TRANSFORMING HEALTH SYSTEMS TO SERVE THE WELLBEING OF INDIGENOUS AND MINORITY PEOPLES

A REPORT BY THE ROYAL TROPICAL INSTITUTE AND THE INSTITUTE OF DEVELOPMENT STUDIES AT THE ROCKEFELLER BELLAGIO STUDY AND CONFERENCE CENTRE JUNE 2012

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SUMMARY

The issue:

Almost a third of the world's poorest people, known as the 'bottom billion', are indigenous and minority peoples living in Asia, Africa and Latin America. A wealth of evidence shows that governments fail in their responsibility to fulfil the right to health of these peoples. In fact, health inequities between majority groups and indigenous people are increasing, both in poorer nations and in countries experiencing rapid economic growth, such as Brazil and India. Often the discrepancies are worse in states where indigenous peoples are engaged in a struggle over land or in their pursuit to be recognised as having distinct rights. In 2007, the United Nations Declaration on the Rights of Indigenous Peoples stipulated that indigenous people have the same rights to the highest attainable standard of physical and mental health as majority populations. Yet health care coverage in most countries fails to take into account the specific challenges that confront efforts to ensure indigenous people's access to their health rights.

The process:

The conference brought together 19 key stakeholders and experts from Asia, Africa and Latin America to share their expertise and establish a common agenda to address inequities in universal health coverage. Building on participants' experiences, the conference explored three themes that highlighted critical issues at the interface between dominant medical norms and practices in state health systems and the socio-cultural realities of indigenous groups. The themes were:

1. territory, mobility and access;
2. traditional medical knowledge and intercultural, culturally sensitive, health care; and
3. gender and sexual and reproductive health, including maternal and child health (MCH).

Participants used 'mind-mapping' techniques to identify the current state of health systems and their vision of what health care for indigenous groups should look like, in order to develop an ambitious agenda for future collaborative work on bridging divisions.

The results:

The outcome of the conference was a better understanding of what interventions to transform health systems have worked and why. Participants shared their experiences with significant and promising efforts in improving health access. These experiences included working with and strengthening networks of healers and indigenous self-help groups, developing mobile and cross-border programmes, reducing stigma, and promoting initiatives to facilitate community empowerment. Health financing, good governance, poverty alleviation and protection of lands and livelihoods were widely recognised as important across the three themes. Yet in reality, few initiatives actually link or integrate health, livelihoods and governance. There was agreement on the need for improved systematic documentation and recognition of indigenous peoples' knowledge, including their medical expertise. There was also an emphasis on the need to improve engagement between indigenous health care practitioners and biomedical providers. The relationship of pharmaceutical companies to traditional medicine was also explored.

Participants identified the need for a global network to share information about what works and why, when it comes to addressing the health challenges faced by indigenous and minority peoples. Such a network would help strengthen advocacy for international policy responses to these challenges.

Recognising the need for a global network, at the end of the conference, participants decided to establish the Indigenous and Minority Peoples Health Alliance (TIMPHA). The mission of TIMPHA is to transform health systems to serve the wellbeing and health of indigenous and minority groups and help ensure universal health coverage in Africa, Asia and Latin America for all citizens. Members of the network developed a research agenda and potential joint action research projects to address key knowledge gaps and pilot innovative responses to indigenous health challenges.

SETTING THE SCENE

There are an estimated 370 million indigenous people, living in some 90 countries. Most live in Asia, Africa and Latin America and are among the regions most disadvantaged and marginalised populations[1]. They typically have low standards of health and shorter life expectancies compared to the majority.

An important question to ask is, 'Who are indigenous people?' Indigenous peoples have unique political histories within nation states. They have specific rights, including rights to ancestral land that are internationally recognised, but often denied in practice. Some countries do not allow the use of the term 'indigenous' in policies and other legally binding documents; they use other terms with a different legal status. They might be called and/or call themselves indigenous, aboriginal, First Nations, tribal or minority groups or peoples. Locally specific terms such as adivasi (in India) and janajati (in Nepal) are also used[2]. As diversity is a unique aspect of indigenous culture, the UN's working approach toward indigenous peoples includes a variety of terms and classifications[3].

In this report, it was decided to use the terms, 'indigenous' and 'minority peoples'. This was a deliberate decision intended to facilitate exchanges between regions of the world where 'indigenous health' is a recognised field (in Latin America, for example) and in places where the discussion tends to be framed in terms of the 'health of ethnic minority peoples' (such as in Southeast Asia) or 'minorities' (such as in Ethiopia).

The poor health status of indigenous and minority peoples is associated with many other social and economic determinants, such as poverty, lack of access to clean water and sanitation, environmental degradation and displacement. Very often health systems fail to respond to their specific needs, providing inadequate, substandard clinical care, culturally inappropriate health information and poor disease prevention services. The diversity within and between indigenous populations is one of the challenges for understanding why this is the case and how their health situation can be improved. Nevertheless, some common issues can be identified among different groups and across different regions. Positive experiences in one locale can generate lessons that are relevant to efforts to improve the wellbeing of indigenous and minority peoples in others.

Some factors and issues that affect the health status and access to services of indigenous and minority peoples include the following:

- Across the globe, there are health disparities between the majority and indigenous and minority groups when it comes to virtually every health condition, from infectious diseases such as HIV/AIDS, malaria, tuberculosis and measles, to cardiovascular disease, diabetes and cancer. Maternal and child mortality rates are disproportionally high among indigenous and minority populations compared with majority groups. This raises questions about the appropriateness of dominant models of development in general, and health development in particular, for such societies.

- Without a special focus on the poorest and most difficult to reach, programmes that increase health coverage typically benefit the higher socioeconomic groups. Universal coverage programmes can benefit indigenous and minority populations when innovative approaches are used that recognise indigenous peoples as partners in transforming health systems and specifically address inherent disadvantages.

- States often have inadequate statistical data. The data they do have is typically not disaggregated for different indigenous and minority groups. This hinders any systematic analysisof the drivers of inequity in health status. The lack of evidence on health and other inequities contributes to the invisibility of indigenous issues on national and international political agendas. There is a need to advocate more effectively for disaggregated health-related data to be made available. Such data would help facilitate the necessary actions to be taken in order to improve the health status of indigenous and minority groups.

- States and indigenous peoples often have divergent views on health priorities and resource allocation. Indigenous voices may not be heard as a result of political and cultural barriers, not to mention language differences. Even where democratic representation systems exist, their minority status and lack of economic power makes it hard for them to use their votes to influence the policy process. These impediments are compounded by racism and other biases, which influence the attitudes of policymakers, who typically belong to the majority. Prejudices are often rooted in ahistorical perceptions of minority cultures as backward, static or homogeneous. They can reflect negative colonial and contemporary stereotypes that include labels such as 'primitive', 'promiscuous' or 'uncivilised'.

- Health systems tend to focus on treating diseases rather than on preventing them. Indigenous peoples own health experts, medicines and practices are often not recognised by the state health care system and may even be illegal in some countries. The governments of several countries experiencing rapid economic growth, such as China, Vietnam and Brazil, have sought to include minorities in their health planning. While this has helped increase access to biomedical care, health systems that follow these biomedical practices tend to simultaneously over-medicalise care and fail to recognise indigenous health care practices.
- Indigenous people in many countries are under increasing pressure to leave their ancestral lands. In Brazil, Peru, Ethiopia, India, China and Vietnam, governments have implemented ambitious infrastructure and natural resource development programmes, which have led to groups being displaced or relocated. Despite rhetoric that suggests that development expands opportunities for all, indigenous people are often excluded from jobs and the material resources made available through development projects. Not only are they labelled as 'savages' but these groups are also seen as not being ready to manage their own resources.

[1] *Stephens C.; Nettleton C.; Porter J.; Willis R.; Clark S. Indigenous peoples' health—why are they behind everyone, everywhere? The Lancet, July 2, 2005, Vol. 366 (9479): 10-13.*

[1] See United Nations Department of Economic and Social Affairs (2009) State of the World's Indigenous Peoples (New York: United Nations).

[2] *United Nations Permanent Forum on Indigenous Issues. Who are indigenous peoples? http://www.un.org/esa/socdev/unpfii/ documents/5session_factsheet1.pdf.*

[3] *Department of Economic and Social Affairs, Division of Social Policy and Development, Secretariat of the United Nations Permanent Forum on Indigenous Issues (UNPFII). State of the World's Indigenous Peoples (2009). http://www.un.org/esa/socdev/unpfii/documents/SOWIP_web.pdf.*

- Indigenous and minority ethnic groups may have ideas and practices related to gender and sexuality that influence reproductive and sexual health choices and options. Governments and development agencies are often unaware of these, leading to failures in sexual and reproductive health service provision.
- At both national and international levels there is a lack of knowledge of the political and land governance systems of different indigenous and minority peoples. These local systems determine how individuals, families and communities relate to one other in key areas of life that affect health, such as marriage, labour, residence and migration.
- The research and knowledge that academics, activists, donors and policy makers have tends to focus on a particular group, country or region, or on a specific disease like HIV. As a result, there is a lack of comparative research evidence that can be used to encourage health systems to acknowledge indigenous and minority peoples' right to health, and place that right on the global poverty and development agendas. In particular, there is a lack of opportunities for researchers, practitioners and policy-makers from different regions to share experiences with regards to what has worked in the cases where health systems have been successfully transformed to recognise the role and value of indigenous health systems, and are responsive to the wellbeing needs and priorities of different indigenous and minority peoples.

