Community consultations on the post-2015 global health agenda: A demand for dignity, respect, participation and accountability

A report by Work Package 2 of Go4Health
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Cover photo: Group interview with Kekchi indigenous families in Alta Verapaz, Guatemala. Photo: Aiken Chew, CEGSS. Guatemala.

Cover design: Raphael Zepeda, CEGSS Guatemala.
Executive Summary

People have a human right to participate in making the decisions that will affect their lives, including health-related decisions at all levels, from local to global. Yet people often lack an opportunity to participate in these decisions – especially when they are part of marginalized communities. In the case of health, not only does this lack of participation violate people’s rights, but it means that policies involving and investments in people’s health will be less well tailored to their needs and realities, and thus be less effective – missing opportunities to close health inequities, and reinforcing rather than helping ameliorate the exclusion that marginalized communities experience. Accordingly, to contribute to the ability of marginalized communities to have their voices heard in the post-2015 sustainable development agenda that will follow the UN Millennium Development Goals, the Go4Health project, designed to offer scientific advice to the European Commission on the post-2015 New Health Development Goals (NHDGs), includes a community engagement component. Here we offer the initial results and recommendations from Work Package 2, the work stream of Go4Health that is undertaking the consultations.

This report covers consultations of marginalized communities – including indigenous communities, ethnic minorities, refugees, highly impoverished communities, and LGBTI communities – in nine countries (Afghanistan, Australia, Bangladesh, Guatemala, Philippines, South Africa, Uganda, Vanuatu, and Zimbabwe). While we have sought to engage a diverse array of marginalized populations in regions around the world, among the limits of our efforts is that we cannot call this a globally representative sample of marginalized populations – to the extent that their diversity and differing degrees of marginalized populations could ever make this possible. We do, however, hope that their numbers and diversity enable us to draw valuable conclusions with broad applicability. In addition, beyond seeking to give voice to these communities, we are striving to connect the communities that we have engaged to ongoing processes, whether of our own organizations or of partner organizations, that will enhance the ability of these communities to mobilize in support of their own health needs, or otherwise contribute to meeting these needs.

We have organized our findings across Go4Health’s proposed overall New Health Development Goal – the right to health itself – and the four aspects of the goal that Go4Health has drawn out as targets and essential elements of achieving this goal: comprehensive universal health care, a healthy environment, governance, and engagement of concerned populations. In some areas, such as community understandings of where the responsibility for their health needs is located and forms of health care that are tailored to people’s particular circumstances, the diversity of the populations we consulted is reflected in a diversity of perspectives. In other areas, such as the importance of health care as well as other essential health needs, and the value people placed on
but their lack of opportunity to participate in health-related decision-making, these communities speak with considerable uniformity.

**Right to health:** Our findings support the inclusion of the right to health as the chief New Health Development Goal. Its holistic coverage of health, both health care and its underlying determinants, is in accord with people’s holistic view – which extends even further than the right as presently articulated to reach the broader determinants of health. Perhaps most critically, the elements of the right that extend to how these elements of health are to be assured of special importance to marginalized populations, from what access to health care and the underlying determinants require – such as non-discrimination and respectful treatment – to what the policies and practices governing health require, such as participation, accountability, and equity.

**Comprehensive universal health coverage:** Communities we consulted consistently place a high priority on their ability to access health care, and draw attention to a wide array of obstacles they face, from the distance to health facilities and high transportation costs to the absence of medicines at these facilities. For some communities, the problem with the health system that engendered the greatest passion was one that was most directly related to their marginalization – the discrimination and mistreatment that they faced when accessing care. Whatever the state of formal access – nearby facilities adequately staffed with drugs in stock and care free or affordable – unless this discrimination and mistreatment is addressed, universal health coverage will remain less than universal, and run counter to the values, such as inclusion and equity, that any plausible post-2015 development agenda will include.

Meanwhile, when raising particular health issues, three central points emerge. First, equity must be a fundamental consideration in ensuring universal health coverage, both to ensure that health care interventions are not limited primarily to only certain segments of the community and that the particular needs of different populations that are specific to those populations are ensured. The discrimination against women that can be a barrier to their access to health care must end. Second, most health issues that people highlight map to health problems of particular prevalence and prominence in their countries and communities, such as AIDS and maternal health in communities in the African countries and mental health in Afghanistan. And third, 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.

**Healthy environments:** Communities consistently express a holistic view of their health. While viewing health care and its constituents, such as a health facility and doctor in their community, as top health priorities, health care was only one of many elements that they view as essential health needs. Hygiene and sanitation, clean water, and nutritious food are common priorities, while communities frequently raised other essential health needs such as employment, housing, education, and an environment free of pollution.
Creating these healthy environments will require more than providing latrines, investing in agriculture and education, constructing quality housing, and other such development activities. Global trends and powerful interests will need to be confronted. For some communities, access to nutritious food has decreased because of lifestyle changes, such as migrants who used to be able to grow their own food but now, in an urban environment, have wages too low to afford buying healthy food, and cannot grow their own. For another community, it was forced migration off their land that led to a comparable unhealthy change of circumstances. Extractive industries, such as mines in Guatemala, are responsible for pollution.

**Governance:** Different communities locate primary responsibility for meeting their health needs at various levels, with some – perhaps for whom national (much less international) authorities and actors seem particularly distant – focusing on community leaders and local authorities, with others placing chief responsibility on the national government, and in several cases, acknowledging as well the role of the international community. Whatever their allocation of responsibility, with rare exception (a refugee community thankful for the health care they now receive), communities overwhelming pointed to the failure of those bearing responsibility. Community leaders did not listen to their concerns or were themselves not listened to by higher authorities. The national government was failing in its responsibilities. In Afghanistan, the impermanence of the international community’s heavy presence is raising concerns about the future of health there, as the international community begins to exit. People in a number of communities evinced a strong sense of personal and family responsibility for their own health, particularly in terms of good hygiene, but also in other areas, such as seeking health care and providing food for their families.

**Engagement of concerned populations:** Members of the communities we consulted overwhelmingly expressed a desire to be able to participate in the decisions that affected their health – in some cases highlighting the importance that women be able to participate – as well as dismay that they were unable to do so. Statements that “no one ask[s] questions to us” and the “government does not pay attention” encapsulate people’s experience. This is the case even when structures for participation are supposed to exist, including throughout the African countries that were part of our consultations, where lack of financing and regulations meant that local health committees had never been established or did not function.

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. Formal and informal processes that could have influence and contribute to accountability – community
leaders or local structures that are supposed to exist as part of national policies – are generally ineffective or absent.

This is an all-encompassing concern. Without this accountability, the potential for comprehensive universal health coverage and securing healthy environments are both at great risk. Catalyzing the development and effectiveness of accountability mechanisms – including and especially for marginalized communities and especially marginalized people within communities – must be a key part of the post-2015 development agenda. So too should empowering people so that they can hold authorities responsible, from knowing their rights and avenues to engage with authorities to having the skills to effectively engage authorities through to having the means to pursue legal, political, or other remedies that may be available – or need to be established.
I. Importance of community engagement, especially of marginalized communities

Even as human beings we all share many health needs, the centrality of health to our lives and the tremendous diversity of our circumstances affect our health needs and priorities. People must therefore have the opportunity to shape the policies that will affect their health and human rights. As the global community shapes the post-2015 sustainable development agenda, the right to health, including its imperative on participation, must be integral to that agenda, establishing the post-2015 goals, targets, and indicators, to translating them to and implementing them at national and community levels, to monitoring them and holding officials accountable.

Society has allocated the power of making decisions on human health, and ultimately whether other people live or die, to certain governmental and other institutions, from the United Nations to municipal authorities. Regular opportunities for community engagement – of meaningful ways for people to input into these life-shaping decisions at every level – can help resolve the tension between human equality and the power asymmetries in how health decisions and policies are made.

There are also a host of practical reasons for engaging communities at every step in making and ensuring the effective implementation of health policies. These include:

1) Ensure that health goals and policies meet people’s actual health needs and understandings of their health.

These understandings are often holistic. Communities from ethnic and religious minorities remote areas of Bangladesh to diverse marginalized populations in Uganda to an impoverished, indigenous community in Guatemala to refugee and migrant communities in Australia affirm that not only health care, but also clean water and sanitation, food and nutrition, the ability to earn a livelihood, education, housing, transportation, and the ability to have healthy lifestyles including physical activity are all important determinants of their health. An approach to health that is confined to health care – as important as that is – or that does not account for the importance of these many determinants of health, and their links to health, will not meet people’s health needs and rights.

Community consultations in Chhattisgarh state, India, revealed the link between health, deforestation, and agricultural practices: the shrinking forest limited access to produce, pesticides reduced crops’ nutritional value, and the breakdown in the relationship between people and the forest reduced food security. Policies to ensure people nutritious food, therefore, must be linked to environmental health. At the same time, certain populations may have particularized needs requiring tailored policies. Children with disabilities and the very elderly required special facilities, yet these were rarely present. A community in Afghanistan voiced their need for a
higher boundary wall in a facility so that it would block examination room windows at a health facility, thus allowing women access health care in way that would be culturally acceptable. A blanket approach to universal coverage would continue to leave people uncovered.

