana, Ameril Ayunan, Morsidin Husain, and the remaining RAs were female: Jasmine Abo, Sittie Merriam Esmael, Noraisa Saban, Nairiah Gayak. All are fluent in Tagalog, the lingua franca of the Philippines, and in English. In addition, each RA is fluent in their own ethnic language.

AR and I shared with our in-country team information around the *Go4Health* project, its objectives, and the interview tools over the course of a 2-day orientation and training workshop. All local team members participated in tools training sessions conducted by myself and AR at BRAC International's regional office in Cotabato city, a federal territory in Mindanao. We conducted team debriefs at the end of each day. During these meetings, we discussed any issues and challenges that arose during research activities, and found solutions to them.

5.2.4 **Reflexivity**

An element of reflexivity is inherent to research, particularly in contexts where there is an "othering"—in this case, of the researcher, but also of the researched, in their own country. The distinct identity of people living in the Autonomous Region is self-defined, largely in terms of the faith they practise. However as described in Section 5.2.1, there are indications that, for Filipino Muslims in Mindanao, preserving this distinct identity also contributes to their marginality—a marginality that extends to other Christian residents of the Autonomous Region. In the Philippines, the Autonomous Region in Muslim Mindanao has the lowest performs in socio-economic development, and people living in the region often require humanitarian assistance from the national government and international community. As a successful NGO, BRAC International's presence in Mindanao embodies South-South cooperation, an increasingly common phenomenon in global development efforts, and more importantly, I understand that my BRAC colleagues are trusted by communities as well as by local and regional government officials due to their Muslim identity. I noted, during my stay in Mindanao, that all of the core BRAC staff in Mindanao are Bangladeshi Muslim males. Local staff, however, include both women and men of Christian and Muslim faith from across the Mindanao archipelago, including outside of the Autonomous Region.

My multiple identities 'othered' me in the research process but also, in some cases, enabled me to gain rapport with interviewees. First, my name clearly identifies me as a Muslim, which, in the Autonomous Region, where there are tensions along religious lines, helped build rapport with the majority of respondents. My geographic identity is apparent: my appearance is South Asian and my accent is North American. In addition, my affiliation with BRAC International placed me as member of the international development community, renowned for its successful service delivery programs in health, microfinance, and education. In several instances, community members and service providers participating in the study requested BRAC International consider launching a health services program or providing assistance in their communities (despite being informed of the purpose of the study).

The fragile nature of our research setting was evident from the moment I arrived in Cotabato city—armed personnel are visible at the airport, businesses and offices, including the BRAC International office. Security is of utmost concern, particularly for foreign nationals, as they are known targets for militia groups—ransom income is used to fund ammunition. To that end, our colleagues at BRAC International ensured they recommended study sites protocol officers deemed as safe. In addition, I was instructed not to reveal my identity as a Canadian citizen as it would render me particularly vulnerable to kidnapping. These concerns affected my fieldwork—AR and I were advised not to accompany our local colleagues to the field site in Parang, where militia groups were particularly active at the time.

5.2.5 **Data collection**

I engaged in formative research that consisted of a desk review of secondary data and informal discussions with institutional partners in the Philippines. This included examining peer-reviewed literature, research reports relating to Mindanao, the Autonomous Region, and the Philippines, as well as other reports from local, regional, and national government offices, international organizations, and government websites. Institutional partners at the locally based BRAC office provided advice and assistance in recruiting the research team, translators, identifying study sites, and with logistics.

My interview tools were guided by framings of the *Go4Health* study; specifically, inquiries relating to community understandings of health, essential health needs, the determinants of health, the roles of relevant actors within and outside of the communities, and community participation in health

decision-making (see Appendix A and Chapter 3). The question guides were translated into Tagalog, the dominant national language and lingua franca of the Philippines, by experienced translators recruited by BRAC International. To ensure accuracy in translation, Tagalog interview guides were back translated to test for consistency with the original English interview guide. Tools were finalised once my colleagues and I were satisfied that the Tagalog interview guides were accurate.

Community members and civil society organizations operating in ARMM were consulted for this component of the study. Respondents were categorised into 4 respondent groups as follows: lay community, community leaders, community health providers, and civil society. I interviewed health providers from both the informal and formal health sector. Respondents from the informal health sector include herbalists, locally referred to as *albularyo*s and one *hilot*, or healer, and from the health sector included a physician, a nurse, barangay health workers, and a midwife. For focus group discussions consisting of gender-segregated community members, we ensured the interviewers were of the same sex. Likewise, we used this approach for interviewing midwives and faith healers in the community. Manderson (2006) views this as an appropriate way to mitigate any discomfort an individual may have in discussing gender-specific health issues. In all other cases, the gender identity of the interviewer was treated as irrelevant. A breakdown of the type of interview techniques and respondent groups is outlined below:

TABLE 5-1 DATA COLLECTION BY RESPONDENT GROUP (N=124)

	Lay community (n=91)		**Health providers (n=12)**		**Local leaders/community representatives (n=9)**	**NGO/UN agencies (n=12)**
	Female	**Male**	**Informal sector**	**Formal sector**		
FGD	6 groups	6 groups	-	-	-	-
IDI	-	-	4	6	4	4
Member checking (FGD)	-	-	-	-	1 group	1 group

We conducted the majority of our interviews and group discussions in Tagalog. In cases where community members' ethno-linguistic group was the same as that of the RA conducting an interview or focus group discussion, RAs were more comfortable speaking in their own language. This helped build rapport with community members and allowed them to participate without being constrained by language barriers. All of the interviews were recorded with respondents' consent,

and later translated and transcribed into documents in English. For further information on transcription, please see Section 3.10.

As an outsider unable to speak Tagalog and other Filipino languages, I observed interviews and focus group discussions. My role as observer allowed me to take note of the surroundings and interactions among and between people during my time in the field. In cases where interviewees were comfortable speaking English, I was an interviewer, and maintained access to an interpreter in case the need arose.

FIGURE 5-5 THE RESEARCH TEAM AT THE BRAC INTERNATIONAL OFFICE IN COTABATO CITY, MINDANAO

Following *Go4Health* protocols, I completed initial data analysis with my colleagues at BRAC University in Dhaka over the course of several months during and after the fieldwork. Almost one year later, when BRAC gave clearance to return to the Philippines, I was able to return to ARMM to do further *Go4Health* work. During this period, I engaged in member checking, a qualitative technique that Lincoln and Guba (1994) posit is the most crucial technique for establishing credibility of data. This consisted of two round table discussions, the first with community leaders—barangay councillors, barangay health workers, and teachers—and a second one with key

informants—including representatives of Mindanao-based NGOs, UNHCR, the World Food Programme, and government-based intervention programs. Both sessions included old and new study participants to ensure in member checking that my findings from my initial engagement with communities and service providers accurately reflected their views. In so doing, I ensured that the requirements for member checking are met while also receiving further confirmation from additional study participants who could provide a broader perspective.

5.3 FINDINGS

These findings are a synthesis of in-depth interviews, focus group discussions, informal conversations with key informants and community members, and my own observations. The responses of community members and their local representatives in Maguindanao province are the main focus of this section—first, because the crux of this study is to bring to light the voices of some of the most marginalised peoples in the world, and secondly, to understand how people perceive, understand, and experience health in their unique environment:

> *Only here in the Philippines, our situation here in Mindanao is very different from Luzon and Visayas. For instance, here in Mindanao, there are internally displaced people. So how are you going to address our concerns? Here maybe different from the way you address same concerns to other parts of the country.* [R8, Civ_Soc_Min_Ph]

In responding to *Go4Health*'s questions, largely framed around health and governance, people describe a life experience that is defined along ethno-linguistic and religious lines. Firstly, social, political, and economic factors are all ominously present in community members' accounts of struggling with issues that come hand in hand with poverty: food security and income generation. All participants, including service providers, share the opinion that life in the remote Autonomous Region in Muslim Mindanao also brings difficulties with water and sanitation, as well as access to education and health care. In Section 5.3.2, health service users and providers alike share frustrations around a public health system that promises universal care but fails to deliver—from service delivery issues to human resource shortages, from medicines and supplies to health promotion and issues of governance—the system is fragile, and, for communities, does not respond to their most urgent priorities. Finally, in Section 5.3.3, community members tell us what is important to them, their sense that they should be included in decision-making that affects their lives, and their desire to know more about their rights and entitlements. Finally, community members ask how they can hold duty bearers accountable for ensuring these are met. All this is

overshadowed by conflict—a mistrust between population groups divided by religion, but also a result of land disputes and clan feuds, also a by-product of identity. For the people of the Autonomous Region in Muslim Mindanao, identities are also defined, in addition to religion and ethno-linguistic terms, so too in relation to economic status, education, gender, and social capital. The voices in these chapters are those of community members and civil society people who are living and working in the Autonomous Region in Muslim Mindanao.

5.3.1 **Everyday life**

Community members linked a number of aspects of daily life with wellness. To study participants, the most important factor contributing to their health status is food, and they elaborate on their struggle for food security in backdrop of poverty and limited opportunity. In Maguindanao, a lack of social services and opportunities cuts across education, water and sanitation, income generation, and study participants convey their awareness that this should not be the case—that there is a disparity with compatriots elsewhere in the country. Representatives of civil society and service delivery organizations provide additional information about the communities through their own lens of working as service providers and activists, and along with these narratives, I include my own observations, interpreting these findings in light of the context. These findings paint a picture of everyday life in this unique part of Mindanao, characterised by a struggle to secure daily needs in a context of insecurity.

5.3.1.1 ***Not enough food, not enough money: poverty and hunger***

When it comes to health and wellness, food was the most frequently and comprehensively addressed topic among study participants. Respondents spoke about the importance of food in influencing health status, particularly in terms of physical strength. They express the need for sufficient food intake in a context where, for the communities participating in this study, that is not possible: respondents report that local food production is insufficient for serving the communities' needs. In addition, most people do not have enough money to buy food. Every member of each community in this study—Parang, Datu Odin Sinsuat, and Upi—spoke about the precarious nature of food security at household and community level:

> *Our community is not producing enough food for our family.* [Spt_FGD_AdulF 2]
>
> *We don't have enough food for our family.* [Smb_IDI_CHW3]
>
> *We need sufficient food [for the community]*. [SS_FGD_EF1]

Food for community consumption is inadequate, and key informants who work in the communities expressed their concerns around food security in the entire Autonomous Region. Community members referred to the presence of an agricultural industry in the Autonomous Region but described their own production of food for personal consumption as insufficient. Interestingly a third of Mindanao's land is devoted to agriculture, and the region supplies over 40% of the country's food requirements and also produces food for export. In Maguindanao, and in the rest of the Autonomous Region, where the average person struggles with food security, this creates a stark contrast to the complexity of national and regional politics relating to land tenure issues, and the presence of global companies purchasing food at a large scale. These are discussed later in this chapter.

Every respondent made a strong link between food and health, responding to questions about their health with references to their own food intake. Sufficient food intake and eating at regular intervals, they report, are both important to being physically strong and maintaining good health. As one woman explained, "to have good health, you must have enough food" [Spt_FGD_AdulF2]. A community leader adds, "good health means having 3 meals a day. Even if it's not delicious food—just a plain meal will do" [SS_IDI_ComL1]. Yet for each of the respondent communities, food security at the household and community level is a challenge. In linking between food with health, community members explained emotionally that poverty as inextricably tied to hunger and ill health. Because of the lack of money to buy food, many report they are unable to eat at regular daily intervals, often doing without meals. Eating food for breakfast is rare in households, and mothers said they send their children to school without food. Community members and key informants report that there is sometimes food assistance through relief agencies, as well as meal programs at schools:

> *Feeding for some elementary children about 3 years ago from the World Food programme through the Department of Social Welfare and Development"* [Spt_FGD_EM_2]

A concern that arises only after the immediate need for hunger is met, is the ability to have adequate nutrition. As a group of young men pointed out: "*Enough of food is not a guarantee. Nutritious food is*" [SS_FGD_AdolM1]. All community members identify fresh fruit and vegetables as foods that are rich in nutrients and vitamins that should be consumed in the interests of good health and well-being. Three respondents, two local government leaders and a traditional healer, made any specific mention of protein or meat. Because securing enough nutritious food to maintain health is a struggle

for most community members, the urgent need to satisfy hunger is a problem that surmounts community members' desire to eat nutritious food. Packages of processed foods available at lower cost even in the Autonomous Region, and community members say that they purchase these foods due to the affordable costs. Many are aware of the dangers of eating salty and fatty foods for those suffering from non-communicable (NCDs), yet as one traditional healer in Parang commented:

> *People in poverty cannot afford most of their essential health needs. They can't afford to buy nutritious foods and follow a proper diet. They just eat what they can afford—mostly salty foods and [foods] high in preservatives.* [Smb_IDI_THP 3]

With poverty also ubiquitous in Maguindanao, health providers explain that people are faced with a difficult trade-off between satiating hunger and spending money on health goods and services:

> *…because sometimes the people of the community can't afford some things needed for their health. Because the priority for them is food instead of other materials.* [Smb_IDI_DSF1]

The need for food security throughout the region is an urgent one, and key informants from civil society confirm this, saying that small scale farmers are encouraged to use genetically modified seeds for planting and pesticides as a strategy to mitigate the issue. Food is also used to incentivise behaviour change: children who attend school are provided food by the government's Fit for School initiative, a project funded jointly by the national Department of Social Welfare and Development and by the World Food Programme (WFP), a topic discussed later in this chapter.

Poverty is entrenched in all 3 communities in this study. Key informants commented that the problem of poverty and hunger extends to other communities and is pervasive throughout the Autonomous Region. For all respondents, then, hunger and poverty are interrelated, and in some cases, satiating the need for hunger, gives rise to crime. As one respondent says,

> *Having a good income will ensure enough food for the table. If there is no income, chances are people might be involved in criminal activities.* [Spt_FGD_AdolM2]

In speaking about the pull of the criminal world due to hunger, people from the community did not elaborate on the nature of those activities. The uncertainty brought about by poverty and hunger in a context of conflict—where a number of armed groups involved in narcotics, kidnapping, and murder operate—leaves people vulnerable to recruitment into those groups, according to an informant from a UN agency, who went on to explain that people begin quite young: children of

adults who are aligned with armed forces are sometimes used as informants or helpers such as cooks in militia groups.

According to a leader from Upi, "The presence of violence and the level of crime rate are alarming". *[SS_IDI_ComL1]*Crime is a pervasive problem in the Autonomous Region that community members largely left unaddressed in their responses to questions. Mindanao is well known as a producer of methamphetamines and is the centre of drug wars among feuding gangs and clans. The thriving drug business in the Autonomous Region is attributed to social issues of kinship and political patronage. Reports of drug gangs protected by the local elite are documented, but a possible explanation for the silence among community members is that some are themselves involved, sheltering their peers, knowing the grey areas of decision-making around going into crime driven by the desperation of hunger.

Study participants feel that problem of hunger is at its worst during cyclones, floods, and drought, causing "lean seasons" when the food supply is so low that food aid becomes necessary. They report that humanitarian efforts are extended to them by international agencies. Adolescent males viewed poverty as a determinant of their health: "*Any person that suffers from poverty like us, our health is at risk*" [Spt_FGD_AdolM2]. This view was echoed by other adolescent males:

> *I really don't think that there is a single person here who is healthy. I mean, most of the people here belong to the poverty line, actually below the poverty line. How can they be healthy if they can't even provide their basic health needs?* [Spt_FGD_AdulM1]

Jobs and other economic opportunities are of utmost importance to communities where few options for income generation are available. Few jobs outside the agricultural sector are available, and those who rely on agriculture for work, are employed only seasonally, usually on a daily wage basis.

> *Because if you have a job, you can provide food and medicines for your family; in other words, you can maintain a healthy lifestyle.* [SS_IDI_ComL1]

All community members echo the sentiment that having a livelihood or having a higher economic status results in better health. Having money means being able to satisfy the most important need: food for survival.

5.3.1.2 *Livelihoods and economic opportunities*

Community members report that opportunities for work are limited in Maguindanao. Most work is available in the agricultural sector. Study participants attribute their poverty and financial hardship to the limited opportunities for earning money in their communities. Most men are small scale farmers or tenant farmers, and others do some fishing. Fishing has limitations due to the cost of purchasing the necessary materials, community members report. For those who working in farming the land, the result is precarious employment. They report that they can only reliably find work in tandem with crop seasons, then only on a daily wage basis or at high borrowing costs from moneylenders who provide loans to buy seeds and other agricultural supplies. In Maguindanao, there are 6 major crop seasons for rice and corn, and job availability is dependent on that cycle. Others still depend on the availability of day labour for income.

> *In our barangay at Samberen, Parang in Maguindanao, there is land, but the problem is to how to get the product supply, the resources are there—but they are too expensive. And if even at harvest time, we buy them, so a very small income. So the farmers is unfortunate because the source of their food is in farming only, no other income.* [R5_Comm_Min_Ph]

This links back to community members' comments about not being able to produce enough foods for their sustenance. For that reason, income generation is even more critical. However, opportunities for earning money are limited and jobs are scarce, leaving people without the means to purchase food for consumption. Community members also describe being caught in a vicious cycle of poverty and debt:

> *Because of the poverty, because in our barangay, like farmers have the shortage of capital, so before they plant they go first to the warehouse to borrow some seeds or money. Then, if at the harvest there is a failure, they need to pay the money back. Then how can they have money left to buy food? Some of them do not have the money.* [R7_Comm_Min_Ph]

Interestingly, members of civil society express concern around farmers, who faced with a dearth of food supply, adopt agricultural methods that they view as harmful to communities:

> *People [in the community] say that we need more food, we need more harvest. They will go into synthetic or chemical farming. Things like that. They wanted to double their harvest but they don't have that knowledge that it has most devastating effect*

when you eat non-organic foods and you eat chemicals frequently. [R3, CivSoc_Min_Ph]

Adult and older males with work experience went further, speaking of adopting modern farming methods and leaving behind the organic farming practices of their ancestors. Many view pesticides and fertilizers as harmful to their health, and are concerned about the effects of chemicals on their food, and in turn their health. Changes in the agriculture sector and the related issues of land reform are discussed later in this chapter.

Using pesticides and synthetic fertilizers in farming could affect our body also. [Smb_FGD_AdulM_2]

Pesticides applied [to crop] may affect our health, unlike the time of our forefathers when they practiced organic farming. [Spt_FGD_EM_2]

Only a small number of respondents expressed any concern around this, and this can be attributed to a lack of options available to farmers: between not producing enough organically and producing greater yields, their choice in the face of hunger is quite clear.

5.3.1.3 ***Housing, water, and sanitation***

The problem of poverty brings with it a struggle for survival. Securing basic needs like food is only one component of the multiple difficulties brought about by poverty for the community members that participated in this study. In the Autonomous Region in Mindanao, housing is an uncertainty for most, and they speak about homelessness and living in shared housing—and these are brought about for a number of different reasons. They speak about the difficulties these in turn bring about, including waste disposal. Running water is available in only some people's homes, and safe drinking water is difficult to find.

The majority of community members identified living conditions as very important to their overall health, emphasizing the need for shelter. Homes in Maguindanao's communities are made of bamboo and dried palm leaves with thatched roofs, or in the case of some homes, with roofs of corrugated iron sheets. Homes belonging to better-off community members are made of brick and mortar. Respondents reported having to share housing with one or more families and having inadequate infrastructure for the number of persons in their barangay. While they did not elaborate specifically around the reasons for this, three major reasons are offered by civil society respondents.

The tropical climate and Philippines' location on the so-called Pacific Ring of Fire[35] makes homes vulnerable to damage—heavy rainfall, flooding, typhoons, earthquakes are common, and destroy homes all too often, making rebuilding too costly for single family households.

The majority of respondents have lived in the same general area for most of their lives, but have moved around within the Autonomous Region. In Upi, some reported they have only lived in their community for a few years. Community members were inexplicit about the reasons, and when encouraged to tell us more, they did not elaborate. From further investigation with a key informant from an international agency,

> *We realised that people have been displaced for a short period of time close to their homes. The largest cause of displacement remains natural disasters. The second cause of displacement is ridos or family feuds, and then armed conflict.* [Cot_KII_NGO4]

Another key informant supported this claim in a different way, mentioning that it is important that "*people are not scared to stay in their homes"* [Spt_IDI_CHW2]. Community members' silences are notable for several reasons: first, the group of people from Upi may have arrived as part of a relocation program—it is notable that all of the respondents who had relocated to Upi have ethnolinguistic backgrounds local to other regions of the Philippines, with faiths of varied denominations of Christianity. Tensions around the influx of Christian settlers in Mindanao have been documented [reference] and are cited as one of the catalysts for armed conflict by Muslim separatists, so their presence within the Autonomous Region is somewhat surprising. Armed conflict in the area continues despite a peace agreement with the largest of Muslim separatist groups, but many smaller ones that are dissatisfied with the current arrangement with the national government continue their secessionist movement.

Rido, or clan based conflict, is more complex and is linked, I learned during informal conversations with key informants, to traditional forms of land ownership—of communal tenure by clans or families—and many traditional landowners, called *datus*, lost their lands as a result of national policies that effectively seized their lands to resettle people from Luzon and Visayas as well as for commercial plantation ventures. In the context of continued conflict between separatists and the Philippine government, *rido* has expanded beyond issues relating to land control, I was given to

[35] (National Geographic Society 2015)

understand, and is tied to the arms and narcotics trade. Divisive in nature, *rido* puts pressure on community people to pledge allegiance to clans, drawing whole communities into feuding and retaliatory violence. This consequently leaves people in danger, forcing them to relocate for their safety.