The Bellagio conference process

The aim of the conference was to construct a common understanding of the issues and produce an action research agenda.

The conference built on successful examples of state health system transformation in the many countries represented. Participants included both indigenous and non-indigenous specialists, who had a broad range of expertise and experiences from across the three continents. They prepared summaries of relevant cases in which they had direct experience, and shared them in advance to provide the starting point for a discussion. A participatory process was facilitated through a mixture of plenary dialogues, small work groups and mapping exercises.

This process began with a plenary discussion to review participants' visions of what constitutes a health system. This discussion contrasted biomedical and broader, more holistic accounts of health systems, and identified key aspects that health systems need to incorporate if they are to provide genuinely effective coverage for indigenous peoples. The conference then moved on to explore indigenous health issues within regional groups. This generated a picture of the ways in which indigenous health is viewed across regions.

Following plenary feedback, the next round of group discussions explored the three themes that framed the conference proposal:

1. territory, mobility and access;
2. traditional medical knowledge and intercultural health care; and
3. gender, sexual and reproductive health, including maternal and child health.

Participants identified cross-cutting themes and research gaps, and located them on a large thematic map. Over the course of the three-day meeting, participants identified those sets of issues with the greatest need and potential for future international collaborative work. On the last day, these discussions and maps formed the basis for a further round of group work organised around the following themes:

1. Policy, governance, rights and representation in health systems;
2. Intercultural practice and biomedical training; and
3. Indigenous people's health choices, provision, practices and knowledge.

In the final plenary, all of these threads were drawn together into an agenda for research and framing for a global network.

Although most of the participants had never met before and came from diverse backgrounds, throughout the conference they established a rich range of connections and links for future collaboration. These links developed through the informal networking and in-depth sharing of experiences that the immersive Bellagio conference model is uniquely designed to promote.

CONFERENCE FINDINGS

Health systems and indigenous peoples

Given the diversity in models of health systems, we did not want the conference to get too sidetracked into definitions, but rather to build on participants' own experience of what was needed to move health systems toward universal health coverage.

We agreed that within the health system literature[2] there seems to be agreement that an effective health system needs:
- Stewardship, leadership and oversight;
- Sufficient and well-skilled human resources;
- Financial resources;
- Effective and efficient services;
- The means to promote fairness and equity; and
- The means to be responsive to people's changing needs.

In the plenary discussion, participants added, that to transform health systems to serve the wellbeing of indigenous peoples, the following also needed to be built in:
- A rights-based approach;
- A learning system;
- Traditional medicine;
- Preventive as well as curative medicine; and
- Multi-sectoral and multi-level approaches.

[2] See for example Frenk J., The global health system: strengthening national health systems as the next step for global progress. PloS Medicine, January 2010, Vol 7(1), and Everybody's business. Strengthening health systems to improve health outcomes: WHO's framework for action. WHO. 2007.
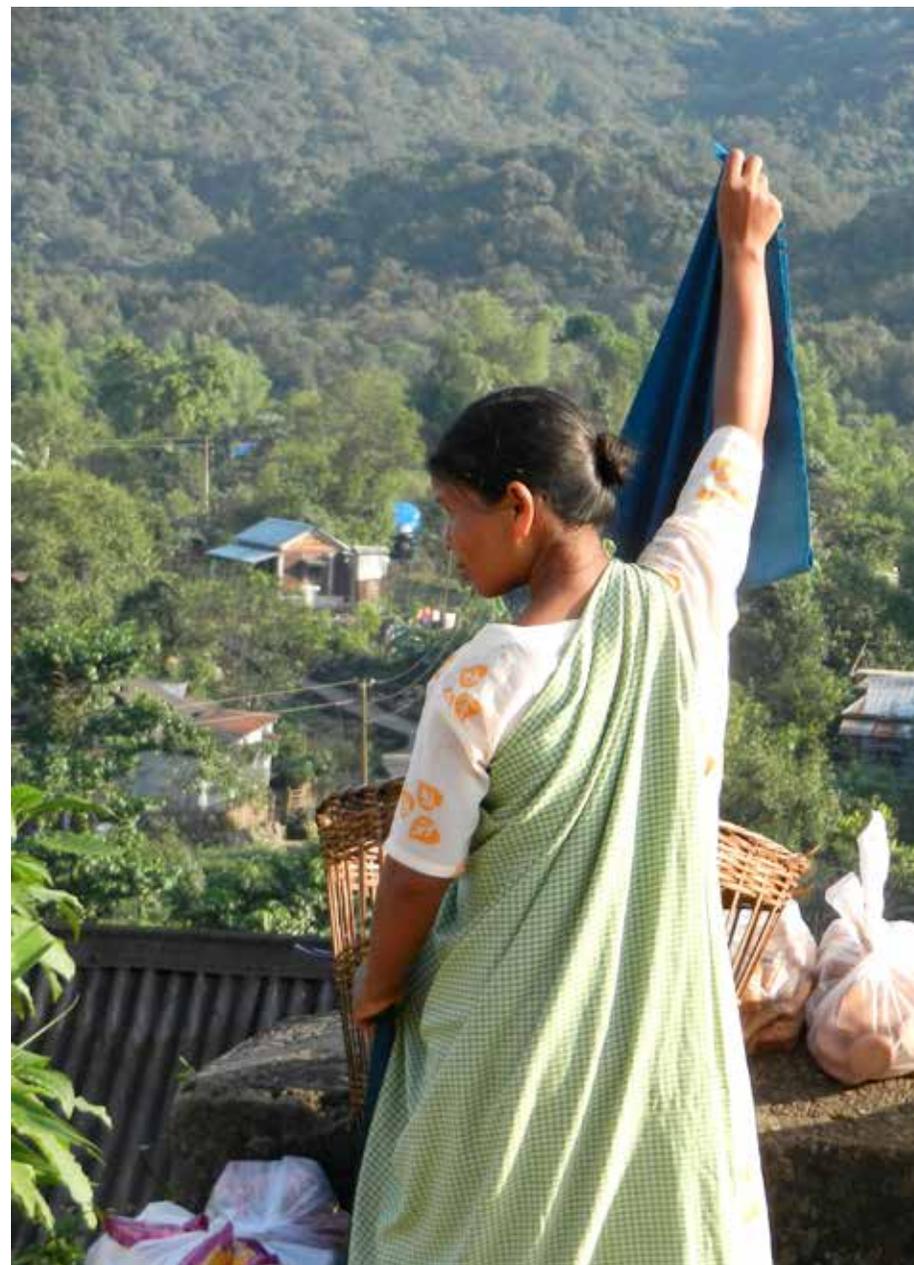
Issues emerging from regional discussions

In the first group work session, participants were divided by continent (Africa, Asia and Latin America). The aim of this session was for participants to brainstorm the important issues related to indigenous health and wellbeing, and at the same time to generate a common understanding of what was at stake in the continent. Each group produced a mind map to capture the relationships between the different issues identified. When the maps were completed, a gallery walk was held in which all the participants reviewed the maps produced by the other groups and reflected on the differences and similarities that had emerged.

Asia

The mind map created by the group focusing on Asia highlighted the issues of marginalisation of indigenous peoples and an overall lack of political opportunities to organise themselves and be heard. In many countries, the status of indigenous groups are not recognised and they are therefore excluded from claiming any rights as indigenous peoples. Where indigenous organisations do exist, they tend to focus on topics such as land, conflicts over resources and human rights. Representation of indigenous women is particularly weak. This of course seriously limits women's ability to shape economic, cultural and educational development models as well as health systems. There are almost no indigenous health initiatives at national and regional levels. In some countries, such as Myanmar and India, there are armed conflicts in areas where indigenous people live. Conflicts between indigenous leaders and the state pose specific challenges for health access and health system reform. There is a scarcity of data on indigenous health in Asia, but the available data show serious health inequities. This has not resulted in concerted action, reflecting an overall lack of opportunities for organisations of indigenous peoples to engage in health policy debates. Indigenous peoples' knowledge and views on health do not inform national health development policies and planning. In a number of Asian states, cultural diversity and cultural heritage are often seen as threats to development rather than as opportunities to improve health system performance.