The Chhattisgarh consultations demonstrated a disjuncture between policymakers and community members. A policy linked the number of primary health centers to population size, but in areas with a low population density, this left some people too far from any health center. Community members offered recommendations to increase health care access, such as opening clinics in the evening, rather than functioning only in the morning and early afternoon when many people are in the field.1

As we will detail more below, one of the most serious disjunctures between marginalized communities and policymakers is a frequent emphasis of policymakers on precisely what health interventions to provide – what universal health coverage programs will cover and what they will not – whereas for many people, the question of whether the health system will meet their needs is be determined by more basic questions, including their ability to access health care at all and whether they are treated with respect and dignity.

2) Develop enabling environments for health-related policies to have their intended impact, including on marginalized and vulnerable members of the community.

This includes an environment where community members and civil society can speak freely, patients are ensured non-discriminatory, non-judgmental, respectful treatment, and cultural practices consistent with health are respected and community members lead efforts to change those that are not.

In Guatemala, the government has provided interpreters in some health centers serving indigenous populations, an appropriate step, but one that did not lead to community members significantly increasing use of health centers. Asked why not – but only afterwards – people explained that they were avoiding health centers not primarily because of language barriers, but because of the disrespect and discriminatory practices with which health providers treated them. The new policy failed to address this.2

3) Build local trust and ownership, use local knowledge, and tailor policies and actions to local circumstances, all leading to more effective health policies and programs and better implementation.3

Health system hierarchies can generate distrust, impeding policy reforms to improve equity. To address distrust between public officials and ordinary citizens, civil society organizations have developed participatory systems to monitor public polices and local health services. In
Guatemala, a participatory monitoring system in six rural municipalities involves community leaders, municipal government authorities, and health workers. Through a cycle of data collection, analysis, action plans, and advocacy, this community engagement has led to concrete improvements: dismissal of health providers for poor performance and corruption, municipal coverage of ambulance fuel costs, improved water services for a district hospital, fewer absentee healthcare workers, and more follow up on complaints. In a country still recovering from the trauma of civil war, the trust the connection between citizens and public authorities engenders is important to rebuilding the social fabric and strengthening democratic practices.\(^4\)

4) \textit{Improve accountability, to ensure that health policies are being effectively implemented, and to facilitate advocacy and policy adjustment to improve implementation.}\n
A study involving 50 communities in Uganda used a community scorecard approach to local accountability. Scorecards were developed based on surveys of community members and health workers. Disseminated to community members and health workers, scorecards then served as a basis for meetings of community members, health workers, and the two groups together, leading to joint action plans to improve health services. Communities using scorecards had a 33% reduction in child mortality, reduced health worker absenteeism, and other health service improvements.\(^5\)

Yet as our consultations revealed, this level of accountability is exception, not the norm. Marginalized communities that we consulted overwhelming felt that there was a lack of accountability. They rarely have channels to community their concerns, and even where accountability mechanisms exist on paper, they are often poorly or non-functioning. In Afghanistan, for example, community members felt that for their elite leaders, “their own health is important, not the health and welfare of the community.” 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.

5) \textit{Contribute to the process of empowerment, fostering health-enhancing dynamics, as people see that their input is valued and can affect health policies and practices.}\n
This can lead people to further participate, including engaging local – and even higher level – health services and officials to ensure that they are responsive to their needs and accountable to them. We have seen demand for action in communities that we have consulted. They want support in mobilization, in engaging health and political authorities, in participating in national post-2015 processes.
6) **Account for the fact that civil society representatives often come from very different circumstances (the middle class) than communities whom they represent, and may have their own (however well-meaning) agendas.**

The importance of engaging communities is particularly vital for marginalized populations, whose voices are least likely to be heard and heeded in policymaking circles without deliberate and strategic engagement efforts, and who often suffer most from health inequities. 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.

Moreover, with persisting and even widening inequalities in health, with the poorest populations experiencing the fewest gains, a special focus on marginalized populations – and understanding their realities firsthand, why they are not sharing in health gains – is warranted. Otherwise, one of the greatest shortcomings of the Millennium Development Goals risks replication in the NHDGs.

The right to health similarly demands a focus on marginalized populations in participatory processes, an implication of the right’s dual focus on participation on equity. An important element of the right to health is “the participation of the population in all health-related decision-making at the community, national and international levels,” while a part of the “core obligations” is that countries develop a public health “strategy and plan of action shall be devised, and periodically reviewed, on the basis of a participatory and transparent process.” Meanwhile, “the process, by which the strategy and plan of action are devised, as well as their content, shall give particular attention to all vulnerable or marginalized groups.” That is, the participatory process requires special efforts to include marginalized population. More generally, “health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact,” and states must ensure “that health care staff are trained to recognize and respond to the specific needs of vulnerable or marginalized groups.”

The link between these two strands of the right to health, participation and the emphasis on equity and marginalized populations, is clear: The best way to understand the realities of marginalized populations, the obstacles to their ability to access quality, acceptable health services, including health care and the underlying determinants of health, is to ask them, to develop policies accordingly, to seek constant feedback on the effectiveness of these policies, and to make adjustments – to remedy shortcomings – as necessary.
There is another very practical reason for paying special attention to marginalized populations, beyond meeting their own needs. If countries can develop the systems, policies, processes, and practices that meet the health needs of, and create conditions of good health for, people with the fewer resources, poorest health, and worst access, these approaches should be sufficiently robust and responsive to meet the health needs of the broader community.
II. The role and approach of Go4Health Work Package 2 and our community consultations

The post-2015 development agenda and the process of developing and implementing it must respond to this importance of engaging communities. As members of the Go4Health consortium – a collaboration of academics and civil society tasked with offering scientific evidence to the European Commission on the next set of global health goals – we seek to contribute in at least a small way to this imperative. Through four regional hubs, we are consulting marginalized communities in nine countries on their health needs, perceptions on accountability, and role in health policymaking. We are grappling with practical and ethical challenges, and recognize we can only reach a handful of the diverse marginalized communities around the world.

The regional hubs are: Africa: Center for Health, Human Rights and Development (CEHURD), Uganda; Asia: James P. Grant School of Public Health, BRAC University (BRAC), Bangladesh; Latin America: Centro de Estudios para la Equidad y Gobernanza en los Sistemas de Salud (CEGSS), Guatemala; Pacific Region: School of Population Health, University of Queensland (U. Queensland), Australia. The O’Neill Institute for National and Global Health Law at Georgetown University Law Center, United States, is coordinating this work package.

We have decided to focus on marginalized populations for the reasons described above. WP2 is committed to our best efforts to enable people for whom the NHDGs could literally have a life and death impact – and whose health experiences they could help transform from a reminder of their marginalization to an affirmation of their dignity – have a real voice in developing these goals.

In addition, our decision is informed by practical opportunities and constraints. We saw three main, practical opportunities in engaging marginalized populations. First, by linking the communities to our own or to our partners’ advocacy and community empowerment processes, we saw an opportunity to directly benefit communities, which was most important for those presently most excluded and with the least power. Second, we hope that our focus on marginalized populations can serve as an example for further UN consultations on the post-2015 sustainable development agenda, as well as how this agenda will be translated and implemented at the national level. And third, for one of our organizations (CEGSS), this was an opportunity to develop a new framework for engaging marginalized populations that we hope will be beneficial beyond our own processes.

Also, given our funding constraints, the particular importance emphasized above of engaging marginalized populations, and the diversity of marginalized communities, we determined that it was best to focus our efforts on these populations. Indeed, even as we have sought to collectively consult a diverse set of marginalized populations, we could hardly begin to be comprehensive in this regard, or to be able to claim that our consultations are representative of all marginalized
populations. However, the diversity of populations that we have consulted, not only geographically but also in their characteristics, provides us confidence that we have been able to draw some widely relevant findings.

While we discussed within Work Package 2 which communities we would consult in each region, so as to ensure this necessary diversity, different hubs used slightly different methods to identify the populations. Our Latin American hub, finding existing frameworks unable to meet their needs, developed their own. Our Asia hub used the PROGRESS framework, identifying populations based on marginalization across the dimensions of place of residence, religion, occupation, gender, race/ethnicity, education, socioeconomic status, and social networks and capital.10 In Africa, our hub and its partners identified marginalized groups based on health indicators as reported by national demographic health surveys, the historical imbalances in some groups including gender considerations, and various cultural and religious factors affecting the health of given communities. In the Australia Pacific Region, the selection of communities was driven by the specific politics of the region. We wished to include a representative of the small island states, Vanuatu, with its particular vulnerability to climate change; Australian Aboriginal people – indigenous, but marginalized within their own country, and; migrant and refugee populations, living out their transitions from disrupted home environments, yet not entirely integrated into their new society.