Adequate housing becomes difficult in a context where homes are easily destroyed due to natural disasters, and with an added stress of people having to flee as a consequence of conflict, in addition to having difficulty with paying the costs of rebuilding, families often choose to share housing. This gives rise to problems of overcrowding. Some homes are equipped with electricity, but do not have piped water supplies or toilets. In general, development infrastructure in the three communities is rudimentary: the majority of study participants reported that they have no electricity or piped water. With only Level 1 water facilities available to them, people have access to manually operated water pumps, but safe drinking water is elusive. Community members all report that their water is not safe to drink, and that they often suffer from diarrhoea as a result. When I began field research in 2013, Maguindanao, was recovering from a cholera outbreak. A barangay leader said

> *Maybe diarrhoea is the cost of not having access to potable water. No, in our community we have the so called NAWASA [National Waterworks and Sewerage Authority], but not all people have access to that. So what we're doing is we if we are not sure if our source of water is safe, we advise them to chlorinate their deep well or water well, and other [advice] is [to] boil their water for drinking.* [R4_Comm_Min_Ph]

While, some water services are available to communities, sanitation services are lacking. There are no toilets in people's homes, nor did I observe any outhouse toilets in the barangays where people live. Study participants use the English term "comfort room" to describe the toilets they do not have in their communities. This is especially difficult among very religious people—both Muslim and evangelical Christians—who associate cleanliness with religious practices. As one male respondent explained,

> *Cleanliness within the person's body and their surroundings. Because cleaning your body, your house, and its surroundings is obligatory for us Muslims*. [Smb_FGD_AdulM2]

Yet in Upi, Datu Odin Sinsuat, and Parang, in a setting of poverty and overcrowded housing where there are no comfort rooms, open defecation is the only option. The normative links between health

and cleanliness are evident throughout all of the interviews and group discussions, and the understanding that hygiene and cleanliness are important for disease prevention is a concept that community members understand and value:

> *Bad health is improper hygiene and unclean surroundings. It will make us sick.* [Smb_FGD_AdulM2]
>
> *The surroundings are dirty—that's why the people in the community are unhealthy.* [SS_FGD_AF_1]
>
> *There is no mechanism that ensures proper sanitation like solid waste management.* [Smb_FGD_AdulM_2]

In Maguindanao, personal safety and personal hygiene are at risk. Housing materials are difficult to purchase where even food is too costly, and where homes are destroyed due to natural disaster or people forced to flee due to violent factions at war with each other. Compounded with poverty, where people can hardly afford the money to eat, people must pool together resources in order to afford even shared accommodation. These compounded issues in addition to the basic infrastructure for health: water is available for use, but not for drinking. Sanitation services are non-existent in the communities, giving rise to health issues like diarrhoea and cholera. The living conditions are literally oppressive, and knowing and implementing the solutions are a rather difficult task.

5.3.1.4 ***Education, health, and nutrition***

In Maguindanao, people are essentially left on their own devices to survive. Community members have discussed their difficulties with securing basic needs where little or no support is available to them. In turning to the topic of education, however, things are more promising for the next generation: "The Department of Social Welfare and Development (DSWD) helps poor children go to school" [SS_IDI_CoML1]. A community leader from Upi explained that the Department of Social Welfare and Development (DSWD), implements food assistance programs and other forms of social support in schools for disadvantaged children. For communities that have problems of food security, this kind of practical support acts as an incentive for parents to send children to school on a regular basis. A male member of the community in Upi recalled there was

> *Feeding for some elementary children about 3 years ago from the World Food programme (WFP) through the Department of Social Welfare and Development"* [Spt_FGD_EM_2]

In addition to the WFP, several development agencies and organizations provide assistance to the DSWD and the Department of Education (DepEd) and target schools as the focal point of health and social welfare initiatives: a respondent from UNICEF explained that in the past they had initiated a WASH initiative for handwashing, and AusAid also provides support through its Basic Education Assistance for Muslim Mindanao (BEAM). Key informants indicated that schools and learning centres are a vehicle through which the DSWD and DepEd address undernutrition and short-term hunger among public school children in partnership with the Department of Health (DOH) in the Autonomous Region. Additionally, civil society respondents described how the DepEd implements an Essential Health Care Program in partnership with the DOH through its Fit for School program. Fit for School promotes health and includes low-cost, effective hygiene interventions like handwashing with soap, brushing teeth, and de-worming. Respondents from civil society spoke about the intersectoral nature of the Fit for School program:

> *Fit for School is not community based but [rather] school-based. With Fit for School we are working with the Department of Education to incorporate the essential health care program in school levels. The essential health program, basically we are targeting the decrease of morbidity when it comes to respiratory related diseases as well as diseases in the digestive tract like for example the diarrhoea. Another thing is the decrease in the prevalence of tooth decay at the school level because previous studies have shown that the main reason why school children are having frequent absences because of having tooth ache. Basically, that is what essential health care program is targeting at the school level.* [R4, CivSoc_Min_Ph]

For all of these reasons, respondents from the communities in Maguindanao have a positive view of education as a determinant of their health. Firstly, they describe its important function in contributing to their development and well-being, particularly that of the children in their communities. Community members view education as a pathway out of poverty. Yet, as indicated earlier, many children are often unable to pursue an education because of the added financial pressures to their already poor families. Due to my affiliation with BRAC, I was aware of the immense success of the BRAC Education Program (BEP) which began implementation in 2012. Within 2 years over 1200 learning centres—small nipa huts with floored seating for children—were established in the Autonomous Region, and their high enrolment and retention rate may be attributed to the provision of funded learning materials in addition to the support of the DOH, DepEd, and international donor support.

While state support structures are put into place, many families are unable to send their children to school. This due to several reasons, the most significant being that financial pressures of affording food makes it difficult for families to purchase school supplies.

Many people withdraw their children from continuing an education because they are unable to purchase required uniforms and school supplies, despite the fact that the Young males express their agreement when one of their peers says that children must instead contribute to the family income:

> *Most of [our families] cannot afford the transportation and other costs like school supplies and school uniforms. We need to help our parents to earn for a living.* [Spt_FGD_AdolM2]

Local government leaders report they are mindful of these concerns, and one states "Books and other school supplies are also part of my plan…" [SS_IDI_LGL 1] A doctor confirmed that materials are needed *"to cater more students, to impart more knowledge to them, and to be able to teach efficiently"* [Smb_IDI_CHP2].

Civil society respondents confirmed that Fit for School is the result of efforts toward an intersectoral approach to development, with DepEd and the department of health (DoH) cooperating to bring the Fit for School program to schools. As a consequence of the intersectoral approach of education and health promotion, a nurse reported that children not going to school prevents them from acquiring important health information provided by the Fit for School program. A nurse stressed the importance of school attendance in order to gain health information, "because some were not going to go to school, they do not know or are not aware…."

All adolescent females participating in this study identified education as an essential health need. Each of them was out of school, and some were mothers. During focus group discussions with them, some were accompanied by their children, and one respondent was a nursing mother. There was consensus among these young mothers and their peers, one of whom said[36] "if I had the opportunity, I would go back to school to continue my studies." [Spt_FGD_AdolF1]

[36] The Autonomous Region has high dropout rates and teenage pregnancies. My questions are framed in terms of health, but the question naturally arises because of my affiliation with BRAC (and its education program) whether there were additional motives for this answer.

Despite the constraints of sending their young to school, young community members value education and expressed the importance of having a proper education in opening up opportunities, particularly jobs:

> *Yes, illiteracy is one of the bottom lines of our problem. With proper education, we can improve our opportunities to have good jobs.* [Spt_FGD_AdolM2]

Schools in the Autonomous Region are designated as evacuation centres at times of disasters such as the destruction of homes due to typhoons and flooding. Given the frequency of disasters and the ongoing conflict, schools are only intermittently available for use by school-aged children for learning purposes. Schools are also not left immune to the ongoing conflict in the region: a key informant from an international agency concerned with child welfare explains that militia groups will sometimes capture schools to use as a base for their operations, sometimes even recruiting children to their cause as messengers and helpers.

> *....before, there were a lot of reports that there are children in the MILF armies. And it's not only as combatants. They have also been used to support the conflict or the war against the government. Like even as cooks, messengers or [other] help—giving information to the armed elements.* [Cot_KII_NGO3]

5.3.2 **Health in our context**

In departing from community members' descriptions of their everyday experiences as they relate to health, we turn to their explicit perceptions around health, focusing on their own health priorities. This section of my findings satisfies the second objective of my research—to explore the experience of marginalised communities with specific reference to their perceptions of health needs. *Go4Health* is especially present here as the vehicle that provided access and structure: for an interface with communities and asking them about their health needs and priorities based on a very specific understanding of the health system. That peoples' imagining of health is quite different becomes quite evident when they reveal their most urgent priorities, which are not about health per se, but everything that contributes to it. The health system described by all study participants—community members themselves, and including service providers, human rights activists, and other members of civil society—is only a small part of what is necessary to improve health outcomes among communities in Maguindanao. I begin this section with a table illustrating people's most urgent health priorities. This is followed by respondents' comments on the health system, which I have unpacked into the following components: (i) paying for health care; (ii) care seeking and provision; and (iii) health knowledge and information. This shift is a direct result of *Go4Health*'s

somewhat biomedical lens—imposed no doubt by the consortium's understanding of public health through frameworks like that of the World Health Organization or international law—and of our own experiences as researchers. In these passages, people respond to that framing, referring to their lived experience to provide a richer and more complex expression of what they feel is needed for improvement, acknowledging the importance of and possibilities for empowerment in working closely with leadership.

5.3.2.1 *Identifying health priorities*

The table below shows the responses of 107 respondents who participated during the first round of data collection in Maguindanao. During each interview and focus group discussion, respondents identified, in their own words, their most important health priorities, and ranked them in order of importance or urgency. One of the most important findings in this table is communities' dual focus on health: first, through a holistic perspective, and the other, a biomedical one. The table is divided accordingly.

All of the lay community people who participated in this priority ranking mentioned this was the first time they had been invited to participate in identifying their needs. Many felt that processes like this are important, and their views around how to ensure needs are met are elaborated in Section 5.3.3.

TABLE 5-2 RANKED ESSENTIAL HEALTH NEEDS BY RESPONDENT CATEGORY (N=107)

Essential Health Need	Community People (n=91)	Leaders (n=4)	Health Providers (n=12)
Infrastructure for health			
Food	69	1	9
Agricultural supplies	59	3	1
Safe water facilities	53	2	10
Sanitation	48	1	2
Clothing	45	-	2
Shelter	45	-	-
Financial security (including income, job opportunities, capital for business startup)	42	1	-
Personal hygiene kits	39	-	7
Livelihoods	31	-	2
Education (primary and secondary)	21	-	-
Cleanliness/clean environment	15	-	-
Paved roads, farm to market	8	-	-
Electricity	7	-	-
Basketball court	6	2	-
Land titles	7	-	-
Health systems change			
Health facility	62	2	3
Medicines and medical supplies	62	2	9
Maternal, neonatal and child health (incl. immunization)	39	1	1
Health providers	24	-	-
Access to DOH programmes	8	-	-
Doctors	7	-	-

Community members' rankings in this table confirm the findings of the preceding section around everyday life in the margins: for everyone, food, or having the means to buy food, is the most essential need for health. As a community health worker explains, a sick person may require

medicine to treat an illness, but their first need for individuals is food. The regular experience of poverty and hunger in the face of conflict and natural disasters renders health facilities and medicines important only after people's basic survival is attended to. What is clear for community members is that there is a dynamic relationship between health and food, livelihoods, and the surrounding environment, both natural and structural. Some of the priorities may overlap—for instance agricultural supplies, food, and financial security—as respondents could use agricultural supplies both for food sustenance as well as financial security by selling surplus. This all points to the dynamic relationships between livelihoods, food security, and financial security however keep these categories separate and true to the community members' perceptions. One unexpected result in the table came from young males, whose identification of basketball courts as a need highlights the importance of play for well-being, pointing to an understandings of health beyond the physical and structural.

Respondents spoke at length about health and its links with cleanliness. Community members all said that an imperative for good health is cleanliness and they iterated these in terms of self, family, home, and environment. Good health is seen as a result of cleanliness which comes about from keeping one's body, home, and surroundings clean—and participants articulated this need in citing their communities' most essential health needs. The recurring theme of cleanliness is strongly evoked in the priority table—respondents spoke about sanitation, personal hygiene kits (these include toiletries like soap, shampoo, toothbrushes, toothpaste, sanitary napkins), and the importance of cleanliness and a clean physical environment.

Some structures in barangays have piped water supplies from water tanks but most barangay residents rely on community water pumps as their source for water, reporting water as a highly essential need for improved health. Pit latrines are visible beside BRAC's community based learning centres. People spoke about the need for toilets, using the term "comfort rooms"—seems there is a discomfort in using terminology to describe the problem of open defecation and waste management. Health promotion messages at schools and a variety of media (posters observed in villages) and behaviour change communication is quick when linked to religious practice and values like cleanliness. Unlike the rest of the country where water and sanitation services are a part of everyday living, these are a luxury for Mindanao's rural communities, creating a tension between the incoming health messages which the rest of the country can act on and in Mindanao people do not have the infrastructure to keep clean.

The intersectionalities of people's multiple identities and experience emerge in community members' understandings of health and their descriptions of the health system. Interestingly, one of the most commonly talked about concerns among respondents does not appear on the table as they did not explicitly speak about it as a health priority: the need for peace and stability. Study participants all identified several determinants of health in the table above, but when asked about what it means for a community to be healthy, people across age groups spoke about the importance of wellness in terms of peace:

> *The community is healthy when there is unity and cooperation…and peace and order.* [Smb_FGD_AdulM2]

> *Well, I guess for me, having peace and order in the community means being healthy. When there's no war or any kind of violence at all.* [SS_FGD_EM1]

The experience for residents of Parang has been particularly difficult: one key informant, a community health worker, speaks about their ideals of having a "community with no armed conflict, so people are not scared to stay in their homes" [Spt_IDI_CHW2], referring to the problem of displacement in Mindanao. Others in the same community echo concern around being forced out of their homes as a result of armed conflict and warfare.

> *A peaceful community is one where no conflict is going on, I mean armed conflict. Those farmers can do their usual work without hazard from outside, and also people in the community are very cooperative.* [Smb_IDI_ComL4]

Peace is integral to the communities' sense of well-being. At an individual level, community members spoke about feeling "safe" and the importance of being able to "sleep peacefully" as a factor of good health. They then went on to speak about peace and order as important for a healthy community, some using peaceful community and healthy community synonymously. If the absence of conflict is seen by communities as a necessary condition for good health, peace is an indicator for the wellness of one's community, and women in particular, linked this with mental health. Community members see mental health as an integral component of health, as demonstrated by a local government leader's own understanding of wellness, "*health is a state of being mentally, spiritually, and physically fit*." [SS_IDI_LGL1] Another community leader points out the anxiety that comes with poverty can be debilitating:

> *However, you're obliged to work hard to have money to feed your family…..you'll recognise it when you feel tired even though you don't do a thing. I guess it has*

> *something to do with being stressed out. Sometimes mental stress is worse than being exhausted from hard day's work.* [SS_IDI_ComL1]

Mental hygiene—that is, maintaining mental health and preventing mental disorder—is a concern for community members. Respondents have different ways for coping with their circumstances that range from being engaged sports and recreation (young adults), trying to be content with their lives (adults), and turning to their faith (older persons and traditional healers). Conversely, respondents' references to the use of narcotics indicates widespread use which they view as a detrimental to both their mental and physical health. The essential pre-requisite for "Good health is not having vices like drug addiction." *[Smb_FGD_AdulM2]*

5.3.2.2 ***Access to entitlements***

With pervasive poverty as the backdrop in Mindanao, being able to afford health care is a concern that prevents people from using health services. We know from their own accounts that problems of poverty result in respondents having to contend with competing priorities in determining which needs they must meet. The urgent need to fulfil individual and family food requirements overshadows all other expenses. It is common for out of pocket expenditures to add up to large sums of money, which people cannot afford. And although PhilHealth is a nationally available insurance program that has funding allocated for the poorest and most marginalised peoples, the majority of respondents report knowing little or nothing of it. In Upi, a community leader explains:

> *They say 90% of us already qualify for PhilHealth, but I think the problem is [the] distribution [of membership cards]*. [SS_IDI_ComL1]

Some respondents reported receiving partial financial assistance for medication and hospitalization through lodging requests with their barangay leaders and mayor. Civil society members agreed that the particulars of PhilHealth's program for "indigent" populations are unclear to most who qualify:

> *For the indigent, speaking of the common [people here], the indigent people are the poorest among the poor. They only pay 150 [pesos] per quarter to maintain enrolment in PhilHealth.* [R3_CivSoc_Min_Ph]

A respondent who works in the public health system provided some conflicting information, saying that Internally Displaced People (IDP) and indigent populations are "immediately covered by PhilHealth" and are expected to pay nothing for health care. Yet the initial respondent explained that nepotism and favouritism are factors that determine who can access specially allocated funds

for the poorest. Links to barangay leaders and the municipal mayor can make health care more accessible financially, according to that respondent, community organiser for a local NGO:

> *This situation of an IDP happened in a very remote municipality. We took her into a barangay health station. The barangay health workers would not provide her any medicine. They said if the Mayor will sponsor you could have medication. We went to the Mayor many times but he wouldn't give the sponsorship. If the health system that we have is still under the control or influence of the local politicians nothing will happen.* [R3_CivSoc_Min_Ph]

Incidents like these are not uncommon at public health facilities, according to community members who already struggle with poverty and wish to avoid incurring out of pocket costs for fear of not being able to afford food. Out of pocket payments are a major deterrent, and people report that they seek care in the public health system only when a patient is seriously ill. Instead, community members seek out the care of traditional healers and midwives when they require medical attention:

> *The hilot was able to cure my fractured bones, and you only have to give donations to pay for their services.* [SS_FGD_AdolM1]

For the residents of Maguindanao, the informal health system is the first and obvious choice for care seeking. They can pay what they want, and still avail services, rather than being turned away for lack of enrolment in a national insurance program that is wrought with corruption.

5.3.2.3 ***Care seeking and care provision***

In the formal public health system, according to respondents, health service delivery primarily takes place at facilities—barangay health centres and at the public hospitals. Because of the time it takes and the difficulty involved with getting to the barangay health centres, respondents say they prefer to seek care in the their own communities. In the

Respondents say they typically seek care from the informal system of *albularyos* and *hilots. Albularyos* are healers in the community who use a variety of methods to treat people that include the use of herbal medicines, prayer, and traditional knowledge passed down through generations. Community members seek out *hilots* exclusively for problems relating to bodily pain—they can be understood to be chiropractors but some people also use the term to describe midwives, possibly because midwives also provide services like pre- and postnatal massage for women and babies. These two roles are very important: *albularyos* and *hilots* are the most sought after health care

providers by community members. Study participants say that this is because they are easily accessible, financially and physically:

> *The albolaryos are always available, they're not costly and we don't have to go far just for us to be treated. Also, albolaryos are more effective than the doctors…. I decided to go to the albolaryo for a consultation. As a result, I was relieved of my stomach-ache and I don't have to pay him large sum of money.* [Spt_FGD_AdulM1]

A cadre of public health workers, called barangay health workers, are accredited to provide primary level health extension services to the members of their communities—these include health promotion, maternal, neonatal, and child care services, and providing assistance at the point of immunization. They live in the communities they serve and work on a volunteer basis, and are provided a small stipend for costs incurred during duty at the discretion of the Local Government Unit. In remote areas like Maguindanao, barangay health workers are well regarded, but are perceived to provide services at facilities. A barangay health worker, also a schoolteacher in the community, explains the kind of services the facility she is linked with provides:

> *[There is] only the health centre. It is funded by the ARMM Social Fund project, which is supported by the Local Government Unit. The centre deals with injuries, tuberculosis, and diarrhoea. We are using it [to provide services] twice a week. We are using it because it will help us sustain our health needs by providing medications. It will help monitor our [community's] health condition, most specifically for our children.* [Smb_IDI_CHW3]

For the community in Upi, the scenario is bleaker, according to one of its local government leaders:

> *We have no medicines or health facilities in our barangay. No organizations have visited us to offer help in terms of health.* [Spt_IDI_LGL2]

Instead, that community shares a health facility with another barangay:

> *There are no available health services here in our community. There may be a health centre but it is not accessible to all. It is too far.* [Spt_FGD_AdulM1]

Communities reiterate their holistic understandings of health in their descriptions of health service delivery, referring not only to the delivery of health services, but also to food, safe water, and sanitation, which they consider to be essential health needs. Respondents view food and water aid as a component in the delivery of health services. Community leaders and health providers report

that services are largely implemented by the national and regional government in partnership with international organizations and local NGOs:

> *We already have a shared health centre with Barangay Gadungan…also a water system which was donated to us by Single Drop*[37]. [Smb_IDI_ComL4]

> *There is the World Food Programme, which provides us food supplies, and Single Drop, which is providing us safe and clean water.* [Smb_IDI_THP 3]

Respondents acknowledge the varying experiences of their different communities, and in particular referred to Upi, the province in which Sitio Solo is located, as a "first-class municipality" with a responsive mayor that results in a satisfied constituency. The mayor, community and civil society respondents report, is especially dedicated and active in his duties, and is lauded throughout ARMM.

