

Every Mother Counts

Reporting health
data by ethnicity

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Health Poverty Action works to strengthen poor and marginalised people in their struggle for health.

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Summary

This report examines the lack of statistical information around the health outcomes of women from indigenous and other marginalised ethnic and cultural groups within developing countries.

Increased access to information on health and poverty has the potential to improve understanding in order to address the health inequalities faced by marginalised groups. Reliable and disaggregated data can ensure that no sections of society are overlooked in the efforts to achieve the Millennium Development Goals (MDGs) and whatever goals are set in a new development framework beyond 2015.

At present there is a dearth of reliable health data broken down by ethnicityⁱ in the poorest countries and the consequences for women from marginalised groups are potentially catastrophic.

This report is part of our 'Mothers on the Margins' campaign to improve indigenous women's maternal health but goes beyond it to call for disaggregated data for all indigenous people and those from cultural minorities such as pastoralist communities in Africa.

Across the world Health Poverty Action works in partnership with poor and marginalised communities – such as cultural minorities and indigenous peoples – enabling them to access culturally appropriate, local and affordable health care. Citing examples from some of the countries where we work – Ethiopia, Namibia, Laos and Guatemala – this report explains why the lack of data matters and considers the extent to which health data is, and is not, currently broken down within national health statistics and major international health surveys.

It goes on to explore the barriers to breaking down health data by ethnicity, and how these may be overcome. Finally we make recommendations for action by governments, international institutions, donors and NGOs.

Unless breaking down health data by ethnicity becomes the norm, the true health situation of some of the world's most marginalised people will continue to be dangerously concealed. There can be no more delay. It is time for the most marginalised communities to be counted.

i. Ethnicity is used throughout this report as shorthand for the category of minorities we are describing – which include ethnic groups but also groups such as indigenous people and pastoralists who might distinguish themselves more by their culture than their ethnicity. Of course this begs the question of how to best disaggregate data if ethnicity is not the appropriate category in every case. The appropriate sub-groups should be determined through a participatory process at the national level in each country.

1. Introduction

We have nurses who speak the Mayan language, but ...when they get in uniform, they don't want to speak their maternal language, and the poor people only speak the Mayan language. This is our reality. Language becomes a barrier and a form of discrimination.

Community leader, Guatemala

Maternal health provides a pertinent example of how different health outcomes can be for indigenous people and those from cultural or ethnic minorities. Every year approximately 287,000 women die before, during or just after childbirth; 99 per cent of these women are in developing countries.¹ These figures, while unacceptable, are a major improvement on the 1990 level of over 543,000 women dying in pregnancy and childbirth. But this decrease masks the fact that within developing countries some women are at much more risk than others.

Indigenous women, and those from other cultural and ethnic minorities, are more likely to die or face complications related to pregnancy.² Maternal and child mortality rates can be twice as high in indigenous communities as the national averages.³ These women can face particular discrimination and difficulties when accessing health services, which puts them at higher risk of death or disability.

The Millennium Development Goals

The plight of women from indigenous and marginalised ethnic and cultural groups is just one example of the special attention that needs to be paid to the health of particularly marginalised communities like indigenous people and pastoralists, in the context of the Millennium Development Goals (MDGs) and now within discussions around a new framework to replace the MDGs after 2015.

Monitoring progress towards the MDGs and any new set of goals means acquiring data to find out what is happening, where, and to whom. Most countries monitor their progress towards meeting MDG targets through aggregate data, meaning that the data uses averages drawn from the whole population. This masks the variations in health levels experienced by different ethnic groups within each country, making it impossible to see which communities are most at risk. The MDGs' numbers-based targets may even encourage development efforts to concentrate on those who are the easiest and cheapest to reach, while leaving the poorest unaccounted for.

Maternal mortality, for example, could be languishing among marginalised communities during periods when a country as a whole may appear to be making steady progress.⁴ The experience from Health Poverty Action's programmes suggests this is the case, but the evidence is largely lacking. To fully understand the health situation of the whole population of a country we must disaggregate data.

There has been increasing recognition of the importance of data disaggregation in recent years. The 2010 MDGs Summit Declaration highlighted the importance of inequalities within countries and noted the need for all countries to have 'adequate, timely, reliable and disaggregated data' which can be used to improve policies and programmes. It called for statistical capacity-building in developing countries.⁵ Yet while the Declaration referenced the particular need to break down data by gender and age, ethnicity went unmentioned.

Likewise, recent discussions about a new international framework to replace the MDGs have also repeatedly mentioned the importance of focusing on the most vulnerable and on measurement. But no specific recommendations have yet emerged, and such discussions usually come with provisos about recognising the resource and capacity constraints on countries in terms of data collection and analysis.

In terms of what is collected now, the breakdown of health data by ethnicity is still not routine in the majority of health surveys. But if the international community is serious about saving the lives of vulnerable people across all sections of society, then reliable data, broken down by ethnic groups, must be an essential part of monitoring progress. For donors keen to improve the measurement of their impact, encouraging and supporting the collection of such data must become a priority so that the effectiveness of health interventions can be accurately assessed.

“It was a really bad experience; I thought I was going to die.”

When Ana Luisa went to give birth at a clinic in Ayacucho, Peru, the midwife she had seen before was away and another member of staff, who didn't speak her native Quechan, would be filling in. She felt too intimidated to stay at the clinic and gave birth on the roadside on the way home.

Women in rural Ayacucho face some of the country's highest maternal death rates. But through Health Poverty Action's programme of introducing culturally appropriate facilities at health clinics, like allowing women to squat rather than lie down, and having health staff speak the local language, the number of women using clinics soared from only 6 per cent in 1999 to 83 per cent in 2007.

■ Before Health Poverty Action began working with pastoralist women in the Bale lowlands of Ethiopia in 2009, just 0.4 per cent of them delivered their babies at a health facility. Nomadic pastoralists are often unable to access basic services such as health care because of living in remote areas, migrating regularly with their livestock and having distinct cultures and traditions. In 2011, 15 per cent of pregnancies seen by trained Traditional Birth Attendants were referred to health facilities, as a result of making services accessible and culturally appropriate for pastoralists and creating referral links between Traditional Birth Attendants, who speak the local language, and government Health Extension