Asia mindmap
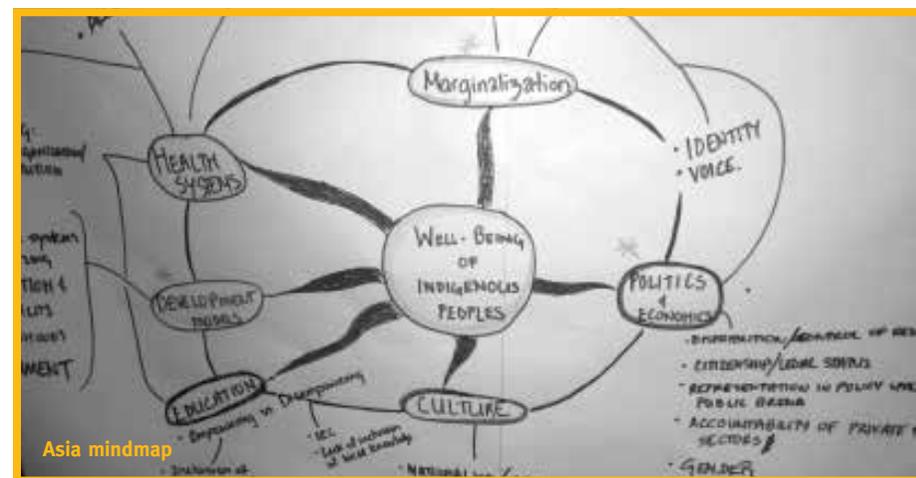
Latin America

The Latin American group emphasised the importance of a sense of belonging as the link between identity, territory, knowledge and community. Indigenous identities have achieved a higher level of official recognition in Latin America compared to the rest of the world, but territories remain under threat, communities are becoming fractured and traditional knowledge is being lost. Health and wellbeing are associated with achieving a balance between individual, social, spiritual and environmental elements. Indigenous peoples' ability to maintain this balance – and especially its spiritual underpinnings – depends on the health of their lands as sources of food, water and medicine. Wellbeing also depends on the health of their communities; shared knowledge through celebrations and oral traditions is the basis of collective action, political organisation and the search for voice. Participants saw the strengthening of indigenous voices as a key element in the struggle for the realisation of indigenous health rights, along with the promotion of intercultural education and the establishment of legal instruments.

This included upholding indigenous peoples' rights to both oppose such development and to informed consent to development interventions and natural resource exploitation in their territories. The right to choose whether or not to use biomedical health services was recognised as important. Physical access to biomedical services is necessary to make this choice possible, and this was considered to have improved in many countries in Asia in recent years. However, participants considered that the current effectiveness of these services is undermined by a widespread inability to recognise indigenous understandings of health, and to integrate this understanding with indigenous governance systems. This has led to the persistence of health inequalities despite increased resource allocations.

Africa

The Africa mind-mapping exercise evolved around power issues related to defining indigenous wellbeing. Whose perspective is the most important and why? How do we balance between biomedical and social realities? Is it even possible to arrive at one shared definition of wellbeing or will we have to accept that at best we will have overlapping views. Should we, for example, distinguish between insiders' (emic) and outsiders' (etic) views, anthropological terms that are possibly divisive? Perhaps we should use those definitions that indigenous peoples themselves use - definitions, for example, that include social aspects of wellbeing, such as a sense of belonging and living in harmony. Within an African context, the question, 'who is indigenous and who is not', is a complex issue and involves borders drawn by former colonial rulers in areas with large numbers of clans and tribes.

Latin America mindmap

Afirca mindmap
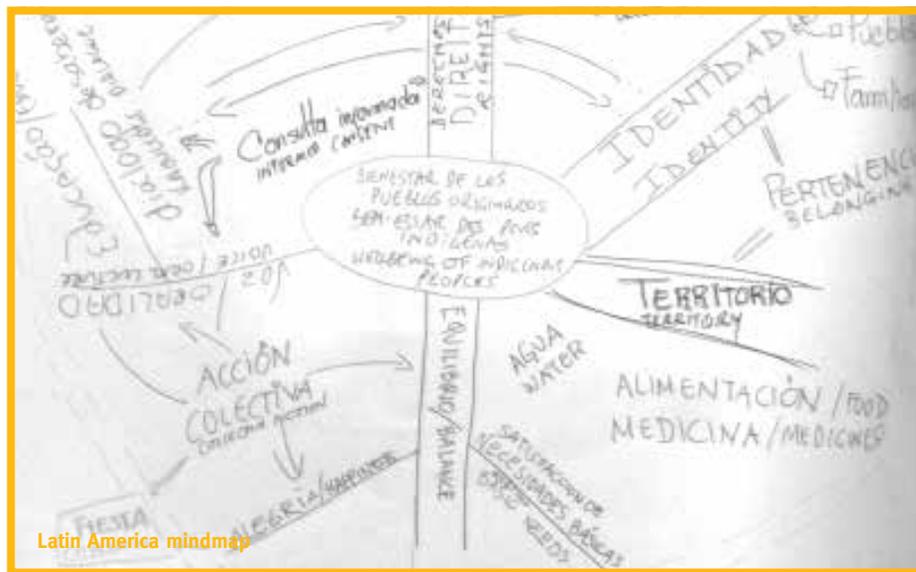
As in other areas of the world, the fight over scarce resources influences the discussion as to who is indigenous, because indigenous peoples can claim access to land and resources, such as oil and water. The entire issue is highly political in Africa, and a number of governments do not recognise the term indigenous. Territory and identity are closely linked. Indigenous Africans, such as the San and the Benet, have been evicted from their lands. Land is directly linked to power, food security and gender relations, which all affect wellbeing. Indigenous groups and indigenous healers are highly diverse between and within countries and regions. Some ethnic groups are reduced to being exotic tribes (Maasai), while others are political marginalised (Afar, Turkana). All these group share the fact that they are politically under represented.

With regards to health systems, participants felt that diverse traditional healing practices need to be acknowledged because this is what many people use in addition to biomedical services. Both systems exist along side one another and are an integral part of many people's lives.

Differences and similarities

In all the three groups, governance and accountability were discussed as obstacles to effective access to health and other services. This was linked to social and political marginalisation and to issues of identity and recognition. In Africa, indigenous people, with a few exceptions such as the San, the Benet, and the Karamajong are not generally seen so much as 'indigenous' but more as marginalised groups living in harsh, hard-to-reach environments. The importance of politics, and the role of civil society in recognising marginalised groups, was raised by the Asian and Latin American groups, but were articulated differently. For the Asian group, the politics of being recognised as an indigenous group is the starting point, whereas for the Latin American group, formal recognition has largely been secured and the critical issue is the effective realisation of indigenous rights through appropriate governance and accountability strategies. In all of the presentations the need for bridging and brokering between the different worlds was stressed. This requires effective political representation but also the strengthening of intercultural approaches and recognition of indigenous knowledge. In the Africa and Asia groups there was discussion about the development and accreditation of traditional medicines, while in the Latin America group the focus was on the preservation of indigenous knowledge alongside the expansion of access to biomedical services.

THEMATIC DISCUSSIONS
THEME 1: TERRITORY, MOBILITY AND ACCESS TO SERVICES

Key challenges and issues at stake

Many indigenous people live in remote areas, far from the resources and services that are concentrated in areas typically inhabited by majority populations. Yet territory, mobility and access to health services relate to much more than the inability of vehicles to reach an area: These issues have physical, economic, cultural and political dimensions. At the same time, these remote regions are increasingly being targeted for 'development'. Roads in China and Laos, and dams in Ethiopia and the Brazilian Amazon, for example, are displacing people as well as damaging the environment on which indigenous peoples depend. Once displaced, their new homes may not support their culture, and the loss of sacred spaces and dislocation from ancestors can have serious implications for wellbeing.

A central issue in the failure of many state health systems to provide adequate coverage for indigenous peoples is that state planning, allocation and monitoring processes are set up with the assumption that populations are static. Many indigenous people and minorities have mobile livelihoods and ways of living, whether as traditional pastoralists, hunter-gatherers, modern migrant workers or displaced persons and refugees. Accessing services for mobile or displaced indigenous populations can involve both exorbitant costs and a high level of risk; as a result, when people finally get medical treatment they are often very ill, which reduces their chances of recovery and increases the cost of treatment. How can movement be accommodated and systems be adapted to reduce these burdens?

Migrant or displaced indigenous populations moving across state lines, such as along the Thai-Myanmar and the Myanmar-China borders, face particularly vexing problems that affect service delivery. While some countries including China and Vietnam are concerned about infectious diseases, and therefore support cross-border treatment and prevention programmes, non-communicable diseases remain neglected. In order to reach indigenous and minority populations, specific, tailored interventions are needed. For example, translators may be needed in order to enable different groups to access services and participate in research. However, the allocation of resources earmarked for vulnerable displaced groups can lead to tensions with host populations.

The issue of territorial control and mobility is also highly relevant within national health systems. Health system organisational units may not match the territories of indigenous peoples, which often cross district and state boundaries. In the decentralised Brazilian health system, for example, the municipality is the basis of assigning services, personnel, resources, etc. Yet indigenous peoples tend to live within territories that cross several municipalities. Because the indigenous population is thinly spread, they are often a minority in all of them. This minority status and the frequent hostility of local political elites to indigenous peoples limits the scope for electoral politics to ensure that municipal bureaucrats feel responsible for ensuring that indigenous peoples' rights of access to services are realised or prioritised.