Even when there are rural health unit and barangay health stations, they are not immune to the conflict in Mindanao. One representative from UNICEF sheds light on why some people are unable to access health services:

> *Sometimes because these facilities are occupied by the armed forces or armed groups. They go there because they use it as their headquarters. So that's another problem in terms of health that because these armed people occupy these health facilities so there's no health services there. And then there have been a lot of reports about that before especially when there was conflict between the MILF and the government. And even here, when you go to - I don't know if you've been to Datu Piang before? On the highway you can see there's a barangay health station that was just occupied by the military. And then in armed clashes, sometimes the barangay stations are hit or when the government used the howitzers, cannons, shelling. So sometimes health facilities are hit. That adds to the problem.* [Cot_IDI_INGO1148]

Another respondent working with human rights issues talked about the same issue, referring to takeovers of rural health units, the first point of entry for community members into the health system:

[37] "A Single Drop for Safe Water" is a Filipino service delivery organization focussing on water, sanitation, and hygiene.

We have also problem to the attacks to these rural health units. When there is conflict, military men or non-state armed groups stay or go near by these health units so people are hesitant to go there. [R5, Dial_CivSoc_Min_Ph]

But some are worse off than others, and civil society members working directly with communities identified specific groups as lacking essential information for securing their health needs:

…people in the community have less knowledge of their right to avail health services. Yeah, especially the women. Specially the ethno-linguistic groups in the pocket villages. They are being left behind in terms of health services. [R3, Dial_CivSoc_Min_Ph]

Respondents from civil society report that the Department of Education is working closely with the Department of Health to improve the health care available in schools. With the availability, I think

DepEd is linking now with the DOH to improve the quality of care available in the DepEd schools… like for example the de-worming done twice a year and it is…done by the DOH. So I think, we are just consolidating the efforts so that one main goal will be met. [R4, CivSoc_Min_Ph]

There is a strong sense among community members that services are best delivered by non-government organizations:

International non-governmental organizations are also active to solve problems in our community. Also international NGOs were very active in assisting us, such as [building a] water system, comfort rooms [toilets] and others. [Smb_IDI_ComL4]

Another leader, a local government representative acknowledges external assistance as responsive, going beyond, perhaps, what was expected of them:

Some NGOs lend us a hand in these matters. OXFAM, Single Drop and World Food [Program] - all of them helps us, not only to make sure we have something to eat, but [they] also ensure that it is safe and healthy. [SS_IDI_LGL 1]

Another health services available to communities in ARMM is:

Currently Muslim Youth Religious Organization (MYRO) is working with World Health Organization with the Central Emergency Response Fund (CERF) Project. We are doing the repair of Barangay Health Stations in Midsayap in Barangay

Sambulawan and Salunayan as well as in Maguindanao. We are also giving medication to them. [R9, CivSoc_Min_Ph]

The Department of Social Welfare and Development (DSWD) provided feeding programs and Philhealth cards. Philhealth is the universal health care program of the Philippines. [Smb_FGD_AdulM_2]

The communities report having a range of different kinds of health providers in Mindanao. This wide-ranging group consists of workers from both public and private sector, with informal qualifications to government-certified physicians. Respondents view barangay health workers and other health providers as responsible for their health.

We have a health worker and midwife, but they do not live in our community. [Spt_IDI_CHW2]

Health care providers are well-regarded, and in this study, a number of providers participated. Community members describe them as "nice". One respondent, a community health worker herself, reports:

About the good experience that I had with the health centre is that, the midwife really treats us very well. They attend our needs. And in terms of bad experience I had, some people don't like me as their community health worker but it is okay. What I have to do is to treat them well and do my responsibilities. [Smb_IDI_CHW3]

As community members, health workers experience face the same challenges as their peers and civil society members are concerned about their ability to work:

There are barangay health workers in the area, but how can they work without any financial security? I mean, there are volunteers in the area but the problem is how can they work without the security of their own needs? Financial security they don't have, so how can they volunteer or how can they help people if they themselves they don't have any food security at all? [R9_CivSoc_Min_Ph]

5.3.2.4 ***Knowledge and information***

Respondents learn about health primarily through schools. DepEd's Fit for School program operates in primary schools and respondents from civil society spoke about their intersectoral approach with the department of Health:

> *Fit for School is not community based but [instead] school-based. Uh… with Fit for School we are working with the Department of Education to incorporate the essential health care program in school levels. The essential health program, basically we are targeting the decrease of morbidity when it comes to respiratory related diseases as well as diseases in the digestive tract like for example the diarrhoea. Another thing is the decrease in the prevalence of tooth decay at the school level because previous studies have shown that the main reason why school children are having frequent absences is because of having tooth ache. Basically, that is what essential health care program is targeting at the school level.* [R4, CivSoc_Min_Ph]

Yet many families find themselves unable to send their children to school due to financial reasons, and report there is a gap in their health knowledge. A doctor in Samberen identifies Muslim communities as particularly in need of health information. Religious identity is ever present—it binds people together, to help each other in an environment of need, but the pervasive limitations this causes for the Muslim community in Mindanao also has underlying tensions:

> *Most of them are Muslim areas. One problem is the literacy, their literacy rate is low… They don't know what they need to know because they lack education.* [Smb_IDI_CHP2]

Some community members express they want to help only those they can identify with:

> *"If I have money, I will help those people poorest among the poor but only the Muslims."* [Spt_FGD_EF2]

One nurse sees health outcomes as directly dependent on group identity:

> *Because we know that there are people that depend on their traditions in their religion, the same as others in Islam, they are not aware that they need immunization for their children to avoid diseases. Some of them they think that if you have a fever the child has no need for vaccination, because they are going to be sick anyway—without knowing that vaccination is a medicine for the body of the child to avoid sickness.* [Smb_IDI_CHP3]

Barangay health workers are primary care service providers who serve the communities as an important resource for health information. One recounts her experience of doorstep immunization services:

> *I had my experience with the community, that during our house-to-house visitation for immunization most of the parents didn't allow their child to be injected by vaccines because of their perception that they might die or might acquire some illnesses that may lead to death.* [Smb_IDI_CHW3]

This mistrust of vaccination and reluctance to immunize their children was confirmed by a respondent working with a UN agency:

> *…Not all parents will submit their child for vaccination or immunization. Because of the limited understanding on the importance of immunization.* [R8, CivSoc_Min_Ph]

For people working within the health system, looking through a biomedical lens at health priorities is perhaps expected to be inevitable, but to this nurse from Samberen, food returns to the list of health needs:"Our urgent needs here in our community are medicines, foods and health education."*[Smb_IDI_CHP3]* Another service provider, a doctor, speaks about the difficulties of changing community health-seeking behaviour:

> *We need to increase their health–seeking behaviour… so not only in Parang but in the entire Autonomous Region. They're not aware of the different programs…. a way for them to be aware is [to have] more advocacy and strengthen health education.* [Smb_IDI_CHP2]

Not having enough knowledge or enough information about health and how to go about acquiring that knowledge is a common problem for community members. Some health workers report providing such information:

> *Yes, because we inform to the people of the community to know and updated about the health related [issues] until the barangay officials are active, and to encourage people to participate all the time.* [SS_IDI_CHW1]

Others expressed hesitation to participate in or contribute to public consultations, relying instead on others:

> *I prefer not to. Besides I have no knowledge in that field and its better if we leave it to our leaders, it's their job anyways.* [SMB_IDI_THP 3]

Health Organization Mindanao (HOM), an organization working directly with communities, reports their successes:

> *I would like to share more on the community health awareness activities and information dissemination with regards to health seeking behaviours of the community because in our part the HOM. As experience in our nutrition program in partnership with UNICEF, we can see the importance of community mobilization learning on informing the community on what is really happening in the field. For example, if they do not have an access to health facility, why not teach them to use the available resources in the community. For example, the use of oral dehydration solution because it is still effective. In south Upi, one of our areas, it is very far from the rural health unit and they have difficulty. Our team went to the area to conduct consultations and health awareness.* [R1, CivSoc_Min_Ph]

But the logistics of supply of medicines remains commonplace in government clinics, with stock outs relatively frequent. Communities report their difficulty accessing basic medicines:

> *Medical supplies are always out of stock, and some of them are expired.* [Spt_FGD_AdulM1]

Another respondent, an *albularyo* [traditional health provider], confirms the use of expired medicines at the rural health centre, and also relates her preference for traditional medicine:

> *There is a health centre in the población [literally 'population', refers to central area of business for the municipality], but I don't go there. The medicines are expired and ineffective. I went to the health centre once, I had a cold and flu, and I was out of herbal medicine. So I decided just for a day or two, I'll take the ones they have at the centre. When I got there and asked for medicine, they gave me an expired one.* [SMB_IDI_THP 3]

A barangay doctor supports the claim that rural health centres are inadequately stocked:

> *The health centre is not providing medicines. So if you're the patient, you'll just go directly to Parang because it is operates 24 hours.* [Smb_IDI_CHP2]

The exception to this appears to be the immunization programs, where vertical programs, well-resourced from international agencies, ensure supply. Respondents report vaccines to be a most readily available and accessible medical product, delivered by barangay health workers offering

periodic doorstep services. While Siput has a shortage of medicines, a nurse reports in from Samberen reports that the clinic in which is provides services is adequately stocked with medicines but that other medical products are lacking. Respondents report having to go to tertiary level health facilities due to a shortage in medical technologies such as X-rays and ultrasound machines.

> *We use our clinic and hospitals but suddenly our hospital here are incomplete like it don't have an x-ray machine if the patient need an x-ray we bring our patient in Cotabato, and we also need to pay for the gasoline of the ambulance with the cost of 500.00 pesos.* [SS_FGD_EF1]

In the end, the most essential of health needs for the communities is food, which one of the leaders in Maguindanao province was quick to identify that:

> *There are also good practices, one example is North Upi, the mayor is doing good in their [community] tuberculosis program. They knew that people cannot sustain their medicines because they have no food when they have to take medicines. So when the mayor knew that—and the doctors and other health officials—they have this program that gives one pastil (plain rice wrap with banana leaves) and one egg every morning before the patient take their medicine. That is why there is a very high rate of cure in Upi.* [R5, Dial_CivSoc_Min_Ph]

Yet in other communities, even the essential infrastructure and resources are not predictably provided: precarious situations do arise because of shortages in resources, seriously impacting on the quality of service offered:

> *Especially in Midsayap because we have many areas there where there is a presence of Barangay Health Stations that really need repair and renovation. And they also need medication. There is an existing structure but they are not using it because they find it useless in the community. Uh… most of the people coming there are the pregnant. Those who have fever go with their children but they don't have paracetamol. The midwife just advises them to drink plenty of water.* [R9, CivSoc_Min_Ph]

> *Because if we have medicines, if don't have enough nutritious foods to eat every day it's useless, because not all the people will provide 3 times a day foods to eat.* [Smb_IDI_CHP3]

An important issue emerging from civil society respondents is their concern around an uninformed citizenry that is unaware not only of the health services available to them, but also of their rights and entitlements. That poor patients had little information around their own rights is understood, but civil society expressed frustration around limited advocacy work and citizens being ill-equipped with the necessary literacy and skills. Only two community members are conscious of themselves as citizens holding rights, but its deeper meanings around what this could translate into in terms of a system responsive to them is elusive:

> *Each and everyone has their own rights; we have the right to choose who will be our leader, we have the right to live peacefully and we have the right to not be abused, we have the right to defend ourselves.* [R6, Comm_Min_Ph]

Civil society respondents are quick to make the relation between health information and having rights as duty bearers—but for community members, the need to know about their rights is crucial in demanding and securing health services:

> *That poor man who went to the hospital that did not receive proper medical attention has to submit to the idea that he deserved what he got. In the eyes of others who have enough knowledge of rights, they felt pity for them. But for the patient, it is fine for them. Because he has not enough information about his rights, he is bound to believe that the way he is being treated is just fine, which is not true. He was taken advantage of by the nurse employed in that hospital, who was being paid to serve that poor man. There is a wide gap between giving services and access to services. But people just tend to be passive. We just submit to what the health providers did to us even they did not provide us services.* [R3, CivSoc_Min_Ph]

In support of her comments, community members describe their feelings of helplessness. Instead, many report seeking solace in their faith, hoping that things will get better:

> *I will pray to God to give us an organization to facilitate solving the health problems in the community.* [SS_IDI_THP]

Change will not easily come about without action—as one young respondent mentioned when asked how she could ensure her health needs could be met: "*be active and participate*" [Spt_FGD_AdolF1].

5.3.3 **The context of change**

The experience of marginalisation in Maguindanao is evident in people's descriptions of their everyday struggles: in the following passages, community people and those who work to improve conditions all point to the social, political, and economic structures that interact together to result in the worst health outcomes in the Philippines. With their most basic needs unmet in a context of fragility, there is a sense among respondents that things are not right, that someone should do something to change the status quo.

In the two previous sections, community members have been the primary respondents, and here, responses from members of service delivery organization and civil society emerge more prominently. Lay community respondents describe problems with knowing about their rights and accessing decision-making mechanisms intended for citizen participation. They place importance on their barangay leaders, but look to NGOs and the international community for more reliable outcomes, but civil society respondents describe their concern around an uninformed citizenry with little capacity to demand their rights and entitlements from a system of health governance they characterise with problems of corruption and internal politics. In the end, we are left with a question of how critical consciousness can be raised so that people have the capacity to act.

5.3.3.1 ***Decision-making spaces***

For the community, priorities are identified primarily by the local elite and people working in decentralised government institutions. Public participation in priority-setting and decision-making matters is a value community members report as important yet they report having little opportunity to do so:

> *We need to engage in such processes and be aware about issues, but we do not know how we can participate.* [Spt_FGD_AdolF1]

They report that decision-making at the barangay level is only sometimes inclusive, in that lay community members are involved, but that one must be *invited* by the barangay in order to participate at such meetings. Invitation-only consultations are the norm according to community members, and the meetings are comprised of members from the community elite and others from the community who are close to or favoured by local leaders:

> *Barangay officials determine the persons who are qualified as a representative to decision-making.* [SS_FGD_AdulF1]

In reference to governance as a component of the health system, community members know there is a structure within which a community voice must be heard. However, such platforms are inaccessible and unknown to the majority of people. Many reported they have never participated in a consultation for local level decision-making, and none of the respondents are aware of national or international processes in which they can participate or contribute. Beyond lodging requests and completing citizen concerns at the barangay level, they report that they do not know of any other pathways or processes to secure their needs. A decentralised DOH means that barangay leaders—the mayor and other officials—have discretionary control over fiscal and administrative arrangements, and because of this civil society members stress the importance of consultative processes for decision-making, referring to national law:

> *According to the law, you have to do this community consultation… Community participation is very crucial in achieving health and also good governance. These two must go hand in hand.* [R5, Dial_CivSoc_Min_Ph]

Practitioners from service delivery organizations all concur on the importance of community participation; however, they are aware that consultations are problematic, that inviting an opinion implies and intention to respond, and expressed their apprehensions:

> *Sometimes, we health workers… are reluctant to do it. For instance, you ask them "What are your problems" [and they respond] "We don't have water". Then those people expect that the next time you go there, they will have water. How can we do that if we don't have money? What do you do after the consultation if you don't have money to address their problem? So we select barangays for consultation only if there is money. We do consultations for specific problems, but if there is no money, don't ask about that problem to the community members. Because if you cannot solve that [problem], they will get mad at you and confront you.* [R11, Dial_CivSoc_Min_Ph]

A human rights lawyer in the civil society group questioned the validity of consultation, the ambiguity of what actually represents valid community representation, and the openness of consultation processes to abuse.

> *For the community participation for example the barangay assembly, there should be percentage of attendance from the community before the IRA will be released. If that will not be achieved there will be no allotment for that barangay. But there is always issue of the credibility of the attendance. The officials may just manipulate it*

so that the budget will be released. If you go to the DILG - the in-charge of the LGUs - the papers are good. There is complete representation of all sectors. But in our recent assessment on the state of democracy in ARMM the people were not really consulted. [R5, CivSoc_Min_Ph]

Others still report that consultative meetings with community members can result in requests for services to which the health system is unresponsive—or where the necessary response of the health system cannot accommodate the clearly expressed desires of the community:

One example is in South Upi. The government is very active and the political will is very good. A local ordinance says that all mothers should give birth at the health centres. When we have the consultation with the IP women they said they are against the Ordinance because it is not relevant to them. The health centres are very far. Along the way they might die. They want to what they call "panday taw" – that means traditional midwives should assess the delivery of the baby at home. Although they are very assertive but because of political will but they don't coordinate so the health system is still inefficient… I know that there are traditional midwives who are trained but in Upi they are eradicating that [program] now. They still stick to the policy that requires all mothers to give birth at the barangay health centres. The IPs feel a loss of their dignity. Even though they are trying to achieve or realise their right to health, that right to health must not compromise the right to dignity. [R5, CivSoc_Min_Ph]

5.3.3.2 ***Leadership***

The issues of consultation overlap with the governance of communities. Respondents place importance on their barangay leaders and, when discussing issues relating to governance, were prescriptive about leadership and the roles and responsibilities of elected leaders in their communities. Local government officials and leaders are responsible for handling government projects and funds, and respondents view them as decision-makers who should ensure positive outcomes for the community. Community members expect action in favour of their community, saying that barangay and other government officials must ensure that community needs are met. As officials of the smallest administrative unit of government, their leadership directly affects the community.

The community asserted that the barangay officials are responsible for them, and must work to solve community problems. In addition to health care providers, respondents feel that the government is responsible for their health, with local government leaders bearing immediate responsibility in ensuring the constituents' good health and overall community development. In an absence of these, older women stressed the importance of responsive and accountable governance:

> *The government should provide us help. Because they're the government; they govern us. They must help us. It's their obligation.* [SS_FGD_EM_1]

Community members stress that the government, whether local, regional, or national, is responsible for their well-being. Because there is a high degree of discretionary power in political, administrative, and fiscal areas of local governances, they report it is important to have someone from within their own community represent them:

> *Yes of course but in this Sitio* [enclave in a barangay] *there are no barangay officials who are from here so we felt disregarded.* [Spt_FGD_EM2]

A local doctor, when he is asked about why health needs are unmet, he answers:

> *We [the people of Mindanao] are less prioritised. The Philippines government is not sincere and does not help us.* [Smb_IDI_CHP2]

Generally, the health system is perceived as politicised, both at national and local levels. One municipal health officer refers to the difficulties navigating the devolved health system, where Local Government Units have control over budgets and priority-setting, but describes the tensions with working with the regional and national health system:

> *There is money. But the money is not going to the place where is supposed to be given… there are a lot of factors that must be considered. Number one is politics. When I say politics, it's not only being done at the local level of politicians but there is politics inside health also. We have the national and regional health offices, and there is politics there.* [R11, CivSoc_Min_Ph]

Conflict flares up often and unexpectedly, and even the government's involvement in the violence is a constraint if community members are prone to mistrust. One key informant working with international agencies mentioned this, referring to the study setting I was asked to avoid:

> *In fact, recently I think there's this conflict in that municipality in Maguindanao. I don't know if you know—this was about one or two weeks ago. So there have been shellings also by government.* [Cot_IDI_INGO1]

The uncertainty around who is responsible for violence—whether it is small militia groups, the regional or national government—is confusing, and this is one of the reasons why respondents, particularly lay community members, are more comfortable speaking about their closest point of contact with duty bearers: the local government.

Respondents from civil society note that governance and health are related, stressing the importance of good governance at local level. Corruption is considered by community and civil society members alike as rife throughout the governmental system. One respondent described corrupt practices of handling money:

> *Public officials at the barangay level, when they are elected, think of internal revenue allotment (IRA), where the budget comes from, as their own money. And they put this money to things that they like putting up their own houses, buying cars, and not for the common good or for the public.* [R5, CivSoc_Min_Ph]

Community members in Sitio Solo in Upi in Maguinadanao revere their mayor, who is referred to as an example of community advocacy and effective leadership. The same is true for Samberen:

> *Barangay Samberen became a healthy community because of the good leadership of the local politicians. We have now better access to development programs and services. It gives hope and inspiration to the local residents.* [Smb_FGD_AdulM_2]

> *The society could affect the health of the community if there is no mechanism that will ensure proper sanitation including solid waste management. Effective leadership is one of the important factors in order to have good sanitation in each community.* [Smb_FGD_AdulM_2]

For all respondents, the relationship between constituents and leaders is an important one, and they feel that that barangay officials must be actively involved with the community, discussing problems regularly. One community leader relates his sense of civic duty:

> *As a barangay chairman, it is my responsibility to know [of] different problems [that] arise in this community. One of these are health problems, so I can do something to address these problems. One solution I can think of is educating the people about health and what it means to be healthy, what they should do to achieve being healthy. Aside from that I can report or inform these to the LGU so that they can give us assistance in solving these health problems.* [SS_IDI_LGL 1]

Community members look to traditional hierarchies for conflict resolution and seek out formal institutions only after these solutions are exhausted:

> *First, the "lopon" the oldest male leader in the community and then, to the BJA or Barangay Justice Association, and if they can't solve, we will go to the kagawad and still they cannot resolved, then that's the time we go to the chairman of the barangay and still he can't solved lastly we go to the office of the mayor to endorse the problem.* [Spt_IDI_THP1]

According to civil society groups, community members place importance in local social hierarchies out of necessity. They report that local leaders have discretionary power around barangay health worker recruitment, their remuneration, and that local health officers must be diplomatic in their dealings with the leaders so as to not jeopardise their positions.