WP2’s primary role within Go4Health, then, is to conduct community consultations and use their lessons to ensure that Go4Health’s recommendations on the NHDGs and global social contract are informed by community perspectives. Given our ethical premise about the importance of respecting people’s own agency and perspectives on their health, and our commitment to the right to health, we are aiming to be as participatory as possible in our own consultations, using participatory research methods. In Guatemala, the team applied a participatory-action research11 approach in which the consultation is the first step in a comprehensive process in which consulted communities will implement a social mobilization process to influence public policy-making at municipal, provincial, and national levels.

Our method, in brief, involved first securing ethical clearance, from relevant institutional authorities or other bodies, as well as permission of community leaders and informed consent from community members. Through focus group discussions and community meetings, as well as individual interviews, we sought the views of community members across five domains:

- Community understandings of health
- Determinants of health
- Essential Health Needs and their provision
- Roles and responsibilities of relevant actors
Community participation in decision-making

In many cases, we also sought the perspectives of others in or working with the community, including community leaders, civil society, local authorities, and community health workers. Within the broad framework, due to the diversity of countries and communities, the specific methods we used varied. Also, in some cases, we – the regional hubs – carried out consultations directly, while in other cases, partners have carried out the consultations (or will do so).

The consultations that we have completed and analyzed, with results feeding into this report, are:

- Afghanistan: rural communities in Paghman, Qarabagh, and Kalakan districts. Respondents were all conflict-affected, including those who fled to live as refugees as well as those who remained in their homesteads. The consultations were carried out with lay community members, community leaders, health providers and representatives of organization working with those communities.

- Australia: 2 refugee communities (Rohingya, Karen), 2 urban Indigenous communities, and 1 migrant community (Samoan), all in the vicinity of Brisbane, Queensland

- Bangladesh: The Tripura and Mro communities, two ethnic and religious minority groups living in Bandarban district of the Chittagong Hill Tracts, who are poor and have difficulty accessing the health system due to their geographical location. Consultations were also carried out with poor rural communities living in the wetland region, seasonally cut-off from the mainland for six to seven months every year.

- Guatemala: Santa Maria Nebaj, a primarily indigenous rural community with high rates of poverty and highly affected by Guatemala’s violence and repression (particularly in the early 1980s) in Santa Maria Nebaj, and Tectitan municipality, with primarily non-indigenous poor populations. The consultations were carried out with community leaders representing the different communities living in each municipality. There were additional consultations to address in depth the issue of discrimination and mistreatment within the health care system. These consultations were carried out with 14 different communities representing 14 different municipalities across four indigenous language regions (Mam, Ixil, Q’eqchi’, and K’iche’).

- Philippines: Communities in Maguindanao province of the Autonomous Region of Muslim Mindanano.

- South Africa: Communities in 4 districts in Eastern Cape Province: OR Tambo District, predominantly rural and the pilot site for the National Health Insurance scheme, the very sparsely populated Joe Gqabi District, the also sparsely populated Cacadu District, and
the predominantly rural Amathole District, which has high rates of poverty. All consultations in South Africa proactively engaged a range of marginalized populations in each district. In all communities, health imbalances caused by apartheid – contributing to the high levels of HIV, as well as teenage pregnancies and overall very poor health indicators – were prominent.

- **Uganda:** 1 conflict-affected community in Gulu district, 1 community in Buikwe district notable for high rates of school dropout, high incidence of HIV in the fishing communities, early marriage, and violence against women, and 1 community very remote community in Kamwenge district. All consultations in Uganda proactively engaged marginalized populations including women, people living with HIV, people with disabilities, lesbian, gay, bisexual, transsexual and intersex people (LGBTIs), the elderly, sex workers.

- **Vanuatu:** Urban and rural communities in this Pacific island nation.

- **Zimbabwe:** Communities in Goromonzi district and in the rapidly growing urban Chitungwiza district (near Harare). These communities have been heavily affected by Zimbabwe’s recent economic meltdown, contributing to very poor health indicators, and also have high rates of HIV. All consultations in Zimbabwe proactively engaged a range of marginalized populations in each district.

Limiting findings are available for this report from several of the consultations described above, including in Vanuatu, with further analysis still required. In addition, certain issues may be explored in several of these communities in further consultations.
III. The proposed New Health Development Goal and targets

1. The right to health

Our consultations affirm the appropriateness of the right to health as the New Health Development Goal (NHDG). As detailed more below, the right’s guarantee of both health care and underlying determinants of health such as nutritious food, clean water, and adequate sanitation are consistent with people’s own understanding of their health needs. Indeed, their essential health needs extend even beyond the underlying determinants of health listed in General Comment 14 of the Committee on Economic, Social and Cultural Rights to also include broader social determinants of health, such as employment (earning a livelihood) and education.

The right’s focus on the multidimensional elements of what is required to secure these entitlements is also consistent with community expressions of their needs. This includes the importance of actual access of health facilities, services, and goods – that even if health facilities are present and the state has policies to ensure the availability of health workers and essential medicines, what matters – and what is often lacking – is that people have the means to reach these facilities, that health workers are present and medicines in stock, and that in line with the right’s incorporation of acceptability and emphasis on non-discrimination, that people are treated respectfully, their dignity respected. This last concern, of respectful treatment, was an overriding one among communities consulted, often providing a barrier to marginal populations to accessing health care services, or receiving quality services if they do access them.

Benefiting from health care and the underlying determinants of health – and social determinants – which broader determinants we collectively term “healthy environment” – will also take effective governance structures and processes. Here, too, the right’s attention to governance issues is consistent with community priorities, most particularly the centrality of accountability and participation in the right to health. Perhaps tied to the failings of health systems today to meet people’s needs, from accessing them to basic issues of respectful treatment, the lack of accountability and participation were major concerns of most communities we consulted.

In addition, we have seen already the priority that the right to health gives to equity. This is an underlying current through our consultations. All of the communities we consulted were marginalized or highly marginalized across one or multiple dimensions (e.g., impoverished indigenous women) demanded that like everybody, their essential health needs must be met. That is, the health system should work for them just as well as it works for anybody. They should be able to access and benefit from healthy environments just like anybody else. This is the fundamental idea behind the equity, as well as non-discrimination and equal access, that the right to health demands. Sometimes, this came up explicitly. For example, elderly and disabled participants in Zimbabwe felt that the government had to do more to meet their needs.
A. The entitlement to health care from the perspective of the people

Much of the human rights and national and international discourse on universal health coverage (UHC), focused on the level of health care and types of interventions that UHC should encompass, is disconnected from the primary demands of the highly marginalized communities that we engaged with. Their priorities lie at a more fundamental level: the need to have ready access to health care, and to have that care be responsive and respectful.

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. The ethnic minority communities in Bangladesh pointed to having access to a health center, a qualified doctor who will treat patients well, and access to medicines (stock-outs were a common concern) as among their health priorities, while these were the top priorities among communities consulted in Afghanistan, who also emphasized the importance of having the medicines be of good quality. Having drugs available (particularly brand name drugs, seen as more powerful than generics), perceived as typically being given only to people with personal connection to health care providers, topped the health care needs of communities in Guatemala – along with respectful treatment by health workers. High health care costs led Samoan migrants to sometimes avoid formal health services in favor of traditional healing practices (to which they also had a strong attachment), while out-of-pocket payments were similarly a concern in Bangladesh. 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 labor 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.”

**Bangladesh: Government neglect of hard-to-reach communities**

Sujatpur is a remote village in Hobigonj district in Bangladesh, and is particularly vulnerable to seasonal flooding. Both the government health system and the NGO community neglect this village because the difficulty accessing the village. Women in this poor rural community are especially vulnerable when the need for emergency obstetric care arises.
Shefa Jahan, a young woman, described the plight of pregnant women during the monsoon, when their village is completely cut off from the mainland:

"Women mostly deliver their baby in their home. If there is a problem then they have to go to Habiganj. There are problems and that is why mothers are dying. During the rainy season all the roads get flooded so we have to travel till Ekram [a nearby village] by boat and then we travel [by] car. During the rainy season it takes three hours to travel by a boat. During the rainy season we have to keep a boat managed and for other times we have to keep a care[ giver] managed."

Villagers have died due to the long delays in accessing appropriate transportation to health facilities located too far away. Neglect of this hard-to-reach district has fatal consequences. Community members “feel like the government doesn’t care about us. The ones who are living in the city [are] getting everything, and we who are living in the villages are not getting anything, but we have the right to all those things, but the government is not giving it to us.”

Community members feel neglected despite having made it clear to their community representatives in local government that their rights must be addressed through making health care accessible for them.

For some communities, as we found, access will also have other components. These include security in Afghanistan – including safety on the way to health facilities – and for women in Afghanistan, the lack of women doctors – physical accessibility for people with disabilities, and language for populations who do not speak or do not primarily speak the dominant language, such as among indigenous populations in Guatemala and refugee communities in Australia.