In the Sierra Tarahumara region of Mexico, state authorities have made attempts to provide health care to indigenous communities but their efforts have been weakened by a failure to adapt service organisations to indigenous territorial governance structures. The effect has been to exclude indigenous practitioners who provide care in large parts of the territory through a well-developed traditional system with six different types of medical specialties.

In several indigenous areas such as the Afar region of Ethiopia and Kachin State in Myanmar, national governments do not have full control over their territories, and the local governments are de facto in the hands of local indigenous leaders. Lobbying national governments to recognise the rights of these people and provide services to them may not yield results as they are in conflict with local leaders who control the area. Clashes with national governments may be both a result of and a cause of neglect of indigenous peoples' rights and health needs. Although recognition of local indigenous governance is essential, caution is also needed against romanticising indigenous leadership. Traditional systems can also be exclusive, manipulative and concentrate power in the hands of a few people, usually men. Women may, for example, have few opportunities to participate in public political arenas, even in matrilocal cultures such as the Khasi of Meghalaya in north-eastern India. Recognition of diversity, including gender diversity, among indigenous peoples needs to be part of discussions of indigenous representation and institutional reforms including health system reforms.

Some of the opportunities to address access issues include global policy frameworks, such as the UN Declaration on the Rights of Indigenous Peoples and the Millennium Development Goals, as well as actions by national governments to boost the supply of health services, such as building new health facilities. However, stronger indigenous voices and greater accountability will be needed to ensure that services are adapted to indigenous realities rather than simply rolled out into indigenous territories without regard to the need for adaptation. Indigenous peoples have embraced new communication technologies, such as mobile phones and social networking platforms, which have the potential not only to improve access to information but also to facilitate political organisation and advocacy.

Examples of promising interventions and practices

Culturally sensitive communication for preventing Podoconiasis (Ethiopia)

Podoconiasis (non-filarial elephantiasis) is a disease of the lower limbs that is easily preventable by wearing shoes. However, conventional top-down health education communication strategies have failed to convince many minority communities to change their habits. Qualitative research in Ethiopia identified the issues that the health messages need to address; the communications strategy that could be used; and the community leaders who could communicate those messages. Qualitative research and collaborations with local organisations were key to organising every step of the work.

Shared by: Getnet TADELE, Ethiopia, Addis Ababa University, dept Sociology

Changing policy to address the specific challenges of indigenous health (Brazil)

In Brazil, the Constitution guarantees both the universal right to health care and the right of indigenous peoples to differentiated policies that respect their social organisation, customs, languages, beliefs and traditions. Following the adoption of the Constitution, spending on indigenous health services increased but a long history of corruption and mismanagement in government health services still left indigenous peoples with an infant mortality rate three times higher than that of the population as a whole. In 2008 and 2009, frustration with this negligence led indigenous leaders to mobilise a series of high-profile political protests, including the occupation of government offices. Their calls for change were supported by a broad coalition of activists, researchers and health professionals, who were able to assemble a strong evidence base and communicate the logic of indigenous demands in accessible terms for policymakers.

The problem with Brazil's centralised system was that it had failed to adapt to diverse local indigenous realities and provide a service flexible enough to cover groups with very different health needs. Peoples like the Guarani have a long history of contact with non-indigenous society and live in territories with easier access to health services, but suffer from severe pressure on land and a growing burden of non-communicable diseases and mental health issues.

Others like the Yanomami have limited contact with non-indigenous society and live in remote Amazonian regions where natural resources are abundant, but face a major threat from epidemics of infectious diseases introduced by miners, loggers and other outsiders.

The municipality-based decentralisation model used by the mainstream national health service (SUS) risked fragmenting health care by splitting coverage of a single indigenous territory among many different municipalities. To rectify the problem, the government agreed to set up an indigenous health department within the Ministry of Health and changed the law to give administrative autonomy to Special Indigenous Health Districts (DSEIs). These districts are charged with covering indigenous peoples whose territories stretch across different municipalities. They are politically independent of the municipalities, where local elites are sometimes hostile to indigenous rights. Today, the DSEIs are overseen by a District Health Council, which has indigenous representatives making up half of its membership, with health system managers and professionals accounting for the other half. Since the council must approve all health service delivery plans and budgets, this provides a very strong framework for ensuring service accountability and responsiveness. The DSEIs' administrative autonomy also provides an opportunity to support local-level innovation in responding to the diverse health challenges faced by Brazil's 238 different indigenous peoples.

Shared by: Alex Shankland, UK, IDS

Engaging with policy by building a network of traditional healers (India)

Eighty-five percent of the people in Meghalaya, a mostly rural hilly state in north-east India, are indigenous. There are few public health services in this area, but there are around 10,000 traditional healers who are not officially recognised by the government. There is a risk that indigenous knowledge is being lost because of social change and the biomedical emphasis within health systems that advance biomedical providers and treatments. Research among healers and their families found that young people are losing interest in traditional healing as a livelihood. It is also becoming harder for healers to find their herbs due to deforestation and changes in land use. Researchers' exploratory participatory work with a group of healers helped these healers to identify their own demands. On the basis of these demands they were able to organise themselves into a network. This enabled them to communicate with elites in a tribal legislative body in advocating for collective recognition. This tribal legislative body passed an act to protect and promote traditional medicine, which is unique in India. Researchers are now working with the healers on the implementation of this policy, including measures to build trust and ensure that knowledge will be protected and not pirated. Establishing a link with national policy has also made it possible to unlock funding from government programmes.

Shared by: Sandra ALBERT, India, London School of hygiene and tropical medicine (LSHTM) Indian Institute of Public Health (IIPH)

Integrating and reorganising services to fit indigenous realities (Mexico)

In the northern part of Mexico, indigenous peoples such as the Rarámuri, also known as the Tarahumara, are affected by double disease burdens. Not only has there been an increase in the number of people suffering 'diseases of poverty', such as diarrhoea and tuberculosis, but there has also been an increase in non-communicable diseases, such as diabetes. Research was initially undertaken to analyse these issues and document them in scientific journals. This helped to demonstrate the impact of disease and influence a national response. The initial research combined biomedical quantitative methods with qualitative social science methods. It was conducted in partnership with a local organisation, which helped to identify and address initial misunderstandings and mistrust towards researchers, who are regarded by many locals as 'leeches'. The local organisation also helped support the public education of indigenous peoples on the grounds that 'people need to know their rights in order to claim them'.

As a result of the research being conducted, social scientists were able to identify the types of territorial organisations and governance that exist among indigenous peoples. This influenced the successful introduction of 'medical brigades' - teams comprised of a doctor, nurse and health educator who travel around remote and isolated communities that were not being reached by urban-based services.

Interventions were initially supported by a diverse assortment of US-based organisations, including universities, religious groups and an Apache Indian organisation concerned about nutrition and child survival among Mexico's indigenous peoples. Mexican partners gradually began to coordinate many disease-specific programmes on the ground. This enabled the medical brigades to move beyond TB control and to work on nutrition, obesity, primary health, immunizations, and sexual and reproductive health and rights (SRHR). New government initiatives, including conditional cash transfers (if you see health staff for specific services), and the Seguro Popular, or the 'people's health insurance' programme, have expanded the availability of services and the incentives to access them. These efforts, however, have not been adapted to indigenous realities.

Shared by: Kiriaki ORPINEL Mexico, SSCh

Cuidar tu embarazo, te dá un parto felíz.

Indicators of success

The Latin American group's discussion concluded that successful adaptation of government health systems to indigenous realities is a governance challenge as well as a technical one. It requires an effective democratic process to reach consensus about health priorities and allocation of resources. Such a process, in turn, requires that diverse voices and views are heard and documented, and that sufficient time is allocated for participatory processes. Health priority setting needs to be underpinned by a policy framework within which non-biomedical systems are recognised and medical pluralism is supported within state health systems.

The allocation of resources also needs to be supported by a solid evidence base on the extent of health inequities. This includes making these inequities visible within health information systems by collecting disaggregated data on the health of indigenous peoples, which can also be broken down according to age, gender and other criteria.

THEMATIC DISCUSSIONS
THEME 2: TRADITIONAL MEDICAL KNOWLEDGE AND INTERCULTURAL HEALTHCARE

Key challenges and issues at stake

Culture influences many aspects of decision-making within health systems. This is true for the majority, not just for indigenous people. For example, if an unmarried girl in Vietnam requests an abortion she is likely to get one because health staff understand the potential negative social consequences of having a baby. But if she is married, young and childless it would be difficult to get an abortion unless her mother-in-law gives permission. Similarly, cultural attitudes affect Caesarean section rates. Among some Asian ethnic groups, such as the Han Chinese or the Kinh majority in Vietnam, Caesarean sections are used to determine the timing of the birth according to the astrological calendar. Hmong women, on the other hand, are very reluctant to have Caesareans because of their beliefs about the sanctity of the body.