One respondent further explains that the expenditures relating to each barangays' Internal Revenue Allotment (IRA)[38] rests on the mayor, bringing about the question of accountability:

> *So for the accountability of public officials at the barangay level—when they are elected, they think of this IRA as their own money. And they put this money to things that they wanted to like putting up their own houses, buying cars—and not for the common good or for the public.* [R5, CivSoc_Min_Ph]

Some key informants added that community members allied with mayors are better able to access entitlements like PhilHealth. They view political patronage as very active in the Autonomous

[38] Funds for local health activities are derived from local income and the Internal Revenue Allotment devolved to Local Government Units (Ramiro et al. 2001)

Region, saying that health worker recruitment depends on patron-client relations. Because of this, they highlighted the imperative for accountability and community participation.

Lay community members do feel a sense of duty, speaking of having responsibilities as individuals, yet could not articulate how these can be manifest in public life. This sense of a lack of process, and the absence of clear pathways for community engagement in decision-making has resulted in a resigned acceptance of the status quo of unmet needs, with some, particularly male adolescents, taking a fatalistic view of their conditions, and "*ask for assistance from God*" [Spt_FGD_AdolM2], and other respondents noting, "*Whatever they [the leaders] will do, we don't care much anymore."* [Spt_FGD_AdulM1]

This is echoed by other lay community members who report they can remind officials about their needs, but that ultimately, the ability and will to take action rests on barangay officials. Instead many report that:

> *We solve our own problems. We don't bother going to the authorities except if it is really needed.* [Spt_FGD_AdulM1]

A city health officer surmises the problem of unmet needs is one of corruption and a lack of accountability in the use of development funds:

> *Somebody may ask if the problem is money. I don't think so. There's money. But how it is spent at the local level is the big question.* [R11, CivSoc_Min_Ph]

If corruption in the health system is a problem, the inverse is political will in order to create change:

> *We have all the best laws in town, in earth but on the implementation there is really a problem especially when you talk about the money. So the appropriation even one percent for example for the children in the barangay units, they cannot implement that for the early child development….. I know one barangay in North Cotabato which enacted a breast feeding ordinance. So now their barangay observes breast-feeding. So it's really on the stakeholders, on the government or the leaders…. Political will to change the condition of their people.* [R5, CivSoc_Min_Ph]

Political will is cited by every civil society respondent as a catalyst for change:

> *Municipal health ordinances, I think, are very important for strengthening health programs. In one of our programs, we asked LGU officials to sign an ordinance to*

support health programs and a manifesto that whenever there is a patient who came from very far, the officials will have to shoulder the transport expenses. They also have to look for an ambulance if there is one. And Alhamdulillah[39]*, they have signed the commitment of support. We apply it to other areas and now there is easy way for delivery of health services. We found out that there is a need for political will in order to implement health programs.* [R1, CivSoc_Min_Ph]

5.3.3.3 *NGOs and the international community*

The role of civil society is important to lay community members. They view social development NGOs and faith-based organizations as dedicated in their efforts to improve the lives of everyday people in Autonomous Region. Programmatic interventions such as health information campaigns in schools, medical missions, food-for-work programs, school meal programs, and a water pump system all address the most urgent needs of the communities. They are primarily funded by international agencies and donors, and implemented by local NGOs—community members specifically mentioned the World Food Programme, Community and Family Services International, Oxfam, BRAC, and Single Drop. One community leader explains that these partnerships fill a gap in terms of what the state—regional or national—is not providing:

My guess is just that we're not prioritised and mostly neglected by the government. Sometimes we are torn by administration's instructions on what should be done around here. For that reason, I'm not really expecting anything from them. [SS_IDI_ComL1]

In a politically tense environment with unclear delineations between roles of the local, regional (autonomous), and national governments, community members located solutions for their needs with NGOs:

Only NGOs have potential to give assistance to our community. [SS_IDI_THP1]

A community leader described the ways in which international NGOs have provided assistance to his community in Samberen:

International non-governmental organizations are also active to solve problems in our community. Also, international NGOs were very active in assisting us, such as water system, comfort rooms[40] *and other things.* [Smb_IDI_ComL4]

[39] Literally meaning "by God's grace" in Arabic, this term is used widely by Muslims regardless of linguistic identity.
[40] Locally used term for latrines/toilets

However, development assistance can bring with it problems of precarious provision: some respondents mentioned that some programs end once funding is exhausted, and others described having to wait for conflict or disaster for food relief. This leaves people feeling helpless:

> *Whoever helps us—we are just here, waiting for your help and response.* [Spt_FGD_EF2]

During field research, I was acutely aware that my affiliations with BRAC may have influenced some study participants to utilise this research engagement to provide feedback on its programs: some respondents spoke about their children and grandchildren attending BRAC schools, adolescents spoke about the importance of continuing their education, and others still mentioned their need for a health program[41]:

> *If BRAC would help us; we are going to welcome those projects.* [SS_IDI_THP1]

[41] BRAC is internationally renowned for its health intervention programs in many countries of the global South. However, at the time of this research, BRAC had none operating in the Philippines.

5.4 CHAPTER SYNTHESIS

These research findings, in a backdrop of fragility and conflict, present first-hand accounts of communities of the Autonomous Region in Muslim Mindanao. The engagement with two Muslim communities native to the region and one Christian settler community was facilitated by the trust they place on BRAC, my institutional affiliate and an enabling factor in bringing their voices to the fore. The roles of the intermediaries in this process were clearly outlined: with BRAC facilitating access and entry to the communities, the research team was comprised of people from the local Moro and Christian communities, conducting interviews in community members' preferred languages. This was important in participants feeling at ease in speaking about their experiences.

Study participants' responses inevitably reflect the structure of the *Go4Health* domains—the interview questions invited a particular construction of responses around an imagining of the health system specific to the *Go4Health* consortium. Not surprisingly then, study participants speak to the "building blocks" of health systems, describing issues of service delivery, human resources for health, health information, access to medical products and technologies, health care financing, and governance—all concerned with an understanding of health largely imposed by the interview guides. Yet they have much more to offer, describing holistic understandings of health, telling us of the importance they place on mental health and hygiene, referring to aspects of life as diverse as kinship, unity, and most importantly their most urgent of needs—food, financial security, and peace—and the difficulties in obtaining these in a complex interplay of patronage, politics, and pilfering of public funds.

Community members in the Autonomous Region in Muslim Mindanao described life as a daily struggle for survival—to grow food or earn enough money to buy the food they need in order to have good health. Deeper reflection on the factors that contribute to individual and community health led respondents to discuss in more detail some of the issues they identified. Respondents from the communities I consulted spoke at length, and often emotionally, about not having enough food or money for their families. Poverty is rife in the communities, and people repeatedly spoke about the trade-offs in paying for necessary goods and services such as food, medication, clothes, personal hygiene products, and school supplies for their children. Poverty also alters the course of the lives of most children—most are forced to drop out of school because of the hidden costs of attending public schools. Instead, they work to provide financial support to their families, becoming entangled in a complex network of the local elite that includes numerous militant groups, feuding clans, and the narcotics trade.

Community members have responded to health promotion messages and given the necessary tools, are keen to adopt practices that will improve their lives. Most are clear on their health needs, relating them to the necessary conditions for good health. Livelihoods are important to secure basic needs like food and water, and living conditions must be improved so that people have adequate housing and live under hygienic conditions. They have described how many of these issues overlap, giving them a sense of helplessness.

That we see issues of poverty and hunger in a part of the Philippines that produces 40% of the country's food is an unjust irony—the Autonomous Region produces crops both for domestic consumption and for export, and yet only some respondents say they are able to produce food for consumption and talk about incurring debt in order to attain seeds and farming materials. In the context of hunger, the availability of food that is nutrient-rich to these communities is constrained: in the frame of absolute food insecurity, adequate and balanced nutrition is a luxury.

Though it is not elaborated by the study participants, there is a sense of quiet around the underlying reasons for food insecurity—foods are available in the market (at unaffordable prices), and the region is known for its food production. The problem, rather, lies with poverty and politics. From the literature, the problem of food security is known to be a symptom of conflict rooted in the region's agricultural productivity and issues relating to land reallocations during its colonial history, and later by the Philippine national government, at odds with the traditional feudal landownership structure in Maguindanao[42]. Issues around land ownership are family or clan based, giving rise to patron-client relations that are detrimental, creating situations of extreme violence resulting in displacement. It is perhaps also safe to infer that the landed elite are also acting as moneylenders to the community members who described having to borrow money or seeds for meeting their food and nutrition needs.

Community members' faith in civil society and the international community is telling—the structures that are in place from national entities do not solve problems, rather these paternalistic arrangements, with funding coming from bilateral and multilateral donor governments and agencies does not give reason for people to place trust on those they view as duty bearers: the local

[42] The conflict in the Autonomous Region is usually attributed to religious differences in broader media, however it is only a part of the problem. The clash of interests in land and other natural resources resulted from agrarian reforms, with leading Muslim landowning families commanding armed groups to defend their villages against Christian migrants from other parts of the Philippines (Schiava-Campo and Judd 2005; Vellema, Borras Jr, and Lara Jr 2011).

government, the government of the Autonomous Region, and that of the state. Instead, respondents look outside the purview of government for listening to communities and working toward meeting their needs. There is a strong sense among community members of NGOs being understanding of and responsive to their needs and concerns, providing food assistance, water systems, medical missions, hygiene kits, mental health support, and education—in essence, filling a gap for state provision. The representatives of international agencies indicated their frustration with the national government in taking responsibility for improving not only their health outcomes, but also the basic needs that urgently need to be addressed. An area of major concern is a dearth in people's awareness—and spaces for public participation in voicing concerns. There are few opportunities for participation in decision-making matters for the health of the community. Some people reported knowing of such mechanisms, but as civil society members explained, due to issues of elite capture in the local governance structure, it is impossible to participate without the invitation of powerful patrons in the community.

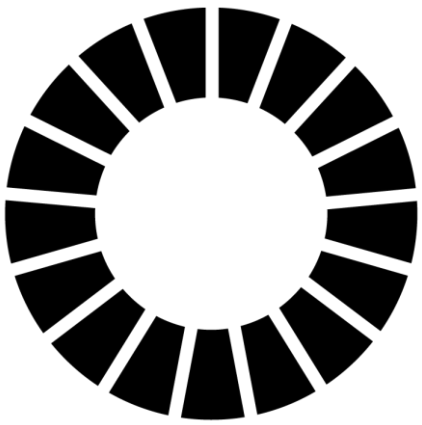
Community members, service providers, and members of civil society all described a health system in dire need of improvement, particularly in relation to governance, which they see as a means to addressing problems of resource shortages. A call for a responsive and reliable health system is shared by every respondent in this study. However, this is easier said than done in a context where the challenge of autonomy is not balanced by the necessary capacity for governance, or the resources for adequate service delivery.

Health issues are complex in the Autonomous Region, and are a result of larger social and economic context—at the crux of it is governance compromised by local, regional, national politics. The highly decentralised system, intended to lessen bureaucracy and increase community participation and empowerment does the opposite—the high degree of discretion awarded to the local government in fiscal, administrative, and recruitment matters. But finances are handled with little transparency and no accountability—as well as very limited service delivery for community needs. What results is a context where community health is perpetually at risk, resulting in the Autonomous Region's reputation as having the worst health outcomes in the Philippines.

The working in the region, agriculture, and income generation emerge as an interlinked and complex issue that has everything to do with a darker side of political society—of patron-client relations that draw people into further poverty as they borrow money for their basic needs, resort to crime to support their families, and send their children to work for patrons and militant groups

instead of school. In this precarious scenario in the Autonomous Region, the difference between Muslim and Christian settlers appears to fade, with communities scrambling to find pathways to stability without losing hope. Both peace and hope seem to be elusive this environment; with local structures of patronage restricting lay community members to voice their concerns, and the regional and nationals structures being unresponsive in service provision in a constant tension of politics in a decentralised system, the need for critical awareness, and a deeply entrenched understanding of rights and entitlements is key in creating communities' capabilities in moving in the direction of a change in which they can have human dignity.

Finally, the role of *Go4Health* as a witness to the experiences people bears a responsibility for action: in hearing their voices, community members were justified in asking us the question *what can we expect from you*? Largely left to fend for themselves, community members, by reason of living in Mindanao—whether Muslim or Christian—are deprived of the rest of the nation's human development gains. With a complex interplay of local, regional, and national political, economic, and social structures constraining people from exercising agency, we must ask ourselves about the same.



CHAPTER 6

How did *Go4Health* represent marginal voices?

6.1 INTRODUCTION

In Chapters 4 and 5, I examined in detail the findings of research in two of the communities that I was responsible for: the Chittagong Hill Tracts in Bangladesh, and Mindanao in the Philippines. In those studies, I documented the responses of the community to the questions that *Go4Health* had been commissioned to explore. But beyond that, I recorded the rich volunteered commentary offered in interviews and focus groups—the perceptions of my respondents on who they were, and how they understood health. In the Chittagong Hills, communities described identity and everyday life as shaped by the geography of the region, that also pushes them to the margins—a geography that is remote and difficult, and "justifies" the limited state infrastructure provision, the militarised violence, the confiscation of lands resulting in the loss of community livelihoods, but a geography rich in large tracts of forest and arable land, and natural sources of water—sources of sustenance for the communities. In Mindanao, a different scenario, defined by armed violence in a complex interplay of local, regional, and national conflict. Communities live in a typhoon belt, where the only certainty is uncertainty—food security issues in a region known for agricultural production and export, housing that is frequently destroyed or abandoned, and peace that is elusive—where change is only possible through informal connections with the local elite. I triangulated this with information offered by those working with the communities, with evidence from other research, corroborating the voices from the community, locating them in a broader context, identifying the gaps, where my community respondents had chosen to remain silent. Those chapters record what I had "heard" from the marginalised in these two communities, the base from which I will examine how well *Go4Health* represented their voices into the post-2015 discourse, through project reports and peer-reviewed publications.

This chapter explores the voices of the marginalised as represented in all the research products produced by the *Go4Health* consortium. Given its EU commissioning to track the development of what were to become the Sustainable Development Goals, *Go4Health*'s work was integral to the post-2015 discourse. Working Group 2—of which I was a member and coordinator of Asian case studies—was tasked to identify the Essential Health Needs articulated by communities, with a view to informing the global social contract that would emerge from the post-2015 deliberations.

Working Group 2 specifically sought engagement with marginal communities in the global South—Africa, Asia, the Pacific, South America, as well as refugees and Aboriginal and Torres Strait Islanders in Australia. For *Go4Health*, this representation of their claims was a critical contribution to the UN-led post-2015 discourse, particularly due to the emphasis on inclusiveness and participation in all of its thematic consultations. The UN driven "*World We Want*" campaign generated close to 100 country consultations, 14 global thematic consultations, and a web-based point of access for individuals to comment. *Go4Health* sought to extend this to identify the voices of marginalised communities, and give them voice. This chapter critically reviews the outcomes of that process: it examines all the research products of the *Go4Health* project to explore how marginal communities are represented into the global health literature around the Sustainable Development Goals from the period between 2012 and 2016.

The 12 papers identified are primarily the products of work undertaken by the members of WP2: four diverse institutions across four continents. BRAC University (BRACU), Centro de Estudios para la Equidad y Gobernanza en los Sistemas de Salud (CEGSS), and the Centre for Health, Human Rights & Development (CEHURD), and the University of Queensland (UQ) contributed to *Go4Health*'s reports. From a common approach and question guide, each published original research that illustrates the complexity and interconnectedness of life lived in the margins into wider discourse that reach the global health community. The communities examined by me in Bandarban and Mindanao are part of a much larger matrix identified by WP2, seeking to provide representation of the marginalised across continents, but also across the breadth of determinants that contribute to marginalisation. It is that diversity that we have sought to represent into the post-2015 discourse. The breadth of *Go4Health*'s WP2 reports go beyond the national borders of each of the research organizations delegated to consult with marginal communities. Table 1 below indicates the reach of each research hub by country and community, and the key characteristics of marginality identified prior to the research. The process of selection of these communities has been discussed in Chapter 3. The strength of the *Go4Health* consortium is its partnership between academic institutions and civil society in an effort to bring ground level insights into policy-setting discourse. The civil society partners that operate in-country, and 'on the ground' have long-standing relationships of trust with communities.

The findings of each of the case studies of marginalised communities share commonalities of experience, but the particularity of experience that shapes community identity. Working Group 2 used a prescriptive framework for its inquiry into Essential Health Needs as part of people's right to

health entitlements to engage with diverse communities from around the world who are marginalised in different ways. We identified five domains: community understandings of health, essential health needs, determinants of health, the roles and responsibilities of relevant actors, and community participation in decision-making processes, with each research hub given the flexibility to tailor interview questions to fit local contexts. Chapters 4 and 5 demonstrated the critical part *Go4Health* played in framing the questions necessary for understanding the perceptions and experiences of health and health systems by marginal communities, but also the extent to which this frame shaped some of the responses. What emerged very clearly, however, not only in my engagement with communities in Bandarban and in Mindanao, but also in the analyses of my colleagues and partners within WP2 and their research teams, is that people's lived experiences cannot be so neatly compartmentalised. The synthesis in this chapter seeks to critically analyse the results of WP2 efforts to include the very voices of those who the UN-led discourse does not want left behind.

Chapter 2 pointed out that one of the main shortcomings of the MDGs is that many people were "left behind". In particular, this included population groups like indigenous peoples, LGBT groups, conflict-affected peoples, and other minority and marginal groups (REF). In acknowledging this, the UN played a pivotal and unprecedented role setting inclusiveness as a core value in the post-2015 discourse across its thematic consultations. *Go4Health* responded to this call with enthusiasm, and sought to provide evidence-based recommendations for a post-2015 global health development agenda to the European Commission (Ooms et al. 2013). It posited that the post-2015 agenda should specify how citizens can participate in decision-making processes around health services and their physical and social environments, but also ensuring that post-2015 health development goals are articulated in collaboration with communities whose health is at stake (Ooms et al. 2013). *Go4Health* aimed to harness the voices of those whose health is most at risk and whose voices are typically unheard—specifically, the most marginalised communities in the global South and indigenous and migrant communities in Australia——for the EU's policy consideration, and by extension, that of the SDG discourse (Brolan et al. 2014). The consortium acknowledges the challenges of "hearing":

> *Power dynamics, discrimination, lack of information, or other obstacles may preclude such communities from meaningful participation even when there are mechanisms to engage communities. Additional measures beyond those for the mainstream population will often be required to meet health needs of socially*

> *excluded members of society, and to enable them to engage in policymaking processes. (Friedman, Akakimpa, et al. 2013)*

Marginalised peoples, by definition, have lived through experiences that contribute to a mistrust of those outside their communities, but to some extent, this was mitigated by the work of our partners who had engaged over time with those consulted for this study. Thus we were able to consult with communities to learn about how they view the health system in terms of responding to their needs, and how a new global health development agenda can address their sometimes unique needs. In the interests of bringing to global health discourse the voices of those whose voices are least heard, *Go4Health* made efforts to publish the results of the community consultations widely. To this end, this report is a review of 12 publications including reports and peer-reviewed journal articles targeting global audiences in the fields of health and development, and directly addressing the voices of the marginalised. People across the global South and migrants and indigenous peoples in Australia contributed their knowledge and experience.

6.1.1 *Go4Health* and the global discourse

A systematic search identifying the availability of *Go4Health's* publications in the literature, and citation of *Go4Health* publications in high impact documents shows that the *Go4Health* research products did make their mark on the global discourse around the emerging post-2015 goals. Of *Go4Health's* total 54 publications, 27 publications were available in the following six databases:

1. Scopus
2. Web of Science
3. EMBASE
4. Global Health Library
5. PubMed
6. Worldwide Political Science Abstracts

As illustrated in the table below, 17 papers were particularly prominent—these are listed in Annex D. Library experts used EndNote file, which includes all the *Go4Health's* publications to search for high impact documents or papers citing the publications through Altmetric or UQ E-space. *Go4Health* publications are highly accessible in health related databases (Scopus, Web of Science, EMBASE, Global Health Library, PubMed) but surprisingly, given a strong focus on governance and the right to health, not in Worldwide Political Science Abstracts. In an analysis undertaken in January 2017, it was clear that *Go4Health* had published in high impact journals: 63.3% (19/32) of

the *Go4Health* dataset published in journals that are ranked in the top quartile for its subject category. In terms of field weighted citation impact, *Go4Health's* citations per publication compared favourably with other subject areas such as Health Policy or Public Health, Environmental and Occupational Health (Table 6-1). The analysis also tracked all publications since 2012 to January 2017 for the six *Go4Health* themes identified in the thematic analysis: the Right to Health was most commonly listed in all databases, followed by Global Health Governance, and then the Voices of the Marginalised. But in PubMed, the Voices of the Marginalised represented close to 60% of all papers published during that period addressing this theme.

TABLE 6-1 MEASURING THE IMPACT OF *GO4HEALTH* (FLODEN ET AL. 2017)

Name (ASCJ subject areas)	Citations per publication	Field-weighted citation impact
Go4Health dataset	5.5	2.24
Health Policy	3.9	1.05
Public Health, Environmental and Occupational Health	4.8	1.00

Of all the publications cited, 91.4% were cited in medical journals, but only 2.8% in Social Sciences journals—a definite skew towards public health rather than development literature. *Go4Health* may have entered the global discourse, but its primary audience was in public health. In January 2017, two *Go4Health* publications were among the 1% most cited, three publications in 5% most cited, and six publications in 10% most cited—compelling evidence of penetration of the literature.