**Uganda: Jimmy’s dream of becoming a doctor shattered by inadequate medical care**

Jimmy Okot, 25, dreamed of becoming a medical doctor in future because he was good at physics, chemistry, and biology. He has since abandoned that dream, following one fateful night in 2001 when he was shot in the leg as he fled from the Lord’s Resistance Army (LRA) in his parents’ home in Unyama, Pacino subcounty, Gulu district in northern Uganda, and the inadequate medical care that followed forced him to drop out of school, and ultimately have his leg amputated. He has since experienced the challenges of living with a disability in Uganda.

The fourth child in a family of six children, Jimmy was then in his first year in secondary school and had returned home for holidays when the LRA, which was notorious for
abducting children, attacked. Being in a war situation, he could only get medical attention two days later at a local health centre before being transferred to Gulu Hospital days later. The doctors there decided he needed surgery, but due to a power blackout that lasted for days, he could not be taken to the theatre.

After being shot, he tried to turn his attention back to his studies, in the hope he would realize his dream of becoming a doctor. But the delayed and inadequate care he had received for his wound cost him dearly. His performance at school deteriorated as had to visit the hospital frequently and was in constant pain, leading him to be able to attend school only irregularly. In addition, after his fourth year in secondary school (two years shy of graduating), his parents could no longer afford to keep him in school while also footing hospital bills and supporting his siblings, who were much earlier in their education.

Eventually, after nine years of unbearable pain and endless hospital visits, in 2010 his leg had to be amputated. This helped reduce the pain, though it took at least a year to heal. After a few months on crutches, Jimmy was lucky to be directed by a friend to AVSI, an Italian agency, from which he got an artificial limb for free. And he was lucky to have the replacement earlier this year from the same organization, after the first began creating a wound on the amputation scar and causing him severe pain.

The artificial limb needs to be replaced when it becomes too old. Reconstructing a replacement takes between two weeks and a month. Sometimes AVSI runs out of materials and one has to wait, which may mean going back to crutches in the meantime. And because of these and other challenges in getting a replacement, Jimmy knows that extra difficulties to maintaining his weight is an additional burden he must bear.

Jimmy regrets that he has to live virtually a beggar’s life. He occupies himself by spending time at a friend’s produce outlet in Gulu town, where he helps with recordkeeping. In return, his friend gives him some money, but cannot pay him a regular salary because the business is seasonal. Indeed, as of the summer of 2013, given the latest drought that burnt out crops and meant there was virtually no harvest, the business was set to be dormant for several months. Jimmy tried to get a job at a local credit business, but could not, as the business needed someone who could ride a motorcycle.

Jimmy’s wish is to get some capital and start up a small business, which would enable him to live a decent life and construct a house to live in, as he currently has problems paying rent for the room he stays in. Unfortunately, he says, people do not feel that he is capable of running a successful business given his disability and do not think he is capable of repaying a loan. But he says he has not lost hope; God will one day give him a breakthrough.
Consistent with this overarching concern about access in general, as compared to a listing of specific health interventions, is the explicit rejection of some communities, particularly indigenous communities in Guatemala, of the very notion of health care priority setting where the needs of only some members of the community (e.g., children) would receive priority, as compared to the needs of the whole community (as required by the right to health). This also implies the importance of ensuring universal coverage covers such areas as mental health, to meet this aspect of the population’s health needs.

Communities have expressed a belief in equality and solidarity. This comes through in large part by the very nature of the demands – marginalized, typically impoverished communities demanding that they have access to health care (and as discussed below, other determinants of health) – just like everybody else. And as in Guatemala, this belief emerged in the demand that no one be left out. Along similar lines, Samoan migrants in Australia, given their relatively easy access to primary health care, highlighted several more expensive forms of health care among areas where they saw need for greater funding – for themselves and their families in Samoa – such as cancer treatment and surgery. Easy access to health care that people need should not be limited to only those who are well-off and can afford private health care. As a Samoan female migrant expressed it, “Making hospitals available to everybody so when they’re sick, they can come to the hospital, get operated on without a waiting list and that, getting the medication free or at a very, very low cost.”

Yet the ability to access affordable care – to be able to travel to a health facility, or have a doctor in the community, is not enough. The very common experience for a wide range marginalized populations with whom we consulted – indigenous populations, the poor, people with disabilities, and many more – is that the health system is hostile to them and their needs. They are discriminated against, ignored, and otherwise mistreated by health workers, even abused and mocked, reinforcing their experience of marginalization, the denial of their dignity and humanity, with the message that they are unimportant, unworthy.

Such discrimination significantly harms people’s health. Members of marginalized communities will often avoid the formal health system because of mistreatment that they anticipate, seeking care from alternative medicine providers (and in the case of pregnancies, traditional birth attendants) or other private providers with unclear diagnostic quality and care, or not seeking care at all. When they do seek care from the formal health system, they may be denied care entirely or have it dangerously (sometimes fatally) delayed. The quality of care may be lower, for example, because of provider preconceptions (as with people with disabilities and LGBTI populations in Uganda) or their failure to listen to people’s expression of their health concerns, such as a Karen refugee in Australia who for three years saw an undiagnosed chronic bone condition worsen until she was able to talk to a health provider in Burmese. The sense of
alienation that many Aboriginal Australians have felt in the health system, despite universal health insurance for primary medical care, has contributed to the development of community controlled health initiatives, where they feel more comfortable with the reception they receive.

**Burma: Discrimination, the doctor as “master,” and barriers to care**

The number one reason that his people do not get medical treatment back home in Burma, explains one Rohingya refugee who is now in Australia, is the discrimination that the Rohingya face as a minority, as part of a different culture. Another Rohingya refugee observes how most doctors in Burma treat people as though they are the people’s “master,” leading people to see the doctor as a “kind of exploiter.” He uses the example of a “no smoking” sign in the hospital. Since the villagers “cannot read…they just start to smoke.” The doctor shouts at them, without explaining that smoking is not allowed. Yet while most doctors act like this, a few doctors are very good, “very passionate about curing people.”

Ethnic minorities also face barriers to care, including language and indifference, when they arrive in Australia. A Karen refugee explains how several years ago, a member of the Chin ethnic group told a doctor of his stomach pain. The doctor’s reluctance to have an appropriate interpreter led the doctor to misinterpret the nature and extent of his patient’s pain, and he prescribed only a basic pain medication, perhaps Panadol. Only as the patient’s pain got worse, to the point where he felt he was dying, did the doctor send him for an x-ray, which revealed that he had stomach cancer. It was, however, too late. He soon died.

The Karen refugee himself felt discriminated against in Australia when he went to a doctor with knee pain, and the doctor told him to buy proper shoes, taking his complaint and suffering too lightly, he felt. “That’s what happens to us.” Two years later, a different doctor sent him to receive an x-ray, which revealed a serious problem requiring an operation. He ultimately received the operation after several years on a wait list.

**Uganda: A lesbian/transgendered person suffers from disrespectful medical care**

Sandra Ntebi, who refers to herself as a lesbian and also as a transgender man, was part of a group of 15 lesbians mobilized by a gay organization to undergo breast and cervical cancer screening at a public health facility in a suburb of the Ugandan capital Kampala. Yet at the end of the day, she was not among those that were tested for cervical cancer, while having had to contend with embarrassing questions from service providers.
Sandra, 30, decided not to proceed with the test at the very initial stages when service providers explained to the group what the procedure would entail. As a transgender man who had never received any penetration, Sandra says she was scared off by the gadget (vaginal speculum), a huge, scissor-like piece of equipment that was to be used to dilate her vagina.

There were all kinds of attempts to convince Sandra, including by her fellow clients, that the procedure was not painful or dangerous. It was then suggested that she undergoes the breast cancer screening as she thought over the cervical bit. This she did. The test was negative, but this did not raise her confidence. She remained nervous, even panic-stricken.

Another health worker was called in to help convince her to undergo the cervical cancer screening, but in vain. In frustration, the health worker asked Sandra what she had come for, to which she timidly responded, “For cancer screening.” “Then, why are you giving us a hard time?” the irritated health worker quizzed her. “How do you play sex? Are you still a virgin at that age?”

Sandra says she felt embarrassed as she was made to look a fool before people who did not understand her. “I think they thought I was teasing them… but my concern was, isn’t there any other method of doing it? Everything has more than one way of going about it, but here I was being given the impression that they either push this scary machine into my vagina or I go with my cancer. Up to today whenever I think of that moment I develop goose pimples.”

According to Sandra, the main problems that sexual minorities face in accessing health care include high levels of homophobia, self-stigmatization, and service providers who do not understand them – even counselors, who are expected to be open-minded. She says each public hospital needs to have a specialist who understands the different categories of sexual minorities, and who can provide care without asking irrelevant questions.