Who can and cannot legitimately acquire and use traditional medical knowledge is typically very restricted among indigenous peoples. In the Rio Negro region of the Brazilian Amazon, for example, some kinds of shamanic knowledge are the property of particular clans, and should not be passed on to other clans even within the same ethnic group. Opportunities to pass down indigenous medical knowledge have been hampered by displacement, migration, urbanisation, Christian missionary influences and a diminishing interest in traditional medicine among younger generations. It has been difficult to preserve this medical knowledge as indigenous healers are reluctant to engage with the biomedical industry for fear that their knowledge will be stolen or even used against them. Although it is understandable if traditional healers are unwilling to impart their knowledge, it makes it more difficult for biomedical practitioners to work with them.

A foundation for all effective intercultural work is to combine the recognition that there are different epistemologies with a willingness to engage. It is important that indigenous communities recognise that they can benefit from science as well as the other way around. Effective engagement of traditional healers and practitioners with biomedicine, however, will also require recognition of broader power inequities.

It was pointed out that individuals often have little difficulty with using both biomedical and traditional healing; it is the practitioners and systems that may have a problem. Sometimes medical personnel are motivated by a desire to preserve power and status, as much as by a desire to avoid harm. While indigenous people are increasingly demanding access to biomedicine, demand for indigenous medical knowledge from mainstream groups is also increasing, and may offer opportunities for sharing and preserving indigenous knowledge. Within biomedicine, standardization of treatments and systematic measurement of results are seen as essential. Traditional healers and healing practices and their ways of recording and measuring results are extremely diverse.

Although it is neither possible nor desirable to standardise training practices across different traditions, it is important to recognise that indigenous healers do have training systems and measure their results. Indigenous healers may be trained through families or through schools. Some of these systems have well-established training principles, apprenticeships and grading. Such training systems may be as rigorous as those provided by biomedicine, although they often look very different. In order to improve collaboration and trust between different systems it is important to have agents and intermediaries on the ground who can cross the boundaries and work interculturally. Whether these are individual citizens or organisations, such as healers' networks or universities, they have to be embedded in, and trusted by, both traditions.

Respecting familial and social, as well as individual, relations is also an important element of working interculturally. Western biomedical approaches often emphasise the rights and duties of the individual patient, which may conflict with cultures where decisions are taken collectively either at a family or at broader (clan or village) level. Family members can also support access by helping to provide translation and interpreting services between non-indigenous health staff and relatives who do not speak the dominant or national languages. Family members also provide emotional support, which patients value. In Mexico and Brazil, governments have recognised that for many indigenous patients, families are integral to the healing process and therefore help relatives make travel arrangements to urban treatment centres.

Examples of promising interventions and practices

Sequencing of treatments by Khasi healers (India)

"Division of tasks and sequencing are both important for collaboration. One example is a patient who I treated for a slipped disc. The nerve had been compressed so she was bedridden. She was in hospital for a month, and surgery was estimated to have 50 percent chance of success. In Khasi healing traditions there is expertise with back and nerve problems, for which we use both herbs and massage. However, in the Meghalayan context it is important to sequence treatment. If I practice at the same time as biomedical practitioners I can be blamed and sued legally. Only when biomedical treatment has ended, and perhaps failed, can the indigenous practitioner come in with less risk. However, there is still some risk of being sued. If a traditional healer treats someone and that patient does die they can be sued, as there is no clear legal protection similar to that of biomedical practitioners. For us, therefore, a more legally enabling environment is important. In order to recognise our skills and weed out quacks we also need better documentation of our traditions and formalised education in an institute, similar to what already exists among Ayurvedic practitioners. These are also aims of our network of traditional Khasi healers."

Shared by: Ms. Alka KHARSATI, India SPIKAP

Intercultural respect and biomedicine among the Yanomami (Brazil)

"I was working as a dentist with a Yanomami patient in the forest. I heard someone crying and screaming. When I went out I saw a small child who was extremely sick with malaria. I asked permission from the relatives to call in a medical team from the government. Simultaneously, Yanomami healers went away to get their treatments. While they were away the medical team arrived and put in an IV drip. I thought that the healers would take out the IV when they returned but they left it in, while the medical team also did not interfere with their healing. There was respect for each other's competence and limits. I think this happened because the incident took place in a Yanomami area, where they could command respect for their healing practices because it was on their territory."

Shared by: Paulo MORAIS, Brazil, MOH, Special Secretariat for Indigenous Health

Studying and integrating indigenous epistemologies (Mozambique)

"Indigenous medicine has a different theory of blood. The human body has different types of blood - saliva, sexual fluids, milk, red blood. Every disease relates to a type of blood. The challenge was how to make sense of HIV in indigenous medicine. We had to find a new name for this HIV blood. In a participatory discussion it was decided that it was 'chameleon blood'. This was not just a name. Intercultural communication is not just communicating language; it is taking local epistemology seriously. Where indigenous medicine hasn't developed a treatment, healers recognise what is going on through the biomedical symptoms. So when there is awareness, then people can get sent to hospital. The outcome of this work was to get more people onto ARV treatments. However, people were starving, and without food they gave up treatment."

Shared by: Narciso MAHUMANA Mozambique, PROMETRA

Building bridges between different traditions by exchanging the roles of healer and patient (Mexico)

"When I lived in Baja, California, where I worked with the Triki people, I think I gained the trust of the community and the healers by becoming a patient of the healer. I was treated by a healer who uses a candle to carry out a cleansing ritual. He in turn allowed me to treat him for his health problems. We would refer patients to each other. I was willing to be his patient and he was willing to be mine, which led to mutual respect. Having such a one-to-one relationship is important to establish a relationship with a community."

Shared by: Patricia BREMER GALLO, Mexico

Indicators of success

The group discussed the differences between biomedical indicators, the indicators of indigenous healers and community-driven indicators. It was pointed out that each might have a different perspective on what were good outcomes. The question was asked as to what might be common indicators. Participants suggested mortality, incidence of side effects and/or complications, and recovery time. A common indicator of fertility treatment, for example, would be pregnancy. The problem according to some participants is that 'trying to come up with indicators for indigenous medicine through a biomedical thought process is a contradiction in itself', since 'measurement is a biomedical thought'.

A lot of discussion centred on outcomes and perceptions. Certain results, such as reduction of fever, can be measured across traditions. However, efficacy of treatment is not only attached to the individual health outcomes but also to the social collective meaning attached to those outcomes, which may not be clearly measurable in biomedical terms. This is the case with spiritual outcomes, which are considered crucial in some indigenous communities.

Satisfaction with treatment can also be measured through verbal reporting or failure to follow up. One of the problems with satisfaction measures is how to interpret people's choices. The members of the group on traditional medical knowledge and intercultural health care clearly established that individuals typically go to both biomedical and traditional healers if both are available. However, in many areas an indigenous person often doesn't have a choice between different health service providers as some options may be absent, inaccessible or unaffordable. Therefore people's health seeking behaviour is not necessarily an expression of their choice or preference. In addition, if there is a choice of both traditional and biomedical systems people will make choices based on many different criteria. Indigenous people, for example, may choose not to use a doctor because of social or cultural reasons even though they might trust his or her medical skills.

Another issue is that health outcomes mean different things to different people. In some indigenous communities, dying or being healed, are both acceptable outcomes. Acceptance of a health outcome can be based on a lack of information on the alternatives. For example, some families and communities accept that women die in childbirth, believing that it is a matter of destiny. They may not realise that medical options exist, taking outcomes out of the hands of fate. On the other hand, successful biomedical results may not be accepted because they do not address the social context. For example, in some Mozambican communities an AIDS widow who avoided infection may still be stigmatised by HIV/AIDS. She will need a cleansing ritual before she can be reintegrated into society, as healing is considered to be for the family, and not just for the individual.

Participants felt that research is needed to examine how indigenous community members and healers judge the success of their healing processes. Research would provide a better understanding of the commonalities and differences between traditional and biomedical criteria.

THEMATIC DISCUSSIONS
THEME 3: GENDER AND SEXUAL AND REPRODUCTIVE HEALTH

Key challenges and issues at stake

The group on gender and sexual and reproductive health identified two kinds of key issues affecting sexual and reproductive health: physical and social accessibility of services, and gender roles and relations.

Some indigenous territories are geographically remote. Those who live far from service providers are more likely to suffer from multiple deprivations, which are exacerbated by under funded services. Unless governments make the extra effort to provide services, indigenous people are often left without coverage or are covered only by non-government organisations. While the high cost of providing services to remote areas with low population densities may be a factor, sometimes the difficulty of reaching people who live in remote areas is used by governments as an excuse to not provide services. However, among hard-to-reach indigenous populations there are both the 'willing' and the 'unwilling': some groups may not wish to be reached by official health systems since access to services is often associated with ceding control to a government that may be hostile to their interests.

Globally, there is a need for greater expenditures on health care, combined with innovative forms of decentralisation of health services, promoting outreach through strategies like mobile health care. In the long run, health systems need more sustainable funding mechanisms, combining government and private sector resources.