Using the UN Official Document System (https://documents.un.org/prod/ods.nsf/home.xsp), our most prominent papers were tracked into UN publications: the search revealed that one publication *"Everywhere but not specifically somewhere": a qualitative study on why the right to health is not explicit in the post-2015 negotiations* (Brolan, Hill, and Ooms 2015)—was cited in the UN General Assembly document published on 05 August 2016, entitled *Right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/71/304. We have established that the voice of *Go4Health* was heard in the post-2015 discourse, and a subsequent thematic analysis of the content of the papers on the marginalised allows us to see how their voices were represented in that literature.

6.2 METHODS

The method adopted in this component of the research is essentially a thematic analysis of the total research products of the *Go4Health* research project. The process was undertaken in two phases: the first was a thematic analysis of the total research output, seeking to identify and synthesise the dominant themes of the research. The *Go4Health* consortium website (www.go4health.eu) lists all of the publications by *Go4Health*'s working groups in open access form[43]. There are 52 publications that are the products of *Go4Health*'s research, among which there are 7 reports, 41 peer-reviewed publications, 4 blog posts, and a newsletter. The thematic analysis of the content of this total output was undertaken in collaboration with colleagues—Nadia Floden, Vannarath Te, Claire Brolan, and Peter Hill, and identified six themes[44]:

1. Formulation of SDG health goal
2. Right to health
3. Universal health coverage (UHC)
4. Voices of the marginalised
5. Global health governance
6. Integration of health across other SDGs.

The "Voices of the marginalised" themes reflected the organizational structure of *Go4Health*. It primarily included 12 publications produced by the consortium members of Working Group 2 (WP2): the University of Queensland (UQ), BRAC University (BRACU), Centro de Estudios para la Equidad y Gobernanza en los Sistemas de Salud (CEGSS), and the Centre for Health, Human Rights & Development (CEHURD). The overall topic for the WP2 working group was marginalised communities, and these publications inevitably clustered around the fourth theme—the voices of the marginalised. In addition, publications from working groups that sought to represent the experience of marginalised communities were included (for list of publications, see Appendix E). The details of the publications, their authors, and year of publication are included in the following table:

[43] It should be noted that in the spirit of 'no one left behind' one of the stipulations for publication was for all written products to be open access so that knowledge users who would otherwise be unable to access research and commentaries due to the restrictive nature of expensive journals.

[44] Presented as a conference paper: Floden N, Te V, Hussain S, Brolan CE, and Hill PS. (2017) How Did The *Go4Health* Policy Research Influence The Sustainable Development Goals Discourse? A Reflexive Review. World Congress on Public Health. Melbourne, Australia. 3-7 April 2017.

TABLE 6-2 *GO4HEALTH* PUBLICATIONS FROM THEME 4: "VOICES OF THE MARGINALISED"

Title	Year	Publication details
Community consultations on the post-2015 global health agenda: A demand for dignity, respect, participation and accountability	2013	*Go4Health* report, Institute of Tropical Medicine (Antwerp)
Community engagement: Global Development Goals: Leaving no one behind	2013	UNA-UK
Health rights in the post-2015 development agenda: including non-nationals	2013	Bulletin of the World Health Organization
Realizing the right to health for everyone: the health goal for humanity	2013	*Go4Health* report, Institute of Tropical Medicine (Antwerp)
Perceptions and experiences of access to public healthcare by people with disabilities and older people in Uganda	2014	BMC International Journal for Equity in Health
Aboriginal medical services cure more than illness: a qualitative study of how Indigenous services address the health impacts of discrimination in Brisbane communities	2014	BMC International Journal for Equity in Health
Making the post-MDG global health goals relevant for highly inequitable societies: findings from a consultation with marginalised populations in Guatemala	2014	BMC International Journal for Equity in Health
Community participation in formulating the post-2015 health and development goal agenda: reflections of a multi-country research collaboration	2014	BMC International Journal for Equity in Health
Achieving equity within universal health coverage: a narrative review of progress and resources for measuring success	2014	BMC International Journal for Equity in Health
Facilitating health and wellbeing is "everybody's role": youth perspectives from Vanuatu on health and the post-2015 sustainable development goal agenda	2014	BMC International Journal for Equity in Health
Achieving equity within universal health coverage: a narrative review of progress and resources for measuring success	2014	BMC International Journal for Equity in Health
Representativeness of the UN post-2015 national consultations	2014	Lancet Global Health
The health-related development goal in the *post-2015* negotiations: the Right to Health—buoyed or drowning in sustainable development?	2014	*Go4Health* report, Institute of Tropical Medicine (Antwerp)
The individual, the government and the global community: sharing responsibility for health post-2015 in Vanuatu, a small island developing state	2015	BMC International Journal for Equity in Health
From knowing our needs to enacting change: findings from community consultations with indigenous communities in Bangladesh	2015	BMC International Journal for Equity in Health
Health for all: Implementing the Right to Health in the Post-2015 Agenda—Critical Interventions from the Global South	2016	Social Medicine

In the second phase of analysis, detailed thematic analysis for each of the themes was allocated to individual members of the team: I conducted the thematic analysis for all 12 papers identified under the theme "Voices of the marginalised". To undertake this analysis I conducted a grounded thematic analysis, first reading and then re-reading each of the publications. For my analysis, I used NVivo software, identifying emerging themes and codes. The WP2 common question guide and domains provided *a priori* themes, with emerging themes identified during the analysis. After producing node summary reports, I organised codes around emerging themes and sub-themes. I tested for internal reliability with my principal advisor, Peter Hill.

6.3 FINDINGS

This section focuses on the content of *Go4Health*'s representation of the marginalised: the research products of the working group (WP2) delegated the task of community engagement. These are the publications on which direct quotes and representations of the voices of marginalised communities appear. All have been published as part of the post-2015 discourse around global health. Because the intent was to inform the priority setting agenda for health, there is no guarantee these will result in change, however, in answer to my titular question, and based on the citations, there is evidence that the marginalised *are* heard in the post-2015 global health discourse.

In the passages below, we learn of communities' sense of belonging and identity comes from a variety of associations, often overlapping and intersecting. Many face barriers because of these identities, but shared identities and experiences also bring people together in the face of unique challenges they face. Sometimes their needs are different from that of the dominant groups in their countries, and in other times—and all other places—their basic needs are the same as that of everybody else. But these are often elusive due to structural barriers, which are described in their own voices. The structures mandated to deliver these entitlements are unresponsive, jeopardizing not only the health of the marginalised, but also the determinants of their health.

6.3.1 **Identity—who we are**

In this chapter, I refer to 'identity' in modern terms: first, to describe social categories, and secondly, to an individual's sense of self-respect or dignity (Fearon 1999). In *Go4Health*'s representation of marginal voices, people self-identify in terms of the geography of their communities, their ethnicity, their education and income levels, among others. Their sense of kinship and community also emerges in this thematic review of the literature that seeks to represent their voices in wider discourse. In communities' understandings of health and their experience of

health systems in their countries, the research undertaken by *Go4Health* shows how the expressions of community identity may serve as barriers to accessing the health goods, services, and facilities that should be provided through the state. *Go4Health* presents their view of the health systems in their countries, and their access to those systems, unpacking their imaginings of the different essential components of health systems in ways that will be accessible to practitioners and policymakers in the post-2015 discourse. What we learn from marginal people of the barriers they face in health systems complements this representation and asks the questions: what could an effective health system look like? And how can health goods and services be delivered such that the system is responsive to people's needs? And finally, in terms of governance, how do people see the structures that could ensure accountability in the delivery of their entitlements, and have a sense of ownership and participation? What is the way forward for ensuring that no one is left behind?

In the *Go4Health* papers published, it is clear that the sense of community is linked through the spatial and temporal—kinship, shared spaces, shared histories, and shared ethnicities are typical among *Go4Health*'s communities. Family is at the core of community, and positive relationships with family, friends, and neighbours are important for life balance and for physical and mental health (Friedman, Akakimpa, et al. 2013; Friedman, Jahn, et al. 2013; Ibell et al. 2015; Ruano et al. 2014; Ruano, Friedman, and Hill 2014; Sheridan et al. 2014). *Go4Health*'s marginalised communities describe aspects of identity, and by extension, life and lifestyles, are interconnected. Understandings of health and wellness are linked with family. The case study from Vanuatu (Sheridan et al., 2014) quotes a health worker from Vanuatu who articulates the important role of family and community in health:

> *"I come from an area where it is a community, it's a big community, people living together, you have different communities from different islands living together so, I think what are the factors that make people continue to be healthy or living together, first probably it's about how family gets together… It's about how one cares for another—we do things together—if there are issues and somebody has a problem communities and families support them."* (Sheridan et al. 2014)

But the research identifies the complexity of identity, with differing representations of the key correlates of identity reported from different studies. What is clear from this analysis is that, while commonalities between marginalised communities are profiled, much of the particularity of experience for communities has been preserved in *Go4Health* accounts in the literature. The studies from Guatemala, Bangladesh, and Australia, concur that ethnicity is the common thread in self-

identification, with people referring often to themselves by ethnic group, and describing themselves as having values, lifestyles and needs that are different from the dominant ethnic groups in their countries of nationality (Baba, Brolan, and Hill 2014; Friedman, Akakimpa, et al. 2013; Hussain et al. 2015; Ruano et al. 2014).

But in Bangladesh, occupation may be a superseding identity: the word "jumma" refers to a person involved in the local agricultural practice of shifting cultivation, called "jum" that is typically practised by many indigenous communities in Bangladesh (Hussain et al. 2015). Others still self-identified in terms of their geography: regardless of their ethnic group, the indigenous people who participated in the Bangladesh study referred to themselves as Pahari, literally meaning "of the hills", in reference to the Chittagong Hill Tracts, where the land they live on shape everyday experience:

> *Participants discussed everyday life as being shaped by the geography of the region. The terrain of steep hills, ridges, and valleys with scarce water and climate conditions affects every aspect of livelihood, lifestyle, and daily activities, and impacts the health of the communities* (Hussain et al., 2015)

Water—or its lack—is a sub-theme that is conspicuous in *Go4Health* papers on marginalised communities. Living deep in the Chittagong Hills elicits for communities a sense of closeness with their traditional lands, but the remoteness of the region, coupled with the difficult terrain, results in an absence of modern utilities such as access to running water, sanitation, and electricity. Location also features strongly in the construction of identity in the Pacific. In their accounts of life in the Melanesian archipelago nation of Vanuatu, where water is central to identity,

> *Participants in half of all focus groups made mention of the importance of the sea to support livelihoods, to swim in to remain healthy and to be used for washing when fresh water is not available. Moreover, fresh water was discussed in all focus groups, regardless of locality, as a scarce resource.* (Ibell et al. 2015)

The irony of being surrounded by water and yet experiencing its scarcity is unique to Vanuatu in the *Go4Health* consultations, however access to safe water is a common problem for other communities as well (Hussain et al., 2015; Ruano et al., 2014b). Communities that identify themselves in terms of the spaces they live in have livelihoods shaped by their physical environment—in many cases, they are engaged in agriculture, farming and fishing (Hussain et al. 2015; Ibell et al. 2015). Those who

live in rural areas, which are often also remote, described the impacts of living outside urban areas in reference to the dearth of services they receive, which contribute to inequities in health:

> *"What contributes to a person being healthy is the services that our government provides. For example, providing health services to the rural areas."* (Ibell et al. 2015)

Remoteness is a shared problem for many of the marginal communities in *Go4Health,* as indicated in the report (2013):

> *The following female participant, for example, spoke about how health services were particularly lacking in rural and remote island areas. "This participant elaborated how faulty equipment, poor medical facilities, a lack of technology and qualified medical staff all contributed to a deficit in services to and for the local people…"*

In Guatemala, Ruano and colleagues (2014) quote a woman who describes the linkages between remoteness and the difficulties it creates in accessing health:

> *They'll ask me why… I only came now that I'm so ill and why didn't I come when I first got sick. They don't think that the distance to the hospital is great for us. They don't know how the road is or how much money we spent getting here.*

The natural and physical environment provides many with a sense of belonging and sustenance, yet a community identity that is tied to land or water in a particular place can also be restrictive in that it isolates communities, with geography acting as a barrier to receiving modern utilities but also having access to important services like health and education. In some instances, communities do not have paved roads leading in or out of their settlements.

While respondents have a sense of belonging and community based on family, ethnicity, occupation, or geographic region, that same difference that defines identity may lead to exclusion by the dominant majority in their countries. This experience is shared in Guatemala, South Africa, Zimbabwe, Uganda, and Australia. Most report they are not able to participate in public life, either due to a lack of information how to go about doing so, feeling discriminated against, and because their concerns are ignored.

> *In addition, their lack of representation at every level of government ensures that their voices remain unheard and that their needs are not seen as a priority.* (Hussain et al. 2015)

Having no voice—or limited voice—is a common problem, causing feelings of helplessness:

> *And where community leaders and local authorities do take up the community's cause, they find that they are not listened to at higher levels of government.* (Friedman, Akakimpa, et al. 2013)

In some cases where people are aware of their rights—as in Guatemala and in South Africa—people have sought to address the discrimination by voicing their concern to leaders in local government, but a debilitating mix of power dynamics, discrimination, and a lack of information preclude many other communities from meaningful participation in purpose-built structures for engaging communities, confirming that social exclusion is active and intentional (Ruano et al. 2014; Friedman, Akakimpa, et al. 2013). A dearth in knowledge and education is considered by many community members as a prohibiting factor not only for knowing about how to make healthy choices, as in the case of migrants and Indigenous groups in Australia, but also for knowing about rights and entitlements, according to the communities in Bangladesh (Hussain et al. 2015; Ibell et al. 2015). This finding echoed one of the early tensions within *Go4Health* where health rights advocates argued that case studies needed a phase of consciousness-raising prior to the research if informed responses were to be expected. While knowledge around human rights is not accessible to most marginalised communities, there is a reported sense of injustice readily communicated by participants in their reporting of being discriminated against due to their identities as "other". Participants across the studies shared their experiences of neglect, discrimination, and outright abuse that they experienced as a result of their identity (Brolan et al. 2014).

Ethnic identity is implicit and intrinsic to the construction of health for the majority of the communities, particularly those in Bangladesh, Guatemala, and the migrant and Aboriginal communities of Australia, and closely linked with discrimination and racism. Study participants pointed to many ways in which their ethnic identities determine the way they are treated when the access social services like health and education, with the experience affecting their mental health. People describe their use or avoidance of the public health system due to experiences of discrimination or perceived discrimination for staff and other health service users. Instead, they describe looking toward their own community and opt for other locally based solutions (Hussain et al., 2015). There are many complex determinants behind the appalling mental health indicators for Aboriginal people, but participants of this study strongly felt that every-day racism was a major cause for mental health issues, and by extension, other health conditions. (Baba et al., 2014)

In their project reports Friedman and colleagues (2013) have synthesised this information, and also showcase the discrimination experienced by each of the communities consulted by the *Go4Health* research. They report that people feel a strong sense of personal responsibility in ensuring their health needs are met, and these meant ensuring that family members have enough to eat, put hygiene practices to use, having adequate sanitation facilities, and seeking health care services when necessary. Family and community as a focus for health are a highlight of the publications (Baba et al., 2014; Mulumba et al., 2014). The failure to have needs met is attributed largely due to state apathy toward marginal groups, and at other times, due to active discrimination and structural violence, as in the cases of Guatemala and Bangladesh, where the state has forced indigenous communities to leave their original homelands (Baba, Brolan, and Hill 2014; Hussain et al. 2015; Mulumba et al. 2014; Ruano et al. 2014). That discrimination is a deep-rooted structural barrier for health is clear—it prevents people from accessing care because of the anticipated ill treatment by health care providers as reported in Baba's research (2014).

6.3.2 **What we want: our basic needs for health**

All respondents who participated in this multi-country study consistently expressed a holistic and communal understanding of health. Wellness is related to living in harmony with family and community members so that in people's times of need—which, for many, occurs more often than not—support is easily galvanised.

Health care in well-functioning public health system may be essential to well-being, but many communities describe having difficulty with daily survival. Avoiding hunger and securing food for adequate nutrition is of imminent concern for the majority of *Go4Health*'s respondents—across the four continents and the Pacific--as are having access to safe water and sanitation.

For many communities who participated in this study, respondents made it clear that clean water and sanitation are an unattainable luxury. Some communities do not have a piped water supply and must rely on natural sources of water nearby. Geography plays a role in this. An indigenous respondent from Chittagong Hill Tracts in Bangladesh explained the implications of using untreated water on his health:

> *This is a hilly area; we do not have a proper source of water. Water is scarce. Even if there is some, it is not safe to use water from the waterfall. It is contaminated, especially during the rainy season. As a result, we get diarrhoea and other water-borne diseases. (Hussain et al. 2015)*

Similar problems surface in Espiritu Santo community in Vanuatu, a nation surrounded by water, which does not have a reliable supply of safe drinking water, and whose residents must drink coconut juice for survival. (Ibell et al. 2015) In Vanuatu and in Bangladesh, people must choose how to make best use of limited safe water:

> *"There's a total of 500 people in our village… desperate for water from the mountain. It's like that in small places. It comes to the village and gets divided into five taps. Five taps will cater for 500 people. Sometimes the water doesn't run that strong so there's no water for that community… Sometimes when there's no water, we have to swim in the sea and get the water there… we don't drink water, we only drink coconut. Yes, that's our main source if there is no water."* (Ibell et al. 2015)

The limited availability of water, sanitation, and hygiene are consequently critical issues for these two communities, as well as participants in Guatemala and in Zimbabwe. The need for improved toilet systems (in both rural and urban settings), personal hygiene, and waste management are all matters that study participants linked with the need for access to safe water and their health. (Friedman, Akakimpa, et al. 2013; Ruano et al. 2014)

A second alarming concern that researchers heard from communities is that of food security. For communities in Bangladesh, getting enough food for basic nutrition is a problem. Older persons in Gulu district of Uganda can expect to eat the least amount of food in their families. In Mindanao, Philippines, seasonal food scarcity forces mothers speak of sending their children to school without breakfast, and to bed without food (Friedman, Akakimpa, et al. 2013; Hussain et al. 2015; Mulumba et al. 2014; Sheridan et al. 2014).

In Vanuatu and among migrant communities in Australia, the problem of food security has a different facet: community members know that the packaged and imported food available for consumption in local markets could be harmful to their health but have no alternative options.

> *…there are more products, I mean we have a lot of [food imports] that are produced overseas and they're not that healthy compared to our local grown crops that are only on our islands. There are substances and chemicals that are put in [the imported food] and in Vanuatu we are not that well educated to know what they contain…It's become a habit for us to [consume these imported products], because local grown foods are quite expensive compared to products that are imported into our country.* (Sheridan et al. 2014)

As in Vanuatu, respondents know that having enough food is not enough—cheaper, imported food brings with it its high fat, high sugar, high salt content—which people understand as having potential to jeopardise health. Similarly in Bangladesh, even when people do have enough food to eat, it does not keep due to the subtropical monsoon climate—resulting in the need to cook meals shortly before they are consumed, in the absence of electricity to refrigerate food (Hussain et al. 2015).

For all the communities *Go4Health* consulted, water, sanitation and food security were shared vulnerabilities: local circumstances varied, but the threat to health was common to all. The shared message of these basic needs *Go4Health* has communicated throughout its key reports and publications:

> *Water, sanitation, and hygiene are emerging as critical issues for a wide range of marginalised communities, from remote ethnic minority communities in Bangladesh to indigenous populations in Guatemala and communities in Zimbabwe. Even in the Pacific islands, even as they are surrounded by the ocean, many communities lack water security. In Vanuatu, rural villagers on a low-lying island often run out of drinking water; residents are forced to draw water from the sea for washing, while coconut juice becomes their main source of hydration when there's no fresh water.* (Friedman, Akakimpa, et al. 2013)

Along with food, water, and sanitation, community members cited other needs that are essential for wellness, such as employment and income generation, housing, education, and a clean natural environment (Friedman, Akakimpa, et al. 2013; Friedman, Jahn, et al. 2013; Hussain et al. 2015; Ruano et al. 2014).

Go4Health as a consortium, incorporated these understandings of health into a main message and recommendation as a goal for global health, stressing the importance of a physical and social environments that support their health and well-being (Friedman, Jahn, et al. 2013).

Specific inquiry into health needs were presented by Friedman et al (2013b) and highlighted the difficulty communities faced in accessing health care: "*Across communities we consulted, access to health care appeared among top essential health needs. Yet obstacles abound, including lack of medicines and qualified health personnel, inaccessible health facilities, costs, and more."*

In some cases, there were unique needs expressed, specific to those communities—but still among the elements of health care that middle and high income countries would take for granted:

> *[There] will be cases where the essential health care needs that communities describe would have been difficult to foresee, such as an emphasis on dental care in Afghan communities. (Friedman, Jahn, et al. 2013)*

Essentially, these are represented by the *Go4Health* literature as a call for Universal Health Coverage (UHC), covering access to not only access to medicines, medical equipment, and health personnel, but also to the facilities at all.

Geography naturally re-emerges here in that while it defines a community's identity, it also acts as a barrier for people to access the health care system. In some cases, there are no roads that lead to facilities, in others still, are cut off due to flooding.

6.3.3 **How can this be delivered? The health system**

In contrast to this sense of holism, the more prescriptive *Go4Health* questions around health systems shaped a different response: asked about health services, respondents perceived health in the public health system more narrowly as biomedical and facility-based—a system in which values like respect and dignity are absent (Baba et al., 2014; Brolan et al., 2014; Hussain et al., 2015; Mulumba et al., 2014; Ruano et al., 2014b). While communities shared a sense of health linked to their own identity, and grounded in their essential needs, their perceptions of the responsiveness of the health systems that they relied on differed qualitatively.