Universal health coverage will thus require a range of measures to transform the nature of care so that it is respectful. These might include the recruiting health workers from communities of marginalized populations (though for some populations, levels of education will create a challenge), having regular meetings between health workers and community members to build trust and understanding. Health worker education will need to incorporate human rights into curricula, and health workers will need to be sensitized to the needs and circumstances of marginalized populations, recognizing the rights of all people to be treated with dignity. Strong leadership will be required in creating a culture of accountability and respect, including by ensuring effective mechanisms for holding health workers accountable for discrimination or other mistreatment. Support for health workers, from sufficient numbers to supportive supervision, safe working environments, and fair compensation, is also necessary.
Even these actions, while helpful, may be insufficient as long as people remain severely marginalized. Broader measures, extending beyond the health sector, are required. All vestiges of discrimination must be removed from laws and policies; educational and media reforms must avoid stereotypes and promote equality and respect for all members of the population, and; respectful engagement needs to be promoted between marginalized communities and the dominant populations. Furthermore, economic and political reforms that give marginalized communities greater political power and reduce economic inequalities are crucial to change. All are ultimately linked to effective, quality universal health coverage, and ensuring healthy lives more broadly.

Guatemala: Fatal barriers to access health care services for rural and poor populations

Don Rogelio is a construction worker living in the municipality of Tectitan, in the rural highlands of Guatemala. He was recently elected the president of his community’s local development council. Earlier this year, Don Rogelio lost his daughter because he was unable to access the health care his two-year-old needed. His story exemplifies the challenges that many poor Guatemalans that live in rural areas face when it comes to obtaining health care.

On March 15, Don Rogelio’s daughter was playing outside her house. At some point during her games, she swallowed some seeds that are common in the area but that can be poisonous for humans. Acting quickly, he took his daughter to the health center where he promptly told the doctor the story. The doctor started referring to the little girl as “the bean girl,” because the poisonous seed resembles a black kidney bean. Don Rogelio thought this was disrespectful to his family and to the situation. However, because it was important to get care for his daughter, he refrained from saying anything antagonizing to the doctor.

The doctor did not provide any care but referred the family to the hospital in San Marcos, the reference hospital located two hours away from his town. Once Don Rogelio and his daughter arrived, they were told that some tests were needed but that the little girl needed to be admitted. They were instructed to return that night. At 10 pm, when he returned to the hospital, following the doctor’s instructions, he was told that the hospital would be unable to help him and that he needed to go to the regional referral hospital in Quetzaltenango (another two hours further of travel). Don Rogelio told us:

*Why in the world did they not tell me this right away? They could have told me that they did not treat this problem there and that I needed a children’s specialist! In the meantime, my daughter had become worse and was having trouble breathing. They told me the poison had gone to her lungs but did not help. We got to the second hospital at eleven in the morning the*
next day but I guess that we didn’t get care because my daughter wasn’t crying and making noise. She had trouble breathing but she could walk, so they didn’t do anything.

Many other community members have reported that only patients that “look sick” receive care, while the others have to stand long waiting times and are even denied care.

Seven hours had gone by and they had still not been seen by a doctor. A nurse told Don Rogelio to go get something to eat next door because “his daughter was not an emergency case” and that they would have an appointment for the next day. Don Rogelio thought about it for a couple of hours and finally decided to go get some food. When he tried to get back to the hospital he was denied access, and realized that by leaving, he had forfeited his place in line. He tried to explain why he left but was still told to return to wait for a new turn the next day.

In the early hours of the third day, Don Rogelio swiftly got in line at five in the morning. His daughter had taken a turn for the worse. While still in line, the daughter stopped breathing and passed away. The doctors apologized for their role and excused themselves by saying that “she didn’t look sick at all.”

What are the health services to which people believe they should have access? Frequently without meaningful access to health care at all, marginalized communities that we consulted therefore concentrated on this prior, higher-level concern of access to respectful care. If people cannot easily access any health care, or if that care is of poor quality (e.g., drugs are not available) or disrespectful, it matters less exactly what health services are offered, because whatever they may be, these communities do not feel that they would benefit.

Yet our consultations have offered some insight in this regard. Health services must be comprehensive, a point made by communities throughout the three African countries in which we held consultations, and in accord with the rejection of leaving out particular populations and the importance of equality noted above. A version of universal health coverage that left out the needs of some populations, or focused narrowly on only several health conditions, would therefore be unacceptable. When communities we consulted raised particular health issues, by and large they were familiar ones, those that may be readily seen as being of particular prominence in their countries and communities, such as HIV/AIDS, malaria, and nodding syndrome in Uganda (at the time of our consultations, the mysterious nodding syndrome was a phenomenon gripping areas in northern Uganda, including Gulu District), HIV/AIDS and maternal health in South Africa, and environmental health and maternal and child health in Guatemala.
There were exceptions, essential health services that communities highlighted that have received less attention from the global community and may be less obvious priorities, notably dental services, an essential health need raised by the Afghan communities.

Ensuring comprehensive universal health coverage that meets people’s demands also entails meeting people’s diverse but particular needs. For example, LGBTI populations in Uganda expressed the importance of circumcision, HIV post-exposure prophylaxis, elective surgery, and psychosocial support, and sensitization of the community. People with disabilities spoke of the need for such disability-specific health aids as crutches and wheelchairs; disability-friendly health facilities, physically (e.g., people with disability-friendly toilets) and with health workers able to communicate with people with different disabilities, and; affirmative action in health care access. Other population groups – men and women, youth and the elderly, and people with HIV, for example – also emphasized different needs. In Afghanistan where people have been exposed to forty years of conflict, mental health issues are of major concern.

The NHDGs should therefore respond to the entitlement to health care by incorporating these issues of access to quality care, addressing both barriers to access outside the health system and discrimination within the health system, including through indicators and guidance. While participation of marginalized populations in monitoring progress in the communities and countries on the NHDGs is needed throughout the areas covered by these – and other post-2015 – goals, here is it especially indispensable. A global social contract that is linked to the cost of ensuring everyone health care and healthy environments will need to account for costs associated with removing these barriers. And as we will see below, the global social contract would need to include other health demands and rights beyond particular interventions and the health worker, medical technology, and other such system costs associated with delivering them. It will also need to incorporate costs of ensuring community and civil society participation in health-related decision-making at all levels, and in establishing and supporting effective accountability mechanisms.

The NHDGs and how they address UHC should also account for health-specific needs and demands of particular populations and marginalized communities. In envisaging the health care that all people must be ensured, not only the needs of the general population should be considered, but so should the needs of specific segments of the population, such as health care needs particular to women, people with disabilities, and different age cohorts. And in defining UHC and how it is to be implemented, they recognize the need for a certain amount of funding that can be used flexibility at the community level to meet very specific needs and demands of a given community. The demand for dental services among communities in Kabul Province may be an example of this – though it could also be that such a demand is nationwide, and such a need would emerge through a participatory national process.
B. The entitlement to a healthy environment from the perspective of the people

Water, sanitation, and hygiene are emerging as critical issues for a wide range of marginalized 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.

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. Such an emphasis points to the importance of the NHDGs ensuring not only universal health coverage, but also universal access to safe drinking water, good sanitation, and healthy food. These have multiple aspects. For example, sanitation and hygiene includes sufficient numbers of sanitary latrines, education on good hygienic practices, and proper trash disposal. Food must be not only sufficient in quantity, and nutritious, but continue to able to play its key role in the cultural construction of health. Samoans in Australia reflected on the fishing and the gardens filled with local staples that once surrounded their homes in Samoa, the difficulties replicating this in suburban Brisbane, and the loss in terms of fresh foods, pleasurable exercise, and the social sharing around food production. Aboriginal Australian diabetics in Inala talked about the need to change the diet of the whole family to meet the needs of diagnosed individuals without losing the central role of meals – and the laughter that accompanied them – in their households.

This is just part of the picture, however. Communities consistently express a holistic view of health. To take just one example, youth in Gulu and Buikwe districts in Uganda pointed to employment, housing and sanitation, and education as their top essential health needs, while emphasizing corruption as an obstacle to all of these. Meanwhile, 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. Communities frequently pointed to all of these as key determinants of health – with employment often explained in similar terms, such as earning a livelihood, having income opportunities, and having financial capital – as well as food, water, and health care itself. In some communities, other aspects of healthy natural environments (including lack of pollution, an important issue among communities in Guatemala), as well as the social environment (e.g., issues of crime, domestic violence, and drug use in South Africa, and issues of violence, substance abuse and fragmentation of families in Afghanistan), the built environment (such as roads), along with spiritual and mental health, emerged as additional determinants of their health. Notably, several of these, including employment and education,
extend beyond the underlying determinants of health as recognized in General Comment 14, though are well recognized among the social determinants of health.