A lack of knowledge about sexuality and limited access to contraceptive methods often result in unplanned pregnancies and early childbearing. The lack of knowledge about indigenous sexual and reproductive health practices by health care providers prevents them from providing optimum care. For example, when health care facilities don't respect local and traditional birthing practices, indigenous people may avoid medical care if they feel their cultural preferences won't be heeded. Miscommunication is often aggravated by language barriers.

In responding to these challenges it is crucial to ensure that interventions are based on the understandings of health and wellbeing of those people being served. Such understanding can be improved through the involvement of community health care providers and trained birth attendants. Effective community-based services need well-trained local people, which in turn requires access to education. The training of non-indigenous health professionals also needs to equip them to work in a way that makes them sensitive to gender, age and culture. This is essential in building up trust, which is a key issue for all sides involved in delivering effective sexual and reproductive health services.

Gender roles and relations affect health-seeking behaviour and this is why health workers need to be aware of them. For example many groups, including the Sabiny of Uganda and the Hmong of Southeast Asia, have a norm that women are supposed to be strong, and ideally deliver on their own. Avoiding assisted deliveries may be driven by a desire to show oneself to be a good, strong and responsible mother. But health staff may consider this behaviour irresponsible or 'deviant'. Participants reported that in both Uganda and Mexico, decisions about where to deliver, with whom, and in which facilities, are highly gendered. Among some nomadic groups in Africa men retain their wives' identity cards while they are away, which prevents the women from accessing services.

Gender differences are inscribed in the body through practices that may be harmful, such as female genital mutilation. Sexually transmitted infections (STIs) are spreading and not being adequately treated among indigenous groups. Some indigenous groups, particularly in Thailand, are increasingly involved in commercial sex. Young girls and women desperate to get out of a life of grinding poverty are easily lured into the sex trade. Many are refugees living in border camps. All of them are vulnerable to STIs, including HIV. Where early marriages and polygamy are encouraged, as is the case in some parts of Uganda, husbands with multiple partners can increase the spread of HIV.

There is a need to develop programmes that support more equitable gender relations and joint decision-making.

Indigenous men's involvement in sexual and reproductive health varies greatly from one context to another. Among the Black Thai of Southeast Asia, men have traditionally assisted in deliveries but now find themselves excluded because of policies that keep men out of hospital delivery rooms. Among the San and Sabiny in Africa, men have not traditionally assisted in deliveries, but participants thought that they perhaps could be encouraged to.

Participants emphasised the need for genuine coordination, and warned of a tendency among some indigenous leaders to use donor jargon and development discourse in order to gain power. Conversely, participants identified a tendency among health system managers to use cultural differences as an excuse for inaction. The reluctance of indigenous people to avail themselves of biomedical services, for example, may not be cultural but may in fact have more to do with access and ability to pay.

Examples of promising interventions and practices

Indigenous Women's Houses (Mexico)

Action research in the Mexican state of Guerrero brought together indigenous women activists and university-based researchers, and led to the creation of the first 'Indigenous Women's House of Health'. This grew into a national network of indigenous women's houses funded by the federal government. These are spaces that support efforts to reduce gender-based violence and improve access to sexual and reproductive health services by combining training, counselling and advisory support with service provision. Training was carried out by national civil society organisations (CSOs) but was built on existing indigenous women's groups. The programme was considered a success in part because it benefited from long-term government funding and close collaboration with civil society organizations working on women's issues, and employed effective advocacy strategies.

Shared: Ana LOPEZ, Mexico, Alternativas y Capacidades

Reproductive health campaigns with minority ethnic groups (Vietnam)

A large number of ethnic minority groups live in the border provinces of northern Vietnam. Border towns have high rates of intravenous drug use and some of the highest rates of HIV in the country. Vietnam is tackling HIV/AIDS head on through widespread HIV testing and offering free antiretroviral medicines to those who test positive. While Vietnam's Ministry of Health is well organised, civil society is relatively inexperienced in dealing with a disease of epidemic proportions. Yet HIV-positive ethnic minority women have begun to organise themselves and work as a group with service providers, helping to improve care and support services. As a result, government health workers are better able to work with ethnic minority women. Women and their families now have full access to antiretroviral therapy through these groups. They can also access a range of other services including reproductive health exams provided by mobile service teams with indigenous women working with health staff to reduce language barriers and increase mutual trust.

Shared by: Tran Thu Thuy, Vietnam MCNV

Creation of safe spaces for women and girls among the Maasai (Kenya)

Safe spaces were created to give girls and women the security and privacy that they needed to freely discuss their sexual and reproductive health needs and concerns. These were places where girls could talk with their mothers and other women about issues such as female genital mutilation. Men, especially local leaders, played an important role because they ensured respect for the spaces. Other factors that contributed to the program's success included outside funding, training of men, training of local political and religious leaders, involvement of men in awareness raising and project implementation, and leadership by local Maasai.

Shared by: Anke VAN DER KWAAK, Holland, Royal Tropical Institute

Community health with the San people (Botswana)

In the sexual and reproductive health (SRH) programme with the San in Botswana, educational assistants from the community are trained in public health, while health workers receive additional training on the culture of the San people. The programme has created local ownership: The San are involved in planning and implementation of SRH activities and there is an exchange of knowledge with health staff and the San on SRH. As a result, there has been an increase in the number of San people accessing health services.

Shared by: Onkemetse Bhibo MARUPING, Botswana, Kuru Community Health Team

Increasing trust in facilities among the Sabiny people (Uganda)

A divide initially existed between the practitioners of traditional medicine and the health workers treating the Sabiny people. This began to change when one of the health providers embraced the positive aspects of traditional practices, creating an opportunity for others to learn about the benefits of Sabiny beliefs and birthing practices. There was initial distrust among Sabiny women, but when men started allowing women to be escorted to the health centres women began to use the services. There has been an increase in the number of pregnant women with complications using the health care facilities. The programme has worked because the health services adopted a continuum of care approach, adapted to the local cultural context, and because there was a mutual respect between traditional birth attendants and biomedical practitioners in the health system.

Shared by: Betty KWAGALA, Uganda, Makerere University

Use of media and mobile services with the Akha people (China, Thailand and Laos)

Historically, there have been few health services reaching the Akha people, tribes that populate the mountains in northern Thailand, Laos and China. As more men in Akha have travelled outside the region, the rate of STIs has begun to rise. To change behaviour, a public information campaign was launched in the Akha's local language with information and stories about the risks of sexually transmitted diseases. Biomedical health professionals in the three countries learned about the Akha culture. Mobile health teams focused on both prevention and treatment. These messages were acceptable to the Akha, unlike previous campaigns. Key factors in the success of this work were flexible outside donor support, local participation in the media production, training of local staff and decentralisation of drugs provision.

Shared by: Chris LYTTLETON, Australia, Macquarie University

Indicators of success

Participants agreed that in order to measure whether things are improving for indigenous people, there should be room for both qualitative and quantitative indicators. Ideally, local people would develop their own indicators, which will not necessarily be the same as those favoured by donor organisations.

Possible indicators of the extent to which community-based health services are addressing sexual and reproductive health, and the rights of indigenous and minority people might include:

- Availability of funding sources for health services over the long term (e.g., percentage of state budget allocation);
- Coverage of services specified according to a wide range of indicators;
- Diversity of services tailored to the local context (e.g., mobile services);
- Linkage of medical services with other complementary services, such as micro-credit, legal support and counselling;
- Adequate and effective representation of local community groups establishing health priorities, planning, management and evaluation;
- Effective referral systems within the biomedical health system and with indigenous healers;
- Documentation of programmes to show integration of indigenous knowledge into planning and other processes; and
- Capacity building both for service providers and for the local community.

Cross-Cutting Themes

Over the course of the conference, participants engaged in a systematic process of identifying important cross-cutting themes. These themes related both to issues that applied across continents and issues that ran between the initially-identified thematic areas of Gender and Sexual and Reproductive Health; Traditional Medical Knowledge and Intercultural Health Care; and Territory, Mobility and Access.

This work was carried out in three phases.
- Phase I involved creating a large mind map on which linkages between issues were drawn. (This map was continually revised and added to throughout the conference in order to build the fullest picture possible).
- Phase II involved identifying where on the map we knew of research and other programs or interventions already taking place. (These were identified with yellow Post-It notes.)
- Phase III involved the identification of projects that participants wanted to carry out in light of the observations above. (These were identified with pink Post-It notes.)

The original mapping indicated a number of important areas where participants felt that key issues have been insufficiently addressed by current research and policy efforts. These included:

Evidence and data on health inequities and health system performance: Lack of disaggregated health data is an obstacle to understanding health and overcoming accessibility challenges, which hinder agenda setting. An increasing number of countries take actions to increase universal health coverage to improve health and financial protection of poor and vulnerable populations. However the effects of UHC reforms on indigenous peoples access to health services are unknown. Most participants argued that it was important to be able to show health outcomes of interventions to facilitate learning. However, what indicators can and should be measured for aggregation when definitions of health differ between and within cultural contexts requires more reflection.