Communities across the study characterised their national health systems as unresponsive to their needs. The research publications emerging from Guatemala and Australia in particular pointed out cultural barriers—that health workers at state facilities are culturally insensitive, ranging from active rudeness and discrimination from workers but also nuanced and subtle forms of indirect and institutionalised discrimination like patient care that does not take into account the cultural cues and beliefs by Aboriginal communities in Australia.

Acceptable and appropriate health care is not easily accessible or available for most of the people in this study. In Vanuatu, participants identified unevenly distributed health services as a major barrier to health-care seeking. In Bangladesh, difficulties accessing health care has to do with the geography of the region, where steep hills and valleys and an absence of proper roads prevent facility-based care-

seeking. In Afghanistan, culture and conflict impact care-seeking behaviour: first, women are unable to go to facilities unless accompanied by a male family member, and secondly, mobility is restricted due to considerations for personal safety in a setting where conflicts unexpectedly arise. Physical access is a problem, and so too is a culturally acceptable environment:

> *"A pregnant Quiche woman went to the health centre to deliver… but the nurse would not help her. Her husband had to all the work and no one paid attention to her. She delivered the baby on her own. This is because they don't care about us, because indigenous people, we get sick a lot… They get tired that we are sick more often than non-indigenous people and they wish we all died."* (Ruano et al. 2014)

While this lack of cultural acceptability in the health care system is illustrated by the Guatemala team in the form of institutionalised discrimination and racism, it also highlights the substandard quality of care available to an indigenous group. That this must be addressed in the post-2015 agenda is a clear message from the *Go4Health* team in the literature (Friedman, Jahn, et al. 2013; Friedman, Akakimpa, et al. 2013; Ruano, Friedman, and Hill 2014).

Respondents in papers from Bangladesh, Uganda and Guatemala describe being treated with discrimination by all levels of staff in public health facilities, and are subjected to rude behaviour and even ridicule (Hussain et al. 2015; Mulumba et al. 2014; Ruano et al. 2014). This is exacerbated by long wait times and resource shortages in personnel, medicines and medical supplies. Faced with this, people resort to making out of pocket payments for better care in public health facilities or seek alternatives in the private sector. Traditional medicine is a popular default choice among respondents as it is readily available within their communities (Hussain et al. 2015; Ibell et al. 2015; Ruano et al. 2014).

The health system is generally perceived as fragmented, and all of the communities described challenges accessing health care, which in some cases caused lethal delays:

> *Communities consulted expressed significant concern about other barriers to care as well, including long waiting times and lack of free ambulance transport to hospitals. Transportation was also a major concern among the rural communities living in remote areas in Bangladesh and in Buikwe, Uganda, where the lack of roads and poor condition of roads was mentioned as a cause for a sometimes lethal delay of women in labour getting to a hospital. The rural poor in the wetland region of*

> *Bangladesh could not access health facilities during the monsoon season due to river overflow and the lack of appropriate transportation (water ambulances). In the Philippines, one community member explained that "we use our clinic and hospitals but sometimes our hospital here is incomplete, like it doesn't have an x-ray machine. If the patient needs an x-ray we bring our patient [to] Cotabato [city], and we also need to pay for the gasoline of the ambulance with the cost of 500 pesos."* (Friedman, Akakimpa, et al. 2013)

Even getting to a facility is a problem: Baba and colleagues point to integration of cultural beliefs and practices for creating a responsive health care system that would encourage Aboriginal peoples to utilise care services:

> *The lack of culturally appropriate health care services remains a barrier to Aboriginal people accessing healthcare, but the successful integration of cultural safety principles—recognising the practitioners' own cultural biases, and consciously engaging those of their clients—into mainstream health care results in dramatic increases in Aboriginal clientele* (Baba, Brolan, and Hill 2014).

6.3.4 **How can we own this? Governance, accountability, and participation in public life**

Communities across the study place express that it is the responsibility to the state to ensure their health and well-being. In their description of the many challenges that prevent them from being able to avail services, an underlying mistrust of the state and its institutions emerges. Communities at the margin have a history that speaks to difference, to discrimination, to disadvantage, to distrust. Not only are health systems perceived as unresponsive because of a lack of resources, community members report that local, regional, and national institutions lack the political will to improve their lives:

> *Wherever people locate primary responsibility, the responsible authorities are frequently failing to meet their responsibilities. For many marginalised communities, the global level was too distant to even form a clear sense of responsibility. National authorities were often seen as ineffective, as in Guatemala, or not simply present despite their formal responsibilities, as in Bangladesh, so not to be relied upon. Where village leaders were seen as particularly important, they were also far from effective, whether failing to take any initiative in Afghanistan (and not being listened to at higher levels) or simply with little interest in community members' health, in Bangladesh. The widespread perception among marginalised populations of the*

> *failure of government to meet their health needs leads to both people's hunger for accountability and their frustration that participation and accountability mechanisms either do not exist at all or are ineffective.* (Friedman, Akakimpa, et al. 2013)

A resounding chorus of voices are represented as feeling discouraged, and as demonstrated earlier, communities search for alternative solutions. This leaves community members feeling hopeless about bringing about changes to the status quo.

> *Notwithstanding this importance, marginalised communities overwhelmingly lack the ability to meaningfully engage and influence policymakers.* (Friedman, Jahn, et al. 2013)

With today's proliferation of rights based NGOs, particularly in the global South, civil society fills a gap not only in service delivery but also in structures for gathering community input—how this information is used by the NGOs is unclear from the consultations, however, what is clear is that people look to non-state actors like NGOs for the provision of public services (Friedman, Jahn, et al. 2013; Hussain et al. 2015; Mulumba et al. 2014; Ruano et al. 2014).

Respondents spoke about spaces for participation in local structures such as health assemblies, however they are not always aware or invited, and face obstacles to their participation. Community members say they would like to have improved awareness and a better understanding of rights in order to participate meaningfully in public life. Respondents place their trust in NGOs help them develop the necessary capabilities for bringing their voice into decision-making. (Friedman, Jahn, et al. 2013). Friedman's report takes the view of those Guatemalan communities who feel that accountability to the community by these NGOs must be ensured for the people:

> *Mechanisms must be structured to represent and ensure accountability to even the most marginalised members of already marginalised communities, such as impoverished women refugees with disabilities. And they should feedback to communities explaining how their inputs have been taken into account.* (Friedman, Akakimpa, et al. 2013)

The increased presence of NGOs as brokers for communities may have resulted in reduced capabilities for people in communities to voice their own concerns, with local authorities then taking little heed of their responsibilities as duty bearers:

> *The lack of opportunity for people to participate, combined with the frequently failings of responsible authorities to take the measures needed to protect people's health needs, demonstrates an extreme lack of accountability. Authorities are not meeting people's needs, yet communities do not have the opportunity to express their needs and concerns* (Friedman, Akakimpa, et al. 2013).

6.3.5 **Marginal voices—a *Go4Health* synthesis**

The voices of marginalised communities in 9 countries—Bangladesh, the Philippines, Guatemala, South Africa, Zimbabwe, Uganda, Afghanistan, Australia, and Vanuatu—are all represented in *Go4Health*'s publications. For our respondents, the role of identity is a dual one—on one hand it has a function in defining communities, yet there is a tension with othering, whereby people and communities experience constraints and limitations due to discrimination by the dominant majority. Community understandings of health are holistic, and closely linked with their identity: relationships within the community, with the surrounding environment, and only after that do people describe their interactions with a dominant majority that is too often responsible for neglect, exclusion, and discrimination. NGOs are seen to bridge a gap of mistrust between marginal communities and the governments they view as failing to meet their health and other basic needs.

Unequivocally, what the people who participated in this study want, and identified as their priorities, is consistent with their human rights. That community members' basic needs—ranging from food, safe water, adequate housing, sanitation, education—are unmet is clear and consistent in the representations of WP2 to the literature beyond *Go4Health*. It is demonstrated in *Go4Health*'s products that human rights, and human dignity are unacceptably undermined everyday, which is contributing to health inequity.

Go4Health stresses the failure of the system in addressing determinants of health, stating that people's human rights must be not only respected, but also defended. This message, coupled with community people's stress on multiple aspects of life intersect in ways that affect health outcomes, though highly synthesised, is apparent throughout out each of *Go4Health*'s products:

> *A human rights framework captures this holistic understanding of health needs and entitlements, with many of these determinants directly covered by the right to health, and others the subject of other rights, including education and work. A right to health goal, complemented by other rights-based goals as part of the post-2015*

> *development agenda, would therefore correspond well with community perspectives on the healthy environments to which they are entitled* (Friedman, Akakimpa, et al. 2013).

Go4Health's single health development goal (Friedman, Jahn, et al. 2013)—"*the realization of the right to health for everyone*" with two targets—"*universal health coverage anchored in the right to health*" and "*a healthy social and natural environment*"—encompassed the health systems concerns as expressed by marginalised communities. With the right to health[45] articulated with the target of a healthy social and natural environment, the consortium essentially suggested that the social determinants of health be also addressed: "*for the communities we consulted, water, food, and sanitation, but also decent education, housing and employment, are essential preconditions for health: as important as, if not more important than, health care*." The entitlement to health care is linked to the communities' demand for "*an accessible, welcoming and responsive health care system,*" where responsiveness is a representation of communities' desire to be consulted for decision-making.

I have demonstrated clearly that the voices of the marginalised have penetrated the global health discourse. Research articles around each country study appear to have highlighted the voices of communities more expansively, also synthesizing their responses for deepened analyses of their conditions, their perceptions and understandings of health, and their experiences of the local and national health systems. The WP2 report "*Community consultations on the post-2015 global health agenda: A demand for dignity, respect, participation and accountability"* also directly quotes people from marginalised communities—indeed from each of the countries the study was conducted.

However, in the overall report that brings together the findings from each of *Go4Health*'s working groups, the voices of the marginalised are homogenised and filtered—subsumed into a larger and important agenda for priority setting grounded in the science of health policy and systems research, but also competing with legal and financial perspectives (i.e. the contributions the other work packages) on that same agenda.

[45] Important characteristics of the right to health can be found in General Comment no. 14 adopted by the Committee on Economic, Social and Cultural Rights, the body responsible for monitoring the International Covenant on Economic, Social, and Cultural Rights—the human right to the highest attainable standard of physical and mental health is expanded in Article 12 (UN 2015).

6.4 Penetration and Representations of Marginal Voices from Bangladesh and the Philippines

Having established that the voices of the marginalised, as documented in the WP2 *Go4Health* publications, did penetrate the post-2015, I am interested to see to what extent the voices I am most familiar with—those of the Chittagong Hill Tracts and the Autonomous Region in Muslim Mindanao—have been taken up in those publications. This section fulfils the final objective of my thesis: to review the representation by *Go4Health* of the voices of the marginalised in Bangladesh and in the Philippines in the post-2015 discourse.

6.4.1 **Marginal voices from Bangladesh—penetration and representations**

My direct engagement with communities in the Chittagong Hill Tracts in Bangladesh and in Maguindanao in the Philippines are represented in *Go4Health*'s products in the broader discourse around the post-2015 global health agenda. A research article in the International Journal for Equity in Health, titled "*From knowing our needs to enacting change: findings from community consultations with indigenous communities in Bangladesh*" (Hussain et al. 2015) was specifically centred around the Mro and Tripura communities from the Chittagong Hill, with direct quotes from community members highlighted, and two *Go4Health* reports: "*Community consultations on the post-2015 global health agenda: A demand for dignity, respect, participation and accountability*" (Friedman, Akakimpa, et al. 2013) and "*Realizing the right to health for everyone: the health goal for humanity*" (Friedman, Jahn, et al. 2013) represented the indigenous communities from Bangladesh.

6.4.1.1 ***Critical needs***

In reference the marginal voices from Bangladesh and how they were represented by*Go4Health* in the literature, there is clear evidence—the direct quotes below have penetrated the discourse. There is also something that resonates in the tone of the quotes selected—a bleak resignation in their communication that was pervasive in interview, and that suggests they are deeply cognizant of the environment's impact on their well-being:

> *This is a hilly area; we do not have a proper source of water. Water is scarce. Even if there is some, it is not safe to use water from the waterfall. It is contaminated, especially during the rainy season. As a result, we get diarrhoea and other water-borne diseases.* (Hussain et al. 2015)

The communities identify water as their most urgent need; in each reference they distinguished this specifically from other issues. *Go4Health* reporting, however, aggregates water with other issues, lumping this distinctive need together with sanitation and hygiene. This is an interesting turn, and reflects, perhaps the conceptualization that is most familiar to the decision-makers within the global health discourse. Arguably, for *Go4Health*, as the intermediary between marginalised groups and the global health community, it became important to use the lingua franca of public health: water, sanitation, and hygiene, commonly known among practitioners simply by the acronym WASH:

> *Water, sanitation, and hygiene are emerging as critical issues for a wide range of marginalised communities, from remote ethnic minority communities in Bangladesh to indigenous populations in….* (Friedman, Akakimpa, et al. 2013)

The *Go4Health* reporting is not incorrect: it is simply not what Bandarban residents experienced: water was different, *it* was the critical issue. Responses around sanitation were ambiguous, and not consistent with what I witnessed—materials for pit latrines long waiting to be built, latrines not apparently used. But water was a community imperative—that alone really mattered.

6.4.1.2 ***Health systems***

The framing of *Go4Health*'s interview questions, explicitly designed to elicit communities' responses around their understandings of health and of their experiences of the health system, naturally gave rise to relevant responses. This is reflected in their voices in the literature, as well as in *Go4Health*'s representations. One such case is illustrated:

> *They come and advise us to build sanitary latrines, wash our hands before eating food, wear shoes, and wear clothes that are washed and then dried in the sun. If these are maintained, they said, people won't be afflicted with disease. They suggested these.* (Hussain et al. 2015)

This shed some light on the kind on the health system: first, people are directly telling us that they receive some form of health extension services, and secondly they provide us a sense of the kind of health information that penetrates their community. In their reference to the importance of keeping clean, there is a sense of the opposite and a for improved sanitation and hygiene practices. However, what is clear from this voice is that there are no solutions offered to them. Not only are is this aspect of the health system pointed out as pedantic, the general view of authorities is that:

> *They do not try to find out what is happening here. They do not perform their duties. They told us earlier that they would be there for us. But they do not concern themselves with us. (Hussain et al. 2015)*

Little confidence is invested into the formal governance structures in Bandarban—othering is entrenched in this statement with—forms of 'they' and its possessive are used 7 times while the word 'us' is used 3 times. A relationship of dominant and subaltern is strongly evoked.

The process of participation, is part of the building blocks of health systems, and is reflected in the following response around who is able to participate in community decision-making meetings:

> *Men participate [at meetings]. If women are invited, they participate. If the meeting is arranged by outsiders [NGOs], women are invited. Everyone's opinion is heard [then]. But in the end they only consider the opinions of those who they think are worthy. (Hussain et al. 2015)*

Here, this article captures a glimpse of the understanding among the marginalised that civil society is more inclusive in their approaches to community level platforms for participation. Civil society also appears to make people feel as though they are "heard", yet there remains a sense that some people's contributions are more valuable. This is a reference, then, to social capital—men's opinions are valued more than women's (at least by state-led structures) and that some people's opinions are more worthy than those of the rest of the community. The sense of injustice people feel for being differently regarded and excluded due to their gender and social standing is evident.

> *National authorities were often seen as ineffective, as in… or not simply present despite their formal responsibilities, as in Bangladesh, so not to be relied upon.* (Friedman, Akakimpa, et al. 2013)

This representation or marginal voices is accurate for the Tripura community, where community members described looking to traditional leadership rather than that of the national government structure for action. This is preference is reflected in the report as well:

> *Among ethnic communities in Bangladesh, where the government commonly contracts out health services, village leaders were seen as primarily responsible for the health and well-being of the community, while NGOs were seen as the most effective health actors.* (Friedman, Akakimpa, et al. 2013)

> *In the Bangladesh ethnic minorities communities, where NGOs have a particularly large role in service delivery and the very low level of government services, the government was responsible for regular door-to-door programs and certain health services (such as immunizations). Yet the government very failure at its own recognised responsibility meant that the national government was barely visible to these communities, perhaps leading communities to focus responsibility elsewhere, on actors that were at least present, with whom there was at least a chance of their interacting.* (Friedman, Akakimpa, et al. 2013)

This representation of marginal voices from Bandarban accurately represents the experience of the population—the health extension services provided by the state are well known in rural parts of Bangladesh. During my research, community members spoke of the patchy services provided by Family Welfare Visitors and Health Assistants, the cadre of community health workers employed by the Ministry of Health and Family Welfare that provide door-to-door services. However in reality, absenteeism is a problem, as it is too at rural health facilities. Instead, community members and key informants told me about health services contracted to NGOs. Community health workers employed by local NGOs are the only ones community members spoke about with certainty, but some mentioned that when foreign funding for such services are exhausted, so are the services.

One voice in particular stands out as empowered and keen for a transformation:

> *The government has a responsibility to create an educated society and informed constituency with health literacy and awareness. But the effort from the government is not sufficient; if the educated people of the community, community representatives and NGOs take initiative and begin working for change then I don't think it's a hard thing to achieve…. The root of everything is unity. If we are united and stand together to raise these issues, they [the government] will have to fulfil our demands. (Hussain et al. 2015)*

While in other quotes there is an underlying sense of injustice due to state neglect of the communities in Bandarban, there is a sense of pragmatic optimism as well—with the right actors and stakeholders working together, conditions can be changed through raising critical awareness.

6.4.1.3 ***Silences among the silenced***

One of the major issues that characterised the Mro community is the injustice of being driven out of their lands by the national army. Forced to relocate, one community health worker is quoted in one of my research articles, speaking about the challenges. No one else raised this, though it was clear from the literature and sources outside the community that this displacement dominated their experience:

> *"We were told to leave. We are [now] facing difficulties… we cannot find enough bamboo or trees to cut; the army comes and cuts all the bamboo. We do not have enough food to eat."* (Hussain et al. 2015)

The issue was highlighted two *Go4Health* reports as follows, first in a WP2 report that focused only on the community consultations, but which supplements this single quote with evidence gleaned from those other sources:

> *In Bangladesh, and army-led government forced the Mro community to relocate in order to create a training facility, meaning that they had to abandon traditional practices of organic farming and contributing to poor nutrition, displaced them from sources of water, and made it difficult for them to earn a living.* (Friedman, Akakimpa, et al. 2013)

In noting the Mro's eviction from their traditional lands, and the implications of being displaced from an environment that sustains them, my WP2 colleagues drew attention to additional difficulties faced by that community that were not—or could not be—addressed in interview. The additional information that they relied on came from my observations and informal conversations—added to the voices of the marginalised themselves—that were synthesised from the internal reports from each regional team by the WP2 coordinating team at Georgetown University. This information then was reiterated in the consortium report launched at the European Congress on Tropical Medicine and International Health in 2013[46] and represented as follows:

> *In Bangladesh, the army forced one ethnic minority community to relocate, driving them to abandon traditional practices of organic farming, which contributed not only to poor nutrition, but also challenged their capacity to earn an income.* (Friedman, Jahn, et al. 2013)

[46] The European Congress on Tropical Medicine and International Health in 2013 took place in Copenhagen, Denmark. The biennial conference that year highlighted the work of *Go4Health* in its opening plenary.

Is this the voice of the marginalised? Looking back now, the critical question for me is "what can I report when the Mro themselves are largely silent on an issue?" Does the forensic piecing together of information that may be implied, but not stated by them, represent an enriching of their "voices", the presentation of a greater truth, or does it betray their silence, perhaps grounded in real fear of speaking? How should their silence be heard?

6.4.2 **Marginal voices from the Philippines**

The communities from Maguindanao were mentioned only twice—in a consolidated WP2 report—"*Community consultations on the post-2015 global health agenda: A demand for dignity, respect, participation, and accountability"* (Friedman, Akakimpa, et al. 2013) . Marginalised voices from the Philippines research of the *Go4Health* project are not directly quoted in the global literature. The essential reason relates to the narrow window of opportunity for the *Go4Health* project to highlight these issues. The absence of quotes from Maguindanao community members in the WP2 report due to the structural constraints of research work: in July 2013, at the time of delivery for the WP2 report from community consultations, I was in Mindanao, conducting field research—delays in another country study led to the postponement of the Mindanao work, consequently affecting my ability to collect and analyse interview data in time for the report printing. However to avoid a loss in including the voices of the marginalised communities from Mindanao, I participated in a Webex meeting with my WP2 colleagues to share emerging findings from an internet café in my compound during my stay in Mindanao.

What I shared with my colleagues was my sense that food is the critical issue in Mindanao, and the WP2 report reflected this accurately:

> *Food, too, is a critical issue for many communities, in particular healthy food, and was the top concern that emerged in Mindanao, Philippines, where seasonal food scarcity was common, with children sometimes being sent to bed and to school hungry.* (Friedman, Akakimpa, et al. 2013)

I later discovered during data analysis that food insecurity is a year-round issue that is acute at specific times of the year. One of the limitations of my sharing the (reported) initial findings was that, without in depth data analysis (which was impossible at the time), it could not—and did not—represent the pervasiveness of the problem. This representation of marginal communities has everything to do with poverty: accessing health care is an issue for the marginalised communities of Mindanao due to their fear of having to incur out of pocket costs. The limited possibilities for

sustained livelihoods and jobs in order to have a steady income make it difficult for people in the Autonomous Region to afford food. Later in the same report, additional concerns of the communities are raised, again, based on my initial and emerging findings:

> *…along with food and health care itself, in particular the quality and hidden costs of care, livelihoods and job security were top concerns in the Philippines.* (Friedman, Akakimpa, et al. 2013)

I have addressed the concern about food insecurity earlier in this thesis. But the translation of evidence from these marginalised communities into a forum where there issues can be heard requires a conjunction of events well beyond their control. The infrastructure—and the resources—of the *Go4Health* project are no longer available. But the problems of food insecurity in Mindanao persist: that limited window of opportunity to represent this into the global debate that informed the development of the SDGs has closed. For these communities to now be heard requires a new platform, a new framing of the issues, that will make publication possible and allow their voices to be more fully heard.