Emerging strongly from marginalized communities is the fact that providing a healthy environment often extends to political, economic, and other realms, including the importance of protecting healthy lifestyles. Particularly for those marginalized communities that have or recently had a lifestyle closely connected to the land, the change of lifestyle means that communities that once produced their own food now must rely on often insufficient income to purchase food. Counter to the global trend of increased access to food, for these communities, access to healthy food is decreasing, not increasing.

A Samoan migrant explains that previous generations, back on their Pacific island, had “fresh food from the plantation” and fish from the sea. But in Australia, no longer able to produce their own food, “we’re eating more processed food,” which is easy to get and tastes good, “but is not good for the body.” Unable to afford healthy foods on their low-incomes, Samoan migrants now have unhealthy diets and problems of obesity, hypertension, and heart disease. One Karen refugee in Australia describes a similar situation. “The food that I ate when I was young, it’s not like the food that we eat here. Here it’s mostly meat or junk food….But back…when I was young [in Burma], what I normally ate was vegetables, fruits, and other food….I loved eating my food when I was young.”

Similarly, lifestyle changes for these migrants – and other internal and international migrants who are part of the global urbanization trends – mean that physical exercise is no longer an automatic part of their daily activities, again contributing to non-communicable diseases. Structuring urban environments to return exercise to a natural part of people’s regular activities will therefore be an important component of addressing NCDs.

A healthy environment can also mean challenging powerful economic and other forces – beyond food and beverage corporations that can have far-ranging impacts on healthy foods, from the ingredients they use to their marketing and pricing techniques. Mines create major environmental hazards for communities in Guatemala and elsewhere in Latin America and beyond. In Bangladesh, an 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.

The importance of healthy environments that marginalized communities express is consistent with the comprehensive post-2015 sustainable development agenda that appears to be emerging, and highlights the importance of ensuring for all people clean water and sanitation, nutritious food and education, economic opportunity, and more, even if not part of the health goal(s) as
such. However, the post-2015 agenda will also require the nuance to ensure that pursuit of some goals – such as economic growth – do not come at the expense of health. Mines may contribute to a country’s economy, but cannot be seen as contributing to sustainable development when they are harming health. Across the post-2015 agenda must be policy coherence for health, which could be promoted through specific strategies such as right to health impact assessments. Healthy environments will also require structuring into people’s regular environments the opportunity to be healthy, such as ready access to affordable nutritional food, with the variety of measures that this could entail, such as how states regulate corporations, structure social programs, design urban environments, and protect both the natural environment and land rights of marginalized communities.

C. Governance

For a wide range of marginalized communities, issues of governance, of the roles and responsibility of government and mechanisms to hold governments accountable to these responsibilities – are focused locally, with community leaders and local authorities, as well as the health workers and (in Afghanistan) the NGOs that have resources and are implementing programs.

For some marginalized communities, the global level is distant, practically an abstraction. For the most part, communities consulted in Guatemala and Bangladesh, for instance, had little to say about the responsibilities of the international community. And perhaps because by virtue of being refugees in Australia, where the national government had become the embodiment of the international response to their plight, the Rohingya community, too, did not point to international responsibilities, while the Karen refugees focused largely on their own responsibilities, which as we will see was a common theme for marginalized communications.

Even among some of these communities, there was certain limited or discrete belief in the role of the international community. A member of a civil society organization working with one of the ethnic communities in Bangladesh expressed his view that a percentage of donor funding should be directed to disadvantaged communities. The Rohingya expressed a general gratefulness towards the Australian government for providing them health services – a significant step up from when they were in refugee camps or living more precarious existences still along the Burma-Bangladesh border. Their own refugee status may suggest an experience that when people’s own government (in their case, that of Burma, and in some cases Bangladesh) is failing to meet their needs, someone else – the international community – does bear certain responsibilities towards them. And yet, in the prelude to an election that is focusing ever more punitively on preventing waves of “boat people” reaching Australia, the Rohingya and other refugee populations are cautious about asking too much of their benefactors.
Responsibility of wealthy countries: Views from a Rohingya refugee in Australia

A Rohingya refugee from Burma, who spent 18 years in Bangladesh before coming to Australia, explains that back home in Burma, some Rohingya never visit a health facility. This was because of a lack of affordability and because of discrimination based on wealth and ethnicity, with certain people not “expected” to visit health facilities. A man who seemed completely healthy when he went to bed may be dead in the morning. And people will say, “It’s God’s will.” Yet after coming to Australia, this refugee’s perspective changed, as “many things came to my mind that I couldn’t understand before I came to Australia….We have seen three or four people here, who were diagnosed with serious heart conditions.” They were able to quickly get to the hospital. If this were Burma, they would have died, and people would have said, “It’s God’s will.”

He ascribes his aunt’s death in Burma four years ago to poorly resourced health facilities. She had a fever, cramps, a headache, felt nauseas, and had other problems. After three days, she was taken to a hospital, where she received only very basic meditation. The hospital did not give her any tests, probably because the hospital did not have the instruments to give her proper tests to learn the real problem for her illness. And so she passed away in the hospital.

Having seen two very different health care realities, he has a message for how to begin to eliminate these disparities. “So these are the realities of a poor country…. [T]here should be medical centers funded by the rich countries, like European countries, in poor countries like Burma and Bangladesh, so that the poor people can get medical attention, so that [the medical centers] can save their lives. If there were a few medical centres, even in the state where I come from in Burma, I think we could have saved thousands of lives.”

Other communities recognize a greater role for the globally community. This recognition came through most in Afghanistan and the African countries in our consultations – perhaps not coincidently, countries that have seen an especially prominent role of the international community, in general and in health in particular. Community members in Uganda offered a familiar view of the role of global health agencies, from providing funding to offering technical guidance and leading in the response to health crises. Our African hub and partners are further exploring people’s perspectives on the role of the international community. In Afghanistan, people expressed concern about what they saw as an impending decrease of international support for health, as the international community begins to pull back from the country after more than a decade of intense involvement.
How communities viewed the roles and responsibilities of the national government varied significantly among the communities we consulted. A number of communities expressed a strong sense of national government responsibility, including in South Africa, Afghanistan, Guatemala, Uganda, and among the Samoan migrants in Australia. In Guatemala, communities recognized the Ministry of Health as having overall health responsibility, including being ultimately responsible for providing public health services. Communities in Uganda had a particularly sophisticated understanding of the national government’s role, from resource raising and policymaking to implementation and monitoring, of the health and finance ministries as well as Parliament to the oversight role of Parliament.

It may be, that akin to few expectations of the international community for marginalized communities for whom the global level is largely an abstraction (unlike, for example, in Uganda and Afghanistan), in at least some cases where the national government is mostly an abstraction, people consequently locate less responsibility of what is in some sense a non-entity. 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 recognized responsibility meant that the national government was barely visible in 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.

Even among communities that emphasized more local responsibility, some community members did recognize the ministry of health or government more generally as holding responsibility for health, including for assuming a leadership role. A Rohingya community member, significantly, perhaps, having been settled in Australia more than most members of the community, expressed the responsibility of the state or federal government to ensure that people have access to medical services irrespective of their income.

While communities expressed varying views (or few at all) on the responsibilities of the national government and international community, local responsibility was a common refrain. 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. The refugee communities in Australia expressed a heavy sense of responsibility with community leaders as well. A significant minority of participants in consultations in South Africa located primary health responsibility at the community level.

Sometimes, particularly, it appears, where people see a greater level of responsibility for the national government, the perceived role of community leaders and authorities, while significant,
was narrower, such as a particular emphasis on health education, in particular on good health behaviors, in Uganda. In Guatemala, community members saw it as the responsibility of community-level developments councils and local health commissions to monitor health authorities and facilities.

Likely linked to the very failings of health workers to treat them with respect, marginalized communities in Guatemala emphasized the responsibilities of health workers, in particular to treat them respectfully and to simply carry out their job responsibility, from not selling medicines that were meant to be free to not shirking their work responsibilities and ignoring their patients.

Beyond authorities, from the community leaders to national and (occasionally) international authorities, members of many marginalized communities expressed a strong sense of personal responsibility. These include communities in Uganda, with individual responsibility for maintaining personal hygiene, seeking health care, participating in health campaigns, and taking medications as prescribed, while families and household heads had responsibilities including teaching their children hygiene and ensuring that the household had basic sanitation facilities and there was enough food to eat. The refugee and migrant communities in Australia all saw a strong role for individuals in their own health including, in the case of the Samoan migrants, maintaining a healthy lifestyle including eating the right food and exercising. Alongside government responsibilities, South Africans evinced a strong sense of individual responsibility as well.

Notably, individuals cannot carry out their perceived health responsibilities without support. Other community members, or the government (or NGOs) must ensure their health literacy – so that they know the importance of good hygiene and what this entails. Members of one of the districts in Afghanistan were upset that a nurse who had focused on the importance of good hygiene had left because of the ongoing role in community education on hygiene she had played. So is the capacity to put their knowledge into practice. Knowing the importance of hygiene and nutritious food may do little good if people’s environments do not allow them to produce their own food but only purchase inexpensive food with little nutrition, and lack readily accessible supplies of clean water.