Recognition and documentation of indigenous healing practices: For indigenous healers, accreditation was another cross-cutting issue. This was seen as a double-edged sword that could both support and undermine traditional indigenous health practices. There is a need to improve knowledge about intellectual property (IP) mechanisms among indigenous peoples and to devote more thought on ethical issues including consent, 'biopiracy', and 'ethical imperialism'.

Governance: The governance of health systems and its relationship to health outcomes was another theme that was raised by all three groups. Most participants work directly with indigenous peoples at decentralised levels responding to the urgent need to build trust in local-level services, and have minimal interaction with national policy and state institutions. Linking experiences and lessons learned at the local level to the central state is important in order to improve the responsiveness of health systems.

Resources and economic incentives: The lack of human resources, inadequate health financing and conflicts over limited resources were recognised as major impediments. However, there is very little experience with applying health economics tools to indigenous health policy challenges. There is, for example, little if any comparative research on the cost-effectiveness of different national strategies to address human resource shortages. Meanwhile, mining and forestry is taking place on indigenous lands, and the resulting migration is disrupting indigenous peoples' relationships with the land. Deforestation threatens the loss of medicinal plant species that are valued by indigenous healers. Many are concerned about indigenous intellectual property theft by the biomedical industry. For indigenous healers, the preservation of the ecosystem is key to preserving both indigenous knowledge and protecting the medicinal plants they rely upon to treat patients. At the same time, these resources are a source of livelihoods. The ability to practice healing professionally is a key incentive in efforts to attract younger generations to acquire ancestral healing knowledge.

Patient choices and preferences: A common theme in all the sessions was that patients are intercultural and move easily between biomedical and indigenous systems. The conflict is between the health practitioners and the health systems. Indigenous patients' choices and preferences need to be taken into account when it comes to making changes to the health systems.

Conference participants developed the research agenda in stages. Participants were first asked to identify what interventions and issues they would like to pursue and to put these onto the map. These were initially clustered in to broad theme areas. Then through group work, the interventions and issues were crystallised into succinct research programme areas with a view to implement them in multiple countries.

FUTURE RESEARCH PROGRAMME AREAS

Individual ideas for research rooted in existing work

RESEARCH IDEA	PROPOSED STUDY LOCATION
Research on UHC and health financing methods for the provision of health care/health insurance to indigenous populations	Brazil, Thailand, India, Kenya
Health vulnerability action research	Greater Mekong region
Action research on valuing riverine communities' culture and promoting production and marketing networks for livelihood and social impact	Jaú Park, Brazilian Amazon
Intellectual property protection options and experiences to protect indigenous healers and prevent "biopiracy"	Global scope; cases from India Botswana, Brazil, Mexico, Mekong region
Research on sustainable responses to health and wellbeing of displaced indigenous people	Benet Uganda, Maasai Kenya, Kalimantan region Indonesia, Mexico, Brazil
Research on safe spaces for women and girls	Afar, Ethiopia, San, Botswana
Research on the Rarámuri health system and network creation	Wachochi, Mexico

RESEARCH IDEA	PROPOSED STUDY LOCATION
Research on how to make traditional medicine a viable livelihood for indigenous healers	Meghalaya, India, Botswana
Research on resource mobilisation for effective SRH practices among the San	Botswana
Development and documentation of indigenous health provision, and research on legal frameworks linking indigenous health providers and researchers	Mozambique
Research on innovative approaches to integrate indigenous and minority peoples cultural priorities into biomedical services	Benet, Uganda, Hmong, black and white Thai, Vietnam
Research on overcoming ethnocentric and hospital-centric attitudes among health professionals and development of methodologies for training health teams to work in intercultural contexts	Brazil
Research on understanding sexual and reproductive health among minority people	Afar and Gumuz, Ethiopia

RESEARCH IDEA	PROPOSED STUDY LOCATION	RESEARCH IDEA	PROPOSED STUDY LOCATION
Research and capacity building on successful strategies, roles and actions to generate more appropriate policies for indigenous people, particularly women	Mexico, Vietnam, India, Ethiopia	Research on Rarámuri and Khasi contraceptive methods and production of audio and other media resources to share this knowledge with communities and policy makers	Wachochi, Mexico, Meghalaya India
Action research to develop better indigenous health policies and training resources for government staff on indigenous representation and social accountability in health system governance	Acre and Rio Negro, Brazilian Amazon	Action research on minority groups' access to health services and promotion of government-to-government and government-to-private sector cooperation	Myanmar
Research on intercultural competence of health staff	Mekong sub–region	Research on birth attendance and construction of indigenous maternity units	Wachochi, Mexico
Analysis of disaggregated data to support lobbying on health issues for minority groups	Myanmar	Documentation of SRH best practices	Botswana
Action research on sustainable development of CBOs	Vietnam, Botswana	Research on what indigenous medical practitioners and communities consider to be good indicators	Global
Research on traditional highland diets to strengthen childhood nutrition with local resources	Wachochi, Mexico		

FUTURE RESEARCH PROGRAMME AREAS

Proposed joint research agendas

Three joint areas for research were identified and participants organised themselves into groups to develop a research agenda for each of these areas. Each group identified the overarching aim of the research, key questions and possible locations and partners.

Programme Area 1:
Policy, governance, rights and representation in health systems

The aim of this research is to arrive at a better understanding of the role of policy and governance in ensuring improved health outcomes for indigenous people. It is intended to identify strategies to allow health systems to adapt better to a rights-based framing of health issues by improving the representation of indigenous health service users.

Key questions include:
- What is the role of civil society in linking indigenous peoples with Universal Health coverage and other health policy development and implementation processes?
- What have the results been of Universal Health Coverage programs for indigenous peoples health status? Are data available to assess the results?
- How can health systems be integrated with indigenous governance structures and territories?
- What are the relations between traditional indigenous healers and traditional indigenous governance structures?
- What are the implications of indigenous governance structures for women and disadvantaged groups within indigenous and minority populations?
- How are indigenous peoples represented in health system governance, and by whom?
- What is the role of human rights-based approaches in ensuring health equity?

Possible locations and local partners include: Mexico (Instituto Nacional de Salud Publica, Women's Health Houses and other CSOs, municipal health service managers, traditional authorities); India (SPIKAP, IIPH, MLCU, State level policy makers, academics, indigenous traditional elites in Meghalaya and AP); Kenia (MOH, AMREF), Kachin State, Myanmar (Health Poverty Action Kachin people, CSOs, particularly youth groups); Brazil (MOH, Special Secretariat for Indigenous Health, Rio Negro, Acre indigenous health districts, and the Yanomami health district), Vietnam (MOH, Hanoi School for Public Health, Provincial health services), Ethiopia, Addis Ababa University, dept Sociology, AMREF.

Programme Area 2:
Intercultural practice and biomedical training

The aim of this research is to arrive at a better understanding of the conditions under which biomedical systems and traditional indigenous health systems can be mutually supportive.

Key questions include:
- What have the results been of efforts to preserve the intellectual property rights of indigenous health practitioners and to fight 'biopiracy'? What are the data that are available and accessible to assess the results? Have these findings been shared with traditional healers to allow them to make informed choices on sharing their knowledge and patenting their products?
- What expectations and perceptions do biomedical health service providers have of the rights and responsibilities of indigenous groups and of local communities to promote their individual and groups wellbeing?
- How can the intercultural competencies of biomedical practitioners be improved upon in medical and public health education?

Possible locations and partners include: Sierra Tarahumara, Mexico (government health services, and the Rarámuri communities, Instituto Nacional de Salud Publica); Sebi, Uganda (Makarere University, Benet Human Rights Group, traditional birth attendants (TBA), Benet, Sabiny and other communities to be determined); Dien Bien, Vietnam, (Ministry of Health, Hanoi School for Public health, SMS Dien Bien, Black Thai and Hmong communities); Meghalaya, India (IIPH, MLCU, SPIKAP, Primary Health Centres and the Khasi, Jaintia and Garo communities); Mozambique, PROMETRA Mozambique, Sub-Saharan Africa PROMETRA International, 26 affiliates in Africa, Brazil (MOH, Special Secretariat for Indigenous Health and the Yanomami health district); and the Greater Mekong border areas (district health services, NGOs and the Akha, Khmu and Dai communities).

Programme Area 3:
Indigenous people's health choices, provision, practices and knowledge

The aim of this research is to broaden our understanding of the health choices that indigenous people have, and why they make the choices they make. This is intended to help to inform the development of culturally sensitive health policy and provide an opportunity to develop concrete interventions with better practices.

Key questions include:
- How do people conceptualise and define health, illness and wellbeing?
- Where do people go when they feel sick, and why?
- What options, therapies and treatments are available?
- What are the factors that lead people to make choices and why do they choose a specific service? (This should take into account belief systems, economic factors, gender relations, expected outcomes, availability or knowledge of options, barriers to service and resource challenges, such as habitat destruction that results in the loss of medicinal plants.)

The research would primarily be qualitative. Action research would take place in one location in each country. While the participants in this group were based in Mozambique, Botswana and Ethiopia, it was anticipated that this work could be carried out across the TIMPHA network.