6.5 Chapter Synthesis

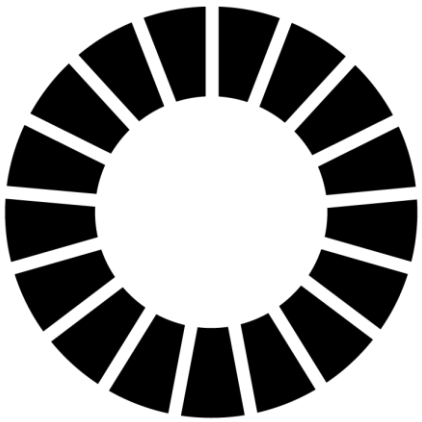
The purpose of this chapter was to review the representation by *Go4Health* of the voices of the marginalised. I have demonstrated a number of ways through which the *Go4Health* consortium represented marginal communities in wider discourse, beginning with a count of all of the publications available to the public. All of the literature included in the thematic analysis is grounded in the work of WP2, the subset of the *Go4Health* consortium that undertook community engagement. These publications are of particular interest due to the research teams' mandate to represent communities into global health discourse for policy setting, and respondents showed their willingness to participate and respond to such a research agenda. The metrics around overall *Go4Health* publications indicate penetration in the larger global health discourse.

The responses of the participants in the WP2 study are articulated around their experiences and expectations of health—yet in their accounts, we are witness to much more. From their discussions, we gain real insight into the intersections between the social, political, and economic barriers they face, preventing them from leading lives in which they feel a sense of dignity and capacity to bring about change. *Go4Health*'s representation of communities' struggles with food insecurity, water

scarcity, financial challenges, and obstacles to education and communication has been clear. And these struggles are paralleled in the other case studies undertaken by WP2 teams.

What is missing from the evidence offered by the marginalised communities in this study is the explicit articulation of human rights abuses, which, in the published *Go4Health* literature, has been sanitised into a milder language that speaks of discrimination and disrespect. In their original exchanges, the communities either spoke far more emotively (as in the case of Guatemala, or Australian Aboriginal people) or offered silence around the major issues (Bangladesh). Interestingly, the eviction of the indigenous communities from their ancestral lands is not portrayed as an abuse of human rights, rather, it is represented as an unjust social event that has repercussions for health—certainly the documenting of marginal voices is satisfied, but it is surprising that *Go4Health* as a consortium, whose positioning is normative in coming from a human rights perspective, did not raise this issue more prominently in its reporting. My learning approach throughout this PhD is a reflexive one, and in revising my ideas as I have come to new knowledge, it occurs to me that diluting information around military action—an event of aggression and direct violence—human rights abuses have not been indicated as such in the representations of the marginalised communities. My two case studies were undertaken in two distinctive regions within their own countries, both semi-autonomous, and, at least from a global perspective, within the purview of the State (i.e. the Philippines and Bangladesh). For the communities I spoke to this semi-autonomous status has not increased their capacity for agency, but in a sense compounds their constraints, with the state presence heavy despite local resistance.

We are then left with a tension: on the one hand, the communities in nine countries provide a rich representation of their lives with a positive articulation of health and identity, describing their unity in the face of structural violence. But they have a very pragmatic understanding of their contexts, a clear assessment of the physical and geographical constraints, of the institutional deficits and barriers, and the need to contend with the threat of state violence and displacement. On the other hand, they have learned to look to other agencies beyond the state for solutions, though their understanding of governance and international solidarity beyond the local is limited. Despite these non-state solutions, all of the communities are aware that transformation is not possible without structural change that must involve the state—without access to resources, developing the capabilities to participate in platforms for being heard and forums for change, continue to be a challenge.



CHAPTER 7
Conclusions

I have answered the central question of my thesis—*did Go4Health represent the voices of the marginalised into the post-2015 global health discourse?*—in the affirmative: the *Go4Health* consortium has been successful in its efforts. Chapter 6 clearly demonstrates that the voices of the marginalised have penetrated the global health discourse leading up to the formulation of the SDGs. But as a consortium, we did not anticipate the richness and breadth of their responses to our questions about their lives and their experience of health. With the extraordinary diversity of people in communities across the world, they share the experience of marginalisation in different forms. This impacts on their access to resources, and their capabilities for using them for constructing lives they value, in countries whose social, political, and economic structures are diminishing their human rights on an everyday basis.

From these communities, we learned that the health system is not an isolated problem. Indeed, study participants offered polite, if limited responses to our framing of questions around *our* understandings of health—a predominantly public health framing. But what they offered when not constrained by the framework of the question guide is a holism in health, embedded in their cultures, a linking of health to identity, to family, to community. Engagement and dialogue with communities in the Chittagong Hill Tracts and in the Autonomous Region in Muslim Mindanao showed that their lived experience was not unidimensional, laying open the dynamic intersectionality of marginalisation. Their accounts of lives lived in their social, environmental and political contexts brought to light issues around essential needs for water, for food, for security, for livelihoods, land tenure and rights, and access to basic services, including health care.

In the Chittagong Hills, communities described an identity and everyday life as shaped by the geography of the region, the very thing that also pushes them to the margins—a geography that is remote and difficult to contend with—a state excuse for limited infrastructure provision—but rich in large tracts of forest and arable land, and natural sources of water—sources of sustenance for the communities, and also the cause of militarised violence in the form of confiscation of lands resulting in the loss of livelihoods for communities.

In Mindanao, a different scenario: wrought by armed violence brought about by a complex interplay of local, regional, and national conflict, communities live in a typhoon belt, where the only certainty is uncertainty—food security issues in a region known for agricultural production and export, housing that is frequently destroyed or left behind, and peace that is elusive in an environment where change is only possible through informal connections with the local elites, rather than the regional or national governance.

Go4Health, through its consultations in Guatemala, South Africa, Zimbabwe, Uganda, Afghanistan, Bangladesh, the Philippines, Australia, and Vanuatu, harnessed the voices of marginalised peoples whose voices were distinctly missing from the post-2015 UN consultations, with others speaking loudly in their absence—even within the UN thematic consultations—where the state governments, civil society, and academics have been prominent (Brolan et al. 2014). *Go4Health* worked with local NGOs and leaders to momentarily create a space to engage with the marginalised in order to hear them. We were witness to their voices, and have documented them, albeit synthesised. While sometimes homogenised and filtered, the voices *are* heard, as shown in the penetration of WP2's publications in a global health discourse that includes citation within UN documentation. And we have been part of the process that the UN called for, where all decisions for development to meet our aspirations—the *World We Want*—must be "*grounded in the voice of people, especially children, youth, women, and marginalised and excluded groups"* (UN 2013).

However, the marginalised continue to be marginalised: politically pushed aside with promises of autonomy with little or no follow through from state governments, their capabilities for exercising the freedom for agency and well-being in contexts of structural violence are severely constrained. They continue to experience a range of inequities that diminish human dignity and rights, that left them behind in the development agenda facilitated by the MDGs. Based on this evidence, I conclude that documenting, and representing the voices of the marginalised in wider discourse is possible. And it is clear that the marginalised have more to say—their silences and their apparent resignation to the status quo do not imply their consent to being subjected to the oppressive structures that obviously contribute to their marginality. They need resources for critical health literacy that will enhance their capability—all of which will need substantial change in social, political, and economic structures.

> *"Human rights work applied should break the silence of powerlessness, a silence that keeps the needs and desires of the poor and marginalised people from being part of national political agendas—and for the disempowered, voice is not enough—*

> *human rights work is about getting them **influence**—and about the processes that lead from having voice to having influence"* (Schuftan 2016).

Enabling the marginalised to truly *speak*, to have agency in their own communities and states, requires the kind of global change that the rhetoric of the SDGs speak to: end poverty in all its forms, achieve food security and improved nutrition, achieve gender equality, ensure healthy lives, ensure water and sanitation, ensure access to energy, inclusive economic growth that entails full and productive employment, build resilient infrastructure, reduce inequality within and among countries, make human settlements inclusive, safe, and resilient, ensure sustainable production and consumption, combat climate change, protect and restore terrestrial and marine resources and ecosystems, promote peaceful and inclusive societies, and strengthen the means of implementation for a global partnership for sustainable development.

Waage and colleagues (2015) recognise this potential in their reconstruction of the Sustainable Development Goals in a configuration that aligns with Sen's theorising around agency to achieve a life that one values—and with our own incorporation of this into my conceptual framework. Sen (2002) distinguishes between achievements and capabilities on one side and the facilities socially offered for those achievements on the other. He posits that factors that can contribute to health achievements and failures go well beyond health care, and include a number of different influences including incomes and food habits on one hand, and the epidemiological environment and work conditions on the other. But these elements are conspicuous by their absence in the communities I have studied. A life of value, as our respondents articulated, is one that corresponds to their central human capabilities—being able to live to the end of a human life of normal length without dying prematurely, having sound bodily and mental health, personal safety, and access to the essentials that these marginalised communities identified so readily.

Waage and colleagues (2015) arrange the SDGs in a similar concentric pattern (Fig 7-1), grounded in the partnership for sustainable development—the outermost representing the natural environment; the second, infrastructure—the resources that will be worked into capabilities. Central to these are the SDGs directly contributing to well-being: the ending of poverty; health; inclusive and equitable education; gender equality; peaceful and inclusive societies. But in contrast to Sen's schema, these are all clearly dependent on the interface between the individual, the community, civil society, industry and the state. Their partnership is critical if these goals are able to be achieved, and the structural violence that these communities experience is dismantled. Structural

violence remains present when people are influenced so that their physical and mental realizations are below their potential realizations—violence increases the distance between the potential and the actual (Galtung 1969).

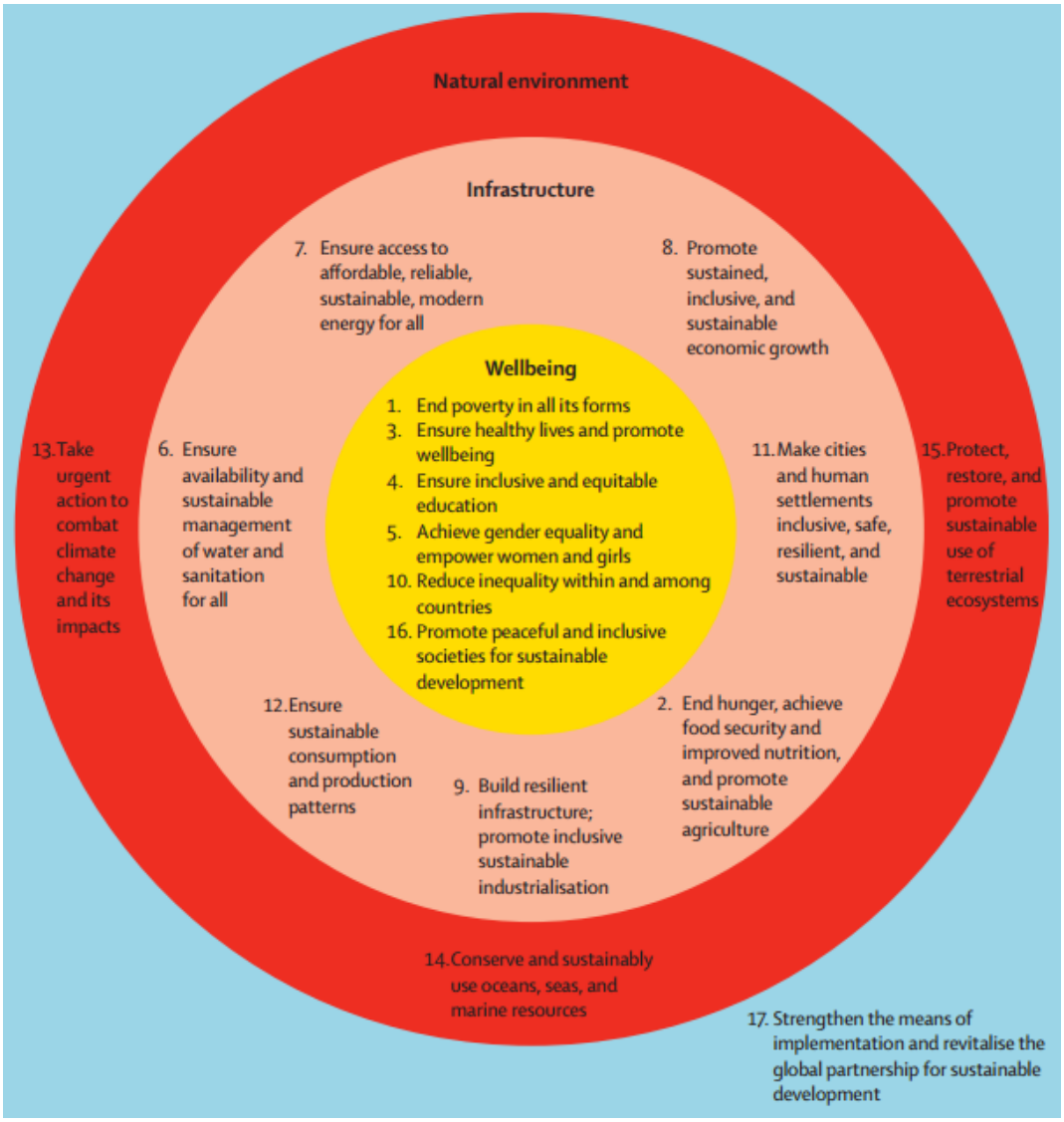


FIGURE 7-1 INTERACTIONS BETWEEN SUSTAINABLE DEVELOPMENT GOALS (WAAGE ET AL. 2015)

Schuftan (2016) argues that "The term globalization is a euphemism for a process of domination. Power differentials are at its crux". If he is right, then in the same way that colonialism created the subaltern, the recent processes of globalization are recreating the same power structures that produced—and silenced—the subaltern. Spivak (1988) presciently turns the question back onto us:

> *Can the subaltern speak? What must the elite do to watch out for the continuing construction of the subaltern?* (Spivak 1988)

If we are not to continue creating the subaltern, and to continue suppressing their voice, perpetuate this disequilibrium in systems, then radical change is required of the elite: we cannot preserve the status quo, because we now have evidence that it has not worked. As my Go4Health civil society colleagues, have written:

> *Neo-liberal globalization is seen to be responsible for effecting and deepening the multiple crises related to the food sector, to ecological systems leading to social inequality and structural discrimination. Not only has this development paradigm failed to benefit the poorest and most marginalised people, it has frequently been the cause of, or has deepened their poverty.* (Meisterhans 2017)

Ultimately, there is no single root cause of poverty and inequity, rather there are a host of forces—and an interaction of oppressive structures—that have conspired to rob people of their agency and their lives (O'Neil 2009). The voices of the marginalised, documented in this thesis and in the *Go4Health* project, have spoken to those forces: we now need to act.

If we are to positively harness—to reverse—the forces of globalization, then a commitment to achieving the SDGs is part of the solution. Pogge and Sengupta (2015), in their recommendations for the SDGs, called for greater efforts by governments and "other powerful agents" for structural reforms of the global institutional order: they agree that the continued operation of the world economy in its current structure is oppression. Given existing economic, technological, and administrative capacity the demand for the international called for by the SDGs is not ambitious—both the know-how and capacity exists. But while I have acted in this research to support their development and engage the voices of the marginalised in their development, I am cautious in my optimism. For change to happen requires the absolute precondition of global—and national and local—political will and good governance. That global political will is not currently apparent.

Shortly before the SDGs were finalised, I wrote, criticizing what I saw as an overzealously long list of targets and the use of development jargon (Hussain and Gaultier 2015). I was anxious lest we get lost in a shallow discourse around "solidarity" and "reducing inequality" in theory, but then complain that it is too difficult to challenge dominant orthodoxies associated with neoliberal global political economy (Benatar 2017). But I recognise that the SDGs do offer an articulated desire for change, and that—despite their lack of binding influence on states—there is an implicit commitment within them that is more than simply sustainable development, but that begins to unpack that structural violence, and allows the voices of the marginalised to be heard and acted on:

The concept of sustainable development is more than just sustainability. While sustainability is frequently understood as properties of, or indicators of, program implementation, sustainable development is a process towards a new normative horizon and implies a paradigm shift from a development based on inequity and overexploitation of natural resources and environmental services, to one that requires new forms of responsibility, solidarity, and accountability (Kjærgård, Land, and Pedersen 2014).

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Appendices

Appendix A

School of Population Health

THE UNIVERSITY OF QUEENSLAND

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To Ms Sameera Hussain

From Lisa Fitzgerald

Date 20 February 2014

Re Ethics Approval SH200214

CC Associate Professor Peter Hill

Dear Sameera,

Thank you for your application for ethics approval for your research:

Research topic: *Informing the Post-2015 Global Health Agenda: Can the Voices of the Marginalized Be Heard?*

The School of Population Health Research Ethics Committee has reviewed the materials submitted and ethics approval has been given.

Yours faithfully

Lisa Fitzgerald

Chair, School of Population Health Research Ethics Committee

School of Population Health, University of Queensland

Appendix B

James P. Grant School of Public Health
BRAC University

Date: February 25, 2013

Ethics Reference No: *Please quote this ref on all correspondence*	25
Project Title:	Formulating new goals for Global Health and proposing new Governance for Global Health that will allow the achievement of these goals, or "Go4Health"
Principal Investigator (s):	Dr. Tim Evans
Advisor (s):	Dr. Hashima E Nasreen
Research Investigator (s)	Sameera Hussain and Atiya Rahman

Thank you for submitting your application which was considered by the James P Grant School of Public Health, BRAC University Ethical Review Committee (ERC). The following documents were reviewed:

1. Ethical Review Checklist
2. Research Proposal
3. Consent Form
4. Questionnaires

The Ethica Review Committee approves this study from an ethical point of view upon the addressing by the researchers of the concerns as raised by the ERC affiliates.

Approval is given for three years. Projects, which have not commenced within two years of original approval, must be re-submitted to ERC. You must inform ERC when the research has been completed.

Any serious adverse events or significant change which occurs in connection with this study and/or which may alter its ethical considerations must be reported immediately to the ERC.

Approval is given on the understanding that the 'Guidelines for Ethical Review' are adhered to.

Yours sincerely,

Dr. Timothy G Evans,
Dean,
Chair of ERC,
James P Grant School of Public Health,
BRAC University

Appendix C

Listing of methods/studies for community consultation and engagement

Ryan et al (2001) conducted a systematic review of quantitative methodological techniques used to elicit public views in priority-setting exercises in healthcare at both the micro and macro level (Ryan et al. 2001). However, the exercise was largely focused on studies conducted in high-income European countries. Still, there are some lessons to learn from their work. It is advised that researchers use at least one quantitative method to help cross-validate and strengthen their results (although a plan to resolve conflicting results will need to be made *a priori*). It should be noted that for different contexts, different methods would be more suitable. Indeed, the way health is conceptualized by different people will also affect the choice. The methods are listed below:

Ranking Techniques

Simple ranking: assign an ordinal number to each option. Simple, easy to use, has been applied in a various contexts, including eliciting preferences for healthcare interventions, distributive justice, and clinical decision-making

Plurality ranking: each participant chooses one option, and the number of times it is chosen in a group gives it a rank.

Borda ranking: weighted ranking (least desired gets zero points, the next lowest gets one point, and so forth; total points are calculated), but was not used in healthcare

Binned ranking: Researchers asked respondents to rank 16 service/areas and treatments, four in each of four bins (essential, most important, important, and less important). Each time an item was listed under essential, it was given 1 point (all the way through to 4 points for less important). The average points give it an overall score, and all 16 were ranked in this way. An adaptation of this may be useful for prioritizing between social determinants of health, or ranking between essentials, if necessary

Qualitative Discriminant Process: Although this was described as computer based and developed in the business environment, this can be done in a focus-group activity without a computer. QDP uses ranks the same list three separate times, independent of each other. Each time, a different qualitative categorization is used, with different numbers of options available. For example, respondents first rank 10 items under very high/high/average/low. They get to move them around until they are completely satisfied with their choices. Next, the pile is mixed again and respondents have to choose between top/middle/bottom. The third round will divide them between upper/lower. Next,

each of the qualitative categories is assigned a range of points from 1 to 100 (e.g., upper 50-100, lower 10-50) and the points are calculated to achieve the ranks. Until 2001, there had been no use in healthcare. This kind of ranking system may be subjective, but this could be a method that can be carried out in various contexts, using local language with local meanings attached to the category names and still get results that can be generalized or compared against each other

Conjoint-analysis (CA) system: This assesses various options on each of a set of predefined criteria (e.g., years of life gained). The criteria are operationalized into categorical variables (1-2 years gained; 5-10 years gained; etc). Several combinations are assessed using ranking, rating or choice exercises. The results are analysed using regression techniques. The strength of this system is that one can estimate the weights of each criterion in the overall decisions; the rate at which individuals trade between these criteria; and the overall scores for different combinations of levels of criteria.