Beyond this, though, is the need to change circumstances and ensure that government at all levels carries out its responsibilities, including obligations under the right to health. Wherever people locate primary responsibility, the responsible authorities are frequently failing to meet their responsibilities. For many marginalized 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 marginalized 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.

The NHDGs should therefore require accountability mechanisms and practices. These are closely tied to people’s participation in health-related decision-making, the issue that we will turn to next, and thus will offer specific recommendations in the next section. Community views on responsibilities will need to be taken into account. For example, given the authoritative role of community leaders among some populations, structures for some populations will need to respect this role, while ensuring that these leaders truly represent even the especially marginalized members of already marginalized communities, such as impoverished women with a disability who are also ethnic minorities or part of a refugee community. They will also need to account for varying levels of understanding of their rights. While some communities, such as in Guatemala, evinced a strong sense of rights, as did people in the South African communities. By contrast, other communities or members of these communities do not. One woman in Afghanistan considered that it would be a “big favor” if women were given the opportunity to participate in decision-making. And even some people in South Africa felt uninformed of their health rights.

Along with accountability, another important aspect of governance for the post-2015 agenda to address emerges from community recognition of the deep interconnectedness among the various issues that affect their health, which cut across much of not the entire likely post-2015 agenda. While challenging to develop, the post-2015 agenda should therefore, as possible, promote global, national, and local governance rooted in this reality, structures and processes that do not create artificial divisions within health or between health and other areas, but rather promote as holistic an approach to governance as possible, maximizing synergies and encouraging national and local structures that take such an approach.

D. Engagement of concerned populations from the perspective of marginalized communities

Community members overwhelmingly express a desire to participate in decisions related to their health, at community and higher levels, along frustration at the lack of opportunity to do so. Authorities rarely ask community members their views, and when community members do seek to express their views, they find that they are not heard. The “government does not pay attention” encapsulates the typical experience of marginalized populations in their efforts to influence health authorities, contributing to a feeling of powerlessness.
We found this desire to participate in Guatemala, for example, where communities greatly value participation to create change, solve problems, and connect with each other. In Uganda, the demand to have their views heard was so great – as was the anger when they were not even asked – that when bicycles manufactured in China were procured for members of Village Health Teams, which are comprised of community members, without any discussion with Village Health Teams about the types of bicycles that would meet their needs, one Village Health Team refused the bicycles altogether, believing that the bicycles would be of low quality because of where they had been manufactured. Ethnic minority communities in Bangladesh believed it very important that they be able to participate in decision-making processes, and believed that they had relevant knowledge that should be taken into account, yet “no one ask[s] questions to us.”

Some communities emphasize the importance of the ability of women to have a role in these decision-making processes – as well as recognition that in some circumstances, such as in Afghanistan, women face special obstacles to participation. Women there want to be able to participate but conservative cultural constraints make this very difficult. Communities in Bangladesh also emphasized the importance of women participating because of their enhanced role for taking care of the health of their families.

**Afghanistan: Women and decision-making processes**

Zia Gul is a 60-year-old woman from Khaldary district in Afghanistan. A *daya*, or traditional birth attendant, she received her training while living as a refugee in Iran after the death of her husband during the Soviet invasion of Afghanistan. Gul *jan*, as she is respectfully addressed by the community, is the mother of eight grown children and has four grandchildren. She lives in a compound with them not far away from where she had lived before she fled to Iran.

Gul returned to Khaldary 10 years ago following the retreat of the Taliban, and was considered lucky to discover that her home was not destroyed during her absence. Better off than most in her district, her compound has an outhouse, a well and some fruit trees.

Given the cultural and religious barriers to women’s mobility, requesting Gul’s services would involve going to a local shop owned by her son to inform him that she is needed. He would then have to close up shop to go home and, in observation of social rules, accompany her to the home of the family that summoned her.

When asked about participation in decision-making processes for health, Gul tells us

*it is very necessary that we ladies also take part in this sort of decision making process. But unfortunately due to our family restriction it is very difficult to secure our presences in such*
kinds of meetings. Though for ladies it is very difficult to take part in meeting that are very far away from home but if we are given an opportunity it would be very big favour on us. Because we can better depict our homes and the problems that exist within our families.

Despite this exclusion of women in health-related community decision-making, Gul mentions that there have been some positive changes for women in Afghanistan in the last decade. Among them: pregnancy tests can be acquired from community health workers. This has significant implications for women’s health. Before women often did not know they were pregnant until halfway through their pregnancy. Now women are now able to seek antenatal care. The use of contraceptives, however, remains taboo. Gul is hopeful that, in the future, women’s health care needs and participation in ensuring met needs will be a reality.

Among some populations, such as refugees, fear of drawing attention to themselves can be a barrier to participation, while other populations view the government as less than beneficent. Samoan community migrants in Brisbane saw themselves as responsible for their own health; Rohingya and Karen refugees were largely uncritically grateful for the health care they received from the government, despite the complexities around accessing health care for asylum seekers. One Karen refugee recommended that Australia’s settlement service for refugees and migrants ensure comprehensive health evaluations, including dental health, for new arrivals.

In some communities, the responsibility of engaging authorities on health matters rests with community leaders, with opportunities varying with people’s ability to access and engage them. Some populations are satisfied with this arrangement, while others are less confident about how effectively the community leaders will represent and advocate for their needs, and would like to themselves have a say in health-related decision-making – but do not have that opportunity, such as the ethnic minority and wetland communities in Bangladesh. Even where community leaders are seen as trying to help, such as community leaders who participate in Guatemala’s health commissions, they themselves often find that higher authorities do not listen to them. Similarly in Afghanistan, communities view their village leaders and local government as having little interest or authority.

By contrast, Aboriginal Community Controlled Health Services in Australia are culturally appropriate, autonomous primary health services that local Aboriginal communities initiate, plan, and govern through their elected Aboriginal board of directors. These services provide a framework for community-driven and controlled services that address the specific health needs of the community they serve, and have also been powerful advocates for Indigenous rights in Australia. However, despite their success in achieving health improvements, these services are inadequate to meet Indigenous health needs, as they are underfunded and understaffed, and have too few facilities.
Often, even where there are spaces for participation, such as a national health assembly, community members might not be aware or invited, or face obstacles to their participation. Local structures may also formally exist, but not receive the funding and other support they required to function effectively, or at all. Or while these structures are supposed to exist and be part of the local government structures, in reality they simply do not exist. And even when they do exist and people can participate, people might not receive any feedback on the result of their participation. Similarly, even where community members or leaders are able to participate, they generally feel that higher authorities do not listen.

In Uganda, structures to participate – Health Unit Management Committees – in community health services generally existed only on paper. Similarly, village health committees through local councils typically had never been established. Where the Health Unit Management Committees did exist and people could proactively offer advice or express complaints, they were dismayed about the absence of any formal feedback mechanisms to learn of the results.

Similarly in South Africa, people felt they should be able to participate through health facility committees, but in only one of the four communities was such a committee active, with committees hampered by a lack of national guidelines. Similarly, South Africans felt that health providers were generally not accountable to the community. Similarly, Health Care Committees in Zimbabwe are largely inactive, a function of an underfunded health sector and the absence of a law governing their operations. Where they do find opportunities to participate, South African communities have felt that they were being lectured at rather than listened to.

The NHDGs should therefore empower people to participate in health-related decision-making (including budgeting), from setting priorities and establishing policies to monitoring how those policies are implemented in their communities (including by generating evidence which, as emerged in our Guatemala consultations, would strengthen accountability by giving people more confidence in filing complaints, including with respect to discrimination and poor treatment) and having effective channels for feeding back the results. And there must be processes to ensure that where they are not being listened to, where policies are not being followed, where their rights are not being respected, there are easy to follow processes to ensure that relevant actors – be they community leaders, health workers, or health or political authorities – respond to their concerns. There must be accountability mechanisms. Through the NHDGs and their targets, indicators, and guidelines – and the broader post-2015 sustainable development agenda and goals – the global community should provide an unequivocal message to every country on the importance of this participation – including ensuring the engagement of marginalized populations. National governments must act on their responsibility to ensure that their populations – including women and marginalized populations – have the space and capacity to participate.
The precise mechanisms should be left for countries to determine. In some cases this will require establishing new structures. In other cases, the priority will be making existing mechanisms function effectively, overcoming obstacles from lack of funding, lack of regulations to govern them, and – perhaps most challenging – political and economic interests that go against accountability, such as where corruption is rife and officials benefit from the absence of accountability.