Further areas where research and interventions are necessary

In addition to the three cross-cutting research themes, and the specific projects that people were interested in pursuing, participants articulated a number of other possible areas for further research and/or interventions.
They included examining:

- Empowerment, participation, advocacy and engagement with civil society;
- Successes and failures of policies and practices to support indigenous intellectual property claims;
- Tensions between individual rights-based approaches and collective, familial or community-based decision-making about health, and the implications for informed consent;
- Land conflicts, displacement and indigenous health status;
- Livelihoods, forestry and traditional medicine;
- The potential of plural (parallel and integrated) health systems to promote health and protect culture and local knowledge; and
- The documentation of indigenous knowledge and the development of shared research methods.

A GLOBAL NETWORK ON INDIGENOUS AND MINORITY PEOPLES HEALTH

One of the main outcomes of the Bellagio conference was the creation of a global network. Participants agreed that this network would play an important role in mobilising resources and providing support for the research work and interventions identified during the conference. It will also help articulate the engagement of policy makers at the global level and promote additional opportunities for learning and exchanges across regions.

What will the network do and what needs to be organised?

In the final plenary, participants explored the sorts of things that they thought a network might be useful for, what was needed to make it work, and what they might be able to offer. A brainstorming process identified the following areas for network member collaboration:

- Develop curricula, capacity building and training to enhance indigenous and minority peoples' health and wellbeing;
- Provide support and advice on policy development;
- Conduct comparative policy research;
- Improve the protection of indigenous and minority peoples' knowledge on prevention, treatment and care;
- Advise on ethics of research conducted among indigenous and minority peoples;
- Facilitate action research;
- Share tools and methods;
- Mobilise resources;
- Conduct advocacy work; and
- Facilitate constructive engagement and dialogue of indigenous and minority peoples with biomedical practitioners and biomedical organisations.

Participants then identified the following elements as being necessary to allow the network to function effectively:

- Working committees
- Website/newsletter/email list/Facebook group
- Ground rules/memorandums of understanding
- Membership rolls
- Reports
- Secretariat

To get the network off the ground, it was decided that there was a need to recruit someone to run the Secretariat for a limited amount of time. Pauline and Anke agreed that the Secretariat could be hosted by KIT for a maximum of one year, after which the aim would be to transfer the Secretariat to a partner institution based somewhere in the Global South.

In the plenary discussion, participants came up with a number of additional suggestions and questions relating to the network. These included the conclusion that 'the network shouldn't be about the network' but rather that it should be linked to activities that generate results, and should achieve some concrete results before being expanded more widely.

The need to broaden the core of the network's organising beyond KIT and IDS was also mentioned. Several people signalled that their institutions might be amenable but this needs to be followed up within organisations to secure institutional support.

Participants also asked whether we would want to bring in health experiences from other areas like the US and Australia. Different opinions were expressed here, but the consensus seemed to be to start with Africa, Asia, and Latin America where indigenous voices are underrepresented, and bring in indigenous voices from other areas later.

Participants proposed a number of possible names for the network. Following a voting process, the network was formally named **the Indigenous and Minority Peoples Health Alliance (TIMPHA)**.

Next steps:
Participants from the Rockefeller Foundation and the Wellcome Trust agreed to explore with IDS and KIT what funding opportunities might be available to develop the network. The organisers agreed to draft a one-page statement about the network to take to potential partners, and to work with network members on plans for a follow-up meeting. The one-page summary was drafted after the workshop and sent out to participants for discussion and approval in July 2012. It can be found in Annex 1.

ANNEX 1
THE INDIGENOUS AND MINORITY PEOPLES HEALTH ALLIANCE (TIMPHA)

Mission and aims:

The Indigenous and Minority Peoples Health Alliance was founded at the Rockefeller Bellagio Centre in June 2012. Researchers from across the world came together to explore and debate indigenous health issues and to plan a coordinated response to the health inequities experienced by indigenous and minority peoples. The mission of TIMPHA is to transform health systems to serve the wellbeing and health of indigenous and minority peoples and improve universal health coverage in Africa, Asia and Latin America. We aim to maintain and strengthen the capacity of our members through information sharing, capacity building and policy dialogue.

Our working principles:

- Promoting meaningful engagement of indigenous peoples in transforming health systems;
- Promotion of equity and fairness;
- Transparency and accountability;
- Change informed by evidence;
- Promotion of locally and culturally informed ownership;
- Strengthening effective and (cost) efficient services;
- Responsiveness to people's (changing) needs; and
- Focus on Africa, Asia and South-Central Americas.

Joint activities of members can include:
- Curriculum development, capacity building and training;
- Advocacy, policy support and advice;
- Conduct and facilitate comparative policy research and action research;
- Support for the protection of indigenous and minority peoples' knowledge;
- Linking and brokering with other organisations and individuals with an interest in indigenous health;
- Pursuing opportunities for joint activities such as interventions, research and events;

- Facilitation of constructive engagement and dialogue of indigenous and minority peoples with biomedical approaches;
- Knowledge exchange around funding, tools and methods, and other opportunities.

Members:

Our founding members are a diverse group of 19 researchers, policy makers, health practitioners and activists living and working in Central and South America, the Asia-Pacific region and Africa, and brought together through their personal and institutional commitment to improve the wellbeing and health of indigenous and minority peoples.

Membership:

Membership may be institutional (organisations) or individual. Members are asked to make a one-year commitment. Those interested should submit a written request for membership that expresses their endorsement of the network's mission and working principles. The request should also articulate what the organisation or individual wishes to contribute. Please fill out a membership form and send a short CV or description of your organisation, highlighting your work in the area of indigenous health to the address below. While several services are for members only, other activities and benefits are open to non-members as well. This reflects our philosophy of forming an inclusive network for information-sharing, expertise exchange and increased collaboration.

TIMPHA's Secretariat rotates. It is currently at the Royal Tropical Institute based in the Netherlands and will be moved to one of the Southern members in 2013.

Contact address: The Indigenous and Minority Peoples Health Alliance (TIMPHA):
P.O. Box 95001, 1090 HA Amsterdam, Netherlands

ANNEX 2
CONFERENCE AGENDA

DAY ONE

9.00 - 10.30	**Opening and welcome (10 min)** **Reporter. Setting the scene and introduction (20 min)** • indigenous and minority peoples, accountable health systems and cultural specificities • themes • aims and structure of the workshop • expected outputs **Introduction of participants** 2 minute pitch in pairs by all: name, background, particular interest in this theme and expectations. Setting the **ground rules** for the workshop etc
10.45	TEA BREAK
11.00 - 13.00	**Mind mapping exercise of topics related to the region** Review themes
13.00	LUNCH
14.00 - 16.00	**Simultaneous discussion on three issues** Theme 1: Territory, mobility and access to services Theme 2: Traditional medical knowledge and intercultural health care Theme 3: Gender and sexual and reproductive health **Group work:** • Sharing and discussion of underlying assumptions and mechanisms and contextual differences • Elaboration on cross-cutting thematic areas • Reflections on rights and realities
16.00	TEA BREAK
16.15 - 17.30	**Continued group work** Reflections and reaction by resource persons
	Reflections on the day

DAY TWO

8.30 - 9.00	**Aims of the day, announcements** Presentation of key points in each group by rapporteur, Suggestions for other groups, and issues parked on day 1
9.00 - 11.00	**Continued group work on chosen themes** Reflections and reaction by resource persons • Sharing and discussion of underlying assumptions, mechanisms and contextual differences • Elaboration on cross-cutting thematic areas • Listing of successful inclusive/ accountable health interventions
11.00	TEA BREAK
11.30 - 13.00	**Continued group work on chosen themes**
13.00	LUNCH
14.00 - 15.30	**Feedback on group work** 30 min per group 20 min feedback 5 min exchange with neighbour 5 min plenary pop-ups
15.30 - 16.00	TEABREAK
16.00 - 17.15	**Plenary group discussions** Reflections and reaction by resource persons
17.15 - 17.30	**Reflections on the day**

DAY THREE

8.30 - 8.45	**Aims of the day, announcements**
9.00 - 11.00	Discussion with the Rockefeller Foundation and the Wellcome Trust
10.00 - 11.00	**Plenary discussion:** How to translate 3 themes into a joint transnational research agenda • how to harmonise development, poverty, rights discourses • how to put indigenous and minority groups in the middle of such an agenda • selection of study sites and key research questions
11.00	TEA BREAK
11.30 - 13.00	**Group work:** Finalizing one pager on sites, themes, research questions
13.00	LUNCH
14.00 - 16.00	**Building a global network** **Planning:** way forwards, decisions with milestones
16.00	TEA BREAK
16.15 - 17.30	**Reflections on the day**
17.30	**Closure**

ANNEX 3
LIST OF PARTICIPANTS

NAME	EMAIL	INSTITUTION	NATIONALITY
LATIN AMERICA			
Mr. Alex SHANKLAND	a.shankland@ids.ac.uk	IDS	UK
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ASIA			
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NAME	EMAIL	INSTITUTION	NATIONALITY
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