Rating Techniques

Rating techniques ask participants to rate criteria, scenarios or statements on a scale according to their opinions, beliefs and priorities. The scales can be numeric or semantic and have been used in economics to estimate utility, in sociology to understand attitudes, and in healthcare for satisfaction-type surveys and to elicit other preferences

Visual analogue scales: A line representing a scale from 0-100 is presented to participants to estimate the utility of an intervention or the desirability of a health outcome. This has been used to weight utilities in QALY literature

SEIQoL: The Schedule for the Evaluation of individual Quality of Life rating system has been used in assessing quality of life (QoL) in patients. Patients first identify and then rate their functioning on five most important areas to their quality of life. They then rate computer generated scenarios representing different combinations of these areas of life. Regression techniques are used to estimate the weights of these criteria to their lives. This is an expensive and time-consuming method but helps analyse the importance of criteria.

Likert scale: This is the most commonly used rating technique, and is commonly used in satisfaction surveys. However, long questionnaires are criticized as being "drawn-out, tedious, a headache to administer," and have their own challenges for data analysis and reliability (Chambers 1994)

Guttman Scale: These scales are used in many disciplines, and require respondents to answer as "agree" or "disagree". The responses to individual questions can be tallied to see how much agreement there is in a group.

SERVQUAL: Using Likert scale, the Service Quality (SERVQUAL) technique asks respondents to answer 22 questions (listed under five dimensions) on expectations of quality, and then a different set of 22 questions on their perceptions. The quality of a service or product is defined as perceptions minus expectations.

Choice-based techniques

Simple choice: This asks respondents to choose between scenarios and has been used to elicit allocation choices when faced with scare resources.

Random paired scenarios: Where several paired scenarios were presented to respondents with pairs differing on some characteristics. Cross-tabulations were conducted to assess how many times certain characteristics were selected.

Conjoint-analysis choice-based questions: Simple choice-based questions (A vs. B) can be regressed against pre-defined and operationalized criteria to understand how criteria affect choices between scenarios, interventions, or social determinants of health. These are becoming widely used in eliciting patient or community preferences in the delivery of health services and in establishing priorities in the clinical environment

Standard Gamble, Time trade-off, Person trade-off: These have been used in QALY literature to explore the utility attached to certain criteria. Here, respondents choose between a certain outcome and a gamble (e.g., 60% likelihood of alternative option; 6-years left to live; a 60-year old man). The gamble likelihood, length or characteristics are changed to see when it causes this gamble to become an equal choice to the certain outcome.

Willingness to pay: This is a choice based on getting the commodity for a certain amount of money, and respondents have to share what the maximum amount of money they will pay for a commodity. In an interview, respondents can circle the value they would be willing to pay from a list of several values written down, or everyone is asked whether or not they would pay a fixed amount for a commodity.

Allocation of points: Respondents place points for various scenarios, but this requires that they will have some discernable value attached to criteria already.

Ryan et al (2001) evaluate each of these methods on the criteria established above and made recommendations on what methods to use, keeping in mind that some methods were general approaches that could be customized for use in a particular setting (e.g., the strength of Likert scales depend on the questions asked). Likert and Guttman scales were the cheapest and simplest methods, but they did not consider the strength of preference, or relative weights of the components that

make up a choice. However, a larger choice range on the Likert scale and more nuanced questions could reveal some of these details. Other methods that met many of the criteria were the qualitative discriminant process, the Allocation of Points, the Standard Gamble and the choice-based Conjoint Analysis technique. SERVQUAL was a particularly useful technique and a well-validated tool, but it would need to be customized for our particular setting. Their conclusion is that qualitative studies are better suited to investigate the values and criteria of social preferences

Chile's Health Reforms

The Social Preferences study used several techniques and methods to understand the criteria that the public and other stakeholders used to understand and rank their health problems and needs. All methods were group-based to increase reliability—group priorities are more stable and shared than individual priorities. Largely qualitative methods were used as they fit the context better and avoided biasing respondents with pre-defined categories as quantitative survey tools often do. A panel of experts was engaged throughout the study to propose items for consideration and questions to ask. The results were combined with the objective cost-effectiveness and disease-burden analyses to inform Chile's health guarantees laws.

Panel discussions (pilots): Two pilots were conducted in Santiago: one with 25-45 year old professionals from the C2 SES, and the other one with 25-45 year old workers and housewives, from the C3D SES. A consensus building model ensured that everyone had a say, despite power dynamics in the meeting. The community had extensive discussions on "their health priorities, tips on improving the quality of care and their role in creating healthy environments and setting accountability measures."

Scenario-based focus groups: 21 citizen focus groups, segmented by age, gender, socioeconomic status and rural/urban divide were formed and the researchers presented them with a scenario-based exercise. Participants were asked, "If each of you had a bag of money, to which health problems or disease and which groups of our society (by age group, gender, rural/urban, SES, etc) will allocate resources and why?" The participants had half an hour to identify the most important health problem and disease in the country, in their community and for themselves. Participants that were selected had to be between 18 and 75 years of age, of all SES groups and industries and regions. Any person being treated for a serious illness (AIDS, cancer, disability, mental health) were excluded, as were healthcare professionals, sociologists and highest ABC1 SES. Participants were allowed to talk to each other, but they were not required to attain consensus on their answers. The answers of various sub-groups (e.g., minorities, low SES) were compared with the rest of the group.

Other studies in Chile used other methods to gain the input of the community. These were carried out a few years prior to the 2008 study.

Opinion polls: Public opinion was sought from public healthcare users and staff through quantitative and qualitative methods. Opinion polls were administered to the public. The questionnaires had 2 main elements: It first invited respondents to list the criteria they use to prioritize their health needs and problems. Then, participants were asked to weigh in on the disability ranking of the DALY's and YPLL**.**

Roundtable Discussions: Private and public sector workers, representatives of community collectives and civil society organizations were convened at panel discussions on health reforms and employee benefits to explore the social discourse of these stakeholders around health prioritization criteria.

Mail-in surveys: The broader community was engaged through mail-in surveys. The surveys asked participants of their health and healthcare priorities. 5600 surveys were completed and analysed.

Townhalls: These were organized in two stages. Initially, 48 townhalls were held and 3000 citizens met to discuss the reform design and proposals. The findings were returned and discussed at 250 townhalls that involved 25,000 people. It was also discussed with 22,500 community leaders and sectoral authorities. This may have been more of a way to open dialogue than a priority decision-making forum. (Infante 2012)

Sgombich and Frenz realize that community values are important in health prioritization, but that there is no perfect way of defining the "mainstream" priorities. The public consultations represent a process that allows citizen participation while also incorporating social values into the government's policies. However, this means that apart from including community values from technical perspective (in budget allocation), the laws have to reflect the community's values in spirit. If this can be achieved, and the prioritization process is transparent, the public need not have a permanent role in prioritization and periodic studies such as this one are sufficient.

By commissioning a literature review of national and international attempts at including public opinion in health prioritization exercises, researchers were able to build on the lessons of previous work and strengthen their methodology. For this reason, their focus groups, which represented the central instrument of their prioritization exercise, were a great improvement over studies that merely give participants a list of diseases to rank. However, they also had challenges. Some respondents wanted to allocate the hypothetical resources to themselves. In this case, the facilitators noted this result but asked them to repeat the exercise, this time by imagining that they were health

officials who needed to allocate these resources across a population. They were also told that officials use a set of criteria when they are making their decisions and do not merely base everything on public input. Some participants asked to use the money to buy universal health coverage and cover everything. They were asked to simulate limited resources which could not buy everything.

The major limitations of the study were that they did not represent marginalised groups, migrants and the Mapuche ethnic groups. Secondly, these consultations focused on common health problems and diseases and generally excluded rare and uncommon diseases. Finally, being a qualitative study, the perspectives of the researchers was considered an important bias. This means that the results may not cover everything that the focus group participants wanted to share.

Finally, Infante (2012) noted that although community participation would help "obtain support [and] credibility" for the health reforms, there was a risk that inclusivity could backfire, and health system users and workers could use it as a platform to make "vindictive demands" that could "destabilize the ministry." There was also the risk that giving union leaders a voice outside their traditional role "could challenge their delicate relationship with the authority". In this context, the explicit aim of building consensus between all stakeholders was important.

Accountability for Reasonableness

The A4R framework was applied in Tanzania using the Response to Accountable Priority-Setting for Trust in Health Systems (REACT) mechanism to initiate a series of health reforms built. The A4R framework "acts as a guide to achieving a fair and legitimate process" but has little to say on the content of those processes and mechanisms to achieve fair prioritization. This is because priority setting involves various, complex contexts, stakeholders, values and agendas, so the actual methodology of implementing it is also open. The methodology used by Tanzania's Ministry of Health was based around decentralization. This brought the process of setting priority diseases and services to the local districts by introducing a council health management team (CHMT) to work with the REACT researchers and advise the local government. Researchers assessed its success in improving the legitimacy and fairness of prioritization and planning by evaluating how well it achieved the four key principles of the A4R framework, namely soliciting local values, publicizing the priorities that were established, creating accountability structures, and creating leadership to guide these three processes.

Activities of community health workers: The data on the activities of the community health workers is an important source of community needs and demands. CHMT members worked with health posts and community health workers in their catchment area to identify health service uptake statistics and what they revealed about community priorities.

Village visits: CHMT members also visited all villages in their district to solicit priorities from the community and from the hospital staff. This process brought a lot of community concerns that were later incorporated into the district health plan. These consultations also empowered REACT researchers in arguing for the community concerns at district council meetings.

User committees and boards: Committees of healthcare service users were formed and the district level health officials were to work closely with them to develop plans and budgets to incorporate them into the district council's health plan on a yearly basis.

Publicity: A4R required that health priorities and the reasons for choosing them be publicized to make the government more transparent, more responsive and fairer. Staff meetings and flyers posted on notice boards at hospital, health centres and the council offices of the districts, villages and wards, in the local language helped in this process.

Appeals process: Although not fully implemented, the appeals mechanism would allow hospital staff to voice their opinions, views and concerns on the publicized priorities and management activities to revise or reverse adverse priorities.

Oversight and enforcement: Sensitivity workshops were organized to create excitement around the role of oversight. The decentralization process created Health Facility Governing Committees (HFGCs) to oversee and scrutinise district health plans and budgets to ensure that they meet and address local health priorities.

There were several issues with making the planning and priority-setting process participatory. The evaluation revealed that although there was much rhetoric about decentralization, there was little actual community participation practiced at the district level. The user committees and boards reported that they did not feel as included. This was confirmed by CHMT members who felt that the public did not have the knowledge, skills, and experience to effectively contribute to priority-setting decisions and carried out most of the discussions and decision-making. This failure was attributed to lack of incentives to become involved, untimely disbursement, budget ceilings, low level of awareness of the users of their roles and responsibilities, and interference from higher authorities to use epidemiological data to decide priorities instead of community consultations. Publicizing the priorities helped make the health system more transparent and legitimate by publicizing the priorities, processes and budgets for each priority. But the user committees complained that they

were not satisfied with the priorities and did not know what the process of publicity entailed. This low level of participation and awareness prevented them from being able to question the decisions of the district officials. Also, the appeals process was not relevant since the publicity of the priorities generated very little local participation, dialogue and feedback. The reasons for this were unawareness of their rights to comment, fear of commenting on the district's work and a lack of an appeals culture. The budgets also seemed to be too rigid to change with feedback. Finally, community oversight taskforces had insufficient capacity, resources, knowledge and unclear lines of authority to be much help in the process of enforcement.

The researchers suggested that a more detailed analysis of the health system elements, the socio-cultural context and the concerns of stakeholders and a way to navigate local power asymmetries can lead to a more legitimate and fair priority setting exercise. There was an urgent need to educate the local health workers on their role in the new process of prioritization. Some of the suggested methods to increase information included popular education, building argumentation, advocacy and lobbying skills and informing staff in the health facilities and village health governing committees about their rights and policies about which they are being consulted.

Appendix D

Interview Guide for FGDs and IDIs with Lay Community Members

Country: District : Village/Area:	Date of interview:
Name of Community/Group:	Name of interviewer:
Name of Respondent:	Notetaker Name:
Interview Start Time:	Interview End Time:

Good morning/afternoon. My name is_____ and this is _____ (if 2 people present). Thank you for agreeing to speak with us. We are here from BRAC University to learn about you and your community's health needs and experiences as part of a global project, Go4Health, to formulate new health development goals after 2015. Your participation and responses will help us in our learning.

Any personal or sensitive information that you choose to share with us will be kept in confidence. This interview should take no more than one hour, and we request you to try to remain for the full period if you can. Of course, if you feel uncomfortable, you are free to stop and we will understand.

Do you have any questions? If not, we will now begin.

Background Characteristics

Name, age, main occupation, religion, ethnicity, gender, family structure, educational qualifications, original residence, duration of stay in this community, marital status, spouse's age and main occupation.

Understanding peoples views on their current health situation and perception on health

1. What does health mean to you?
2. What do you mean by good health? What do you mean by bad health? Why?
3. What makes a person healthy? Why?

4. Please tell us about your health. How do you measure your own health? Are you healthy or unhealthy? Why?
5. If you are ill/unhealthy, what are you doing to improve your health?
6. When do you recognise that your health condition is not good or deteriorating?
7. Have you seen healthy people in your community? Who are they? Why are they healthy, in your opinion?
8. Have you ever seen any unhealthy people in your community? Who are they? Why are they unhealthy, in your opinion?

Determinants of Health

We talked about your concept of good and bad health and about your perception on your own health. Now we will discuss these issues in a broader way.

9. How do occupation, social, mental and environmental issues determine health?
10. If someone has good physical health, is he/she actually healthy? Why/why not? (ask respondents about other determinants)

Health and Community

11. What do you mean by healthy community? How do you know when your community is healthy?
12. What do you mean by unhealthy community? How do you know when your community is unhealthy?

Understanding Essential Health Needs (EHNs)

13. What are your most urgent health needs?
14. What are the goods and services needed for your community (irrespective of who they are and where they live) to be in good health?

(for FGDs, start free listing, severity ranking and preference ranking)

<u>Directions for free-listing:</u>

a) Respondent can list as many essential health needs as they want. Notetaker should list items sequentially as mentioned.
b) Prepare card for severity ranking excersize and ask respondent to sort the card based on highly essential, moderate essential and least essential and justify their grouping
c) <u>Preference ranking</u>: ask participants to ensure they votes for their **most** important essential health needs and records reasons for their preferences.

15. Are these essential only for you or your community? Why?
    Are the above mentioned health needs are available to you? In your opinion what EHNs can you access easily?

Understanding Services, Resources and Essential Health Needs

16. What kind of health services are available to you? Who/what organization are the provider? How do they provide and what issues?
17. Do you use them? for what services? Why/Why not?
18. If you have used these services, can you please tell us about your experiences? What good experiences have you had? What bad experiences have you had?
19. What kind of health services are available to the community, free of cost or at low cost?
20. Beside these, do you get health services from others (person/organization)? From whom/where? If not, why not?
21. What kind of health services do you get from 'informal' health care provider? Why? Why not?
22. What other services are important for you to be in good health?
23. What are these other services not available in your community?
24. What are the reasons for your not having these needs addressed?
25. Do you think these resources can address the essential health needs of help you and your community If not then how this problem can be solved? What resources or program is needed to meet your community's essential health needs?
26. If you had a bag of money, to which EHNs would you allocate resources (financial, human, facilities/equipment)? For which people? Why?

Roles and Responsibilities of Relevant Actors

27. What can you do to ensure these health needs are met ?
28. Whose responsibility is to ensure that your essential health needs are met? (this can be a scenario-based question).
    - Health service providers
    - Local government/administration
    - State or central government
    - NGO
    - Private organizations (pharmaceutical companies, industries, etc)
    - Community based organizations
    - international organizations
    - Others (i.e., local leaders/elite persons/worker's organizations/farmer's organizations etc.)
29. In past what have your health providers and local actors work about your health needs and health matters?how did they responsible?
30. Who forwarded your complaints to the authorities? Can you give an example of when this happened in your community?
31. Do they perform as expected?

32. Do you think it is your health provider's/organization's and/or local leader's responsibility to help you achieve essential health needs? Why?
33. What should be done if they do not do so? Why? How?
34. If they do not do then what should be done ? why? how?

Community Participation in Decision Making

(LOCAL LEVEL)

35. Have you or any other member of this community ever engaged in any health related decision-making process? Why?
    - ***if answer is no, proceed to Q 37***

    How? To what extent do you think was functional? Why? Can you tell us about it?
36. Are you or any community member engaged in such a process at local level at present?
37. Do you think you should participate this type of decision-making process? How do you ensure your participation?
38. Who should be your representative from your community in health related decision-making? Why?

(NATIONAL LEVEL)

39. Have you or any other member of this community ever engaged in any health related decision-making process at the national level? Why?
    - ***if answer is no, proceed to Q 41***

    How? To what extent do you think was functional? Why?
40. Are you or any community member engaged in such a process at national level at present?
41. Do you think you should participate this type of decision-making process? How do you ensure your participation?
42. Who should be your representative from your community in health related decision-making? Why?

(INTERNATIONAL LEVEL)

43. Have you or any other member of this community ever engaged in any health related decision-making process at the international level? Why?
    - ***If answer is no, proceed to Q 45***

    How? To what extent do you think this was functional? Why?
44. Are you or any member of your community currently engaged in such a process? Why?
45. Do you think you should participate this type of decision-making process? How do you ensure your participation?
46. Who should be your representative from your community in health related decision-making? Why?

Other

47. Would you be willing to share your personal experiences in relation to your health or health services around you with us? If so, please begin….
    - ***If no, proceed to next question***
48. As we conclude our discussion, do you have any questions or comments?
    - ***Address questions/comments***

I/We would like to thank you for your valuable inputs and time.

Appendix E

VISIBILITY OF *GO4HEALTH* LITERATURE IN SELECTED DATABASES

***Go4Health* Publication**	**WoS**	**Scopus**	**EMBASE**	**PubMed**	**GHL**	**WPSA**	**Total**	**UN ODS**
Health rights in the post-2015 development agenda: including non-nationals	✓	✓	✓	✓	✓	✓	6	None
Sexual and reproductive health and rights in the evolving post-2015 agenda: Perspectives from key players from multilateral and related agencies in 2013	✓	✓	✓	✓	✓	✓	6	None
Universal Health Coverage and the Right to Health: From Legal Principle to Post-2015 Indicators.	✓	✓	✓	✓	✓		5	None
"Everywhere but not specifically somewhere": a qualitative study on why the right to health is not explicit in the post-2015 negotiations.	✓	✓	✓	✓	✓		5	A/71/304
A global social contract to reduce maternal mortality: the human rights arguments and the case of Uganda.	✓	✓	✓		✓	✓	5	None
Back to the future: what would the post-2015 global development goals look like if we replicated methods used to construct the Millennium Development Goals?	✓	✓	✓	✓	✓		5	None
Community participation in formulating the post-2015 health and development goal agenda: reflections of a multi-country research collaboration.	✓	✓	✓	✓	✓		5	None

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Go4Health Publication	WoS	Scopus	EMBASE	PubMed	GHL	WPSA	Total	UN ODS
Is universal health coverage the practical expression of the right to health care?	✓	✓	✓	✓	✓		5	None
Making the post-MDG global health goals relevant for highly inequitable societies: findings from a consultation with marginalised populations in Guatemala.	✓	✓	✓	✓	✓		5	None
Perceptions and experiences of access to public healthcare by people with disabilities and older people in Uganda.	✓	✓	✓	✓	✓		5	None
Universal Health Coverage's evolving location in the post-2015 development agenda: Key informant perspectives within multilateral and related agencies during the first phase of post-2015 negotiations.	✓	✓		✓	✓	✓	5	None
What could a strengthened right to health bring to the post-2015 health development agenda?: interrogating the role of the minimum core concept in advancing essential global health needs.	✓	✓	✓	✓	✓		5	None
Aboriginal medical services cure more than illness: a qualitative study of how Indigenous services address the health impacts of discrimination in Brisbane communities.	✓	✓	✓		✓		4	None
Facilitating health and wellbeing is "everybody's role": youth perspectives from Vanuatu on health and the post-2015 sustainable development goal agenda.	✓	✓	✓	✓			4	None

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Go4Health Publication	WoS	Scopus	EMBASE	PubMed	GHL	WPSA	Total	UN ODS
From knowing our needs to enacting change: findings from community consultations with indigenous communities in Bangladesh.	✓	✓	✓	✓			4	None
Health, equity and the post-2015 agenda: raising the voices of marginalised communities.	✓	✓	✓	✓			4	None
Rights Language in the Sustainable Development Agenda: Has Right to Health Discourse and Norms Shaped Health Goals?	✓	✓		✓	✓		4	None
Achieving equity within universal health coverage: A narrative review of progress and resources for measuring success	✓	✓	✓				3	
How can health remain central post-2015 in a sustainable development paradigm?	✓	✓	✓				3	
Cautionary Notes and Future Directions: Cautionary Notes on a Global Tiered Pricing Framework for Medicines						✓	1	
Global health governance after 2015						✓	1	
Governance and Financing of Global Public Health: The Post-2015 Agenda						✓	1	
Health for all: Implementing the right to health in the post-2015 agenda: Perspectives from the global south		✓					1	
The emergence of a global right to health norm - The unresolved case of universal access to quality emergency obstetric care			✓				1	

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Go4Health Publication	WoS	Scopus	EMBASE	PubMed	GHL	WPSA	Total	UN ODS
Universal health coverage anchored in the right to health						✓	1	
What do core obligations under the right to health bring to universal health coverage?		✓					1	
Will Ebola change the game? Ten essential reforms before the next pandemic. The report of the Harvard-LSHTM Independent Panel on the Global Response to Ebola						✓	1	

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