Guatemala: Tools to gather evidence that supports the demand for accountability

Nebaj is a municipality located in the Ixil region of Guatemala, one of the hardest hit by the Guatemalan armed civil conflict. During the war years (from the 1960s to 1996), people in this town were subject to systematic violence, mostly because they were indigenous, poor, and rural. Today, not much has changed for the people that live in Nebaj: maternal mortality rates are still higher than the country average and access to education and social and health services is deficient. To address this, local leaders have organized themselves in a citizens’ health council, which aims to implement community-based monitoring of public services as a way to improve the allocation of resources and quality of health facilities, and to demand overall accountability from authorities.

Don Juan is a community leader from this municipality. In an interview, he described his and his fellow leader’s work around accountability. Although they have made advances, he expressed that there is real need to advance accountability work through gathering evidence of the problems communities face to accessing health care services. As Don Juan told us:

… in our town we don’t get any support. We want to gather evidence but no one gives us the tools we need. People from the villages complain but authorities require evidence and we don’t have the means to buy cameras, voice recorders, video recorders…having those would make our work go faster since we would be able to collect the evidence of the problems and barriers we face.

The opinion of Don Juan indicates that in addition to learning about the legal framework, rights, and responsibilities, community organizations also require audiovisual equipment and basic media skills to carry out accountability work. This will allow them to make reports and present evidence to stakeholders and policymakers in a way that will impact the policy process.

We also believe that members of marginalized communities and civil society organizations should have a formal role in the post-2015 negotiation process. While through our consultations
we seek to have an impact on the NHDGs, and bring voices of at least a limited but diverse set of marginalized communities to them, far more powerful will be enabling people who are traditionally most excluded to be directly included in international policymaking, in the negotiations that will occur to develop the post-2015 sustainable development agenda. This could mean UN guidelines on how civil society and community members, especially from an array of marginalized populations, should be able to join national delegations. Another possibility would be to form a civil society and community committee or forum that participates in the negotiations, and which UN members agree must endorse the post-2015 agenda before they adopt it. The post-2015 agenda must also ensure that marginalized communities must be central to processes to translate and implement the goals at the national level, with effective means to monitor progress and hold their governments accountable.
IV. Recommendations for the NHDGs and global social contract

Universal health coverage

Comprehensive UHC and the health systems required to deliver it would respond well to one of the top essential health needs of marginalized communities, access to health systems that function as they ought, from having in stock the medicines, medical supplies, and equipment that they are supposed to have to having health workers who treat patients with respect. UHC must respond thoroughly to the obstacles to ready access, including those that are greatest for marginalized communities, such as discrimination and mistreatment, as well as barriers to accessing health care in the first place, such as cultural barriers (e.g., for women in Afghanistan), lack of roads and transportation, and insecurity on the roads (as in Afghanistan).

The financing of comprehensive UHC in a global social contract allocating health funding responsibilities should include investments required to ensure access to quality and respectful care, including transportation to health facilities and the training and other measures to sensitize health workers to the rights and needs of marginalized communities. The financing will need to be sufficiently flexible to respond to country and community circumstances. UHC in national health strategies should cover specific needs that different communities (e.g., people with disabilities, LGBTI, those living in post-conflict areas) identify, and should identify and include policies to address specific barriers – both within and beyond the health system (which may be as varied as lack of transportation to discriminatory laws and policies and discriminatory stereotypes in the media) to the full and equal access to health care that different marginalized populations face. And it should incorporate a level of additional funding for allocation based on community decisions to respond to local health priorities, including for health services that might not emerge at the national level as a health priority based on epidemiology, national participatory processes, or equity concerns, but are important to particular communities.

If the international community sets a global health financing target to create clear national and international obligations, this target should incorporate the investments described above.

Beyond financing, the NHDGs and global social contract should recognize that communities have a holistic understanding of health and respond to those needs in a way that is contextually relevant. They should also explicitly incorporate and monitor non-discriminatory care and dignified treatment as an indispensable ingredient of comprehensive UHC, to be accomplished through measures including training and sensitization, effective remedies for negligence, discrimination, and mistreatment, community monitoring, and investments in the health workforce to create positive practice environments.
To meet people’s essential health needs, the post-2015 development agenda will need a broad reach, far beyond the health sector alone, meeting such needs as clean water, hygiene and sanitation, nutritious food, education, roads and transportation, employment, housing, and a healthy natural environment. Given the importance of policies and actions to support health that cut across sectors, the NDGs should promote global, national, and local governance that do not create artificial divisions across sectors, but rather promote collaboration and synergy. The NHDGs and global social contract should explicitly incorporate the principle of Health in All Policies, so that elements of a healthy environment, development more generally, and other policies consistently support health, as this cannot be taken as a given. For example, transportation is needed so that people can quickly get from home to a health facility, but transportation systems can also contribute to deadly pollution. Communities recognize the need for employment as an essential health need, but employment and economic growth through mining, for instance, will similarly create an unhealthy natural environment. Similarly, the global social contract should ensure policy coherence for health in international and transnational investments, policies, and laws. For example, countries should ensure that transnational corporations under their jurisdiction are not harming health in communities where they operate abroad, and that trade and investment agreements do not impede health care, such as by creating barriers to access to medicines, or undermine healthy environments, such as by disrupting people’s ability to grow nutritious food for themselves and their families or otherwise disrupt people’s ability to have healthy lifestyles.

One practical step that the NHDGs and global social contract could promote is conducting right to health assessments for policies and action that affect health to help guide decision-making.

Governance and engagement of concerned populations

The NHDGs and attendant governance structures – and in some cases the post-2015 agenda beyond any specific health goal(s) – should encompass key features of mechanisms for participation and accountability. These could include:

- Functioning mechanisms at the community and higher levels in which community members have structured participation, with measures to ensure the full participation of marginalized members of particular communities and of communities that are themselves marginalized. This participation should cover all stages of policy-making, from priority-setting to monitoring and evaluation, and include budgeting.
• Mechanisms to feed back to the community information on how community inputs have been taken into account in the design and implementation of health policies and programs at all levels, from local to national (including those supported with international funding).

• Complaint mechanisms for discrimination or other mistreatment in the health sector, as well as other health system health systems (e.g., stock-outs), along with facilitation for using these mechanisms and clear procedures for responding to people using them and for any rights violations and other problems uncovered.

• Measures to increase access to the justice system, enabling people to access and utilize courts, including ensuring their affordability; effectuating people’s right of access to information, enabling people to gather evidence, and; implementing policies and promoting community education and outreach so that people understand how to use the legal system and do not fear negative consequences from doing so (as might be the case for migrants with irregular status, for example).

• Accountability not only for the government’s own actions, but also for its effective regulations of third parties that may harm health – from corporations to religious leadership make false claims. (Uganda has seen cases of religious leaders encouraging people to stop taking tuberculosis drugs and turn to prayer instead, advice that when heeded led to several deaths.)

• Accountability systems that are designed with the principle that accountability of all stakeholders is ultimately to communities, to rights-holders, the people meant to benefit from health programs. For example, national government accountability for funds received from development partners should first and foremost be to communities, even as accountability to development partners is needed as well.

A specific target on participation – phrased here in terms of the health sector but with the potential of being expanded to the post-2015 sustainable development agenda more broadly, could be: “Provide a genuine role to the public in health-related priority-setting, policy-making, budgeting, and other decision-making and monitoring and evaluation at all levels (local, national, global) through informed, inclusive public participation that includes active outreach and support to ensure the full involvement of marginalized populations and provides feedback to the public, and ensures accountability for the effectiveness of these processes and for the decisions and policies to which they contribute.”

In addition, in its support for human rights more broadly, the post-2015 agenda should include a target and indicators on empowering people to know and have the means to enforce their human rights, including having the skills to effectively engage policy-making processes and authorities, as well as using political and legal avenues to express their concerns and seek change. Civil
society organizations, especially those working closely with marginalized communities, will be particularly important to achieving this.


6 For example, in thirty-eight countries containing the highest levels of maternal mortality, more than 80% of women are attended by skilled health personnel, compared to a mere 30% for women in the poorest quintile. Zulfiqar A. Bhutta et al., “Countdown to 2015 Decade Report (2000-10): Taking Stock of Maternal, Newborn, and Child Survival,” 375 *Lancet* (2010): 2032, 2040 fig. 8. The disparity between under-five mortality between the richest and poorest 20% of households grew or remained the same in 18 of the 26 countries that had reductions in under-five mortality of at least 10% in the ten year period before the most recent data collection. UNICEF, *Progress for Children: Achieving the MDGs with Equity, Number 9* (September 2010), at 23, 85. Available at: http://www.unicef.org/publications/files/progress_for_children-No.9_EN_081710.pdf.


11 Participative-action research (PAR) systematizes local experiences and organizes shared collective analysis on relationships and causes of problems. PAR links these analyses to reflection and action, organizing shared experiences and perceptions to generate new learning and knowledge.

12 In Guatemala, some of the communities consulted have been part of a process of human rights’ literacy facilitated by CEGSS. This could explain why some of them showed this strong sense about rights.

V. Community consultations: some photos from different communities and countries

**GUATEMALA**
BANGLADESH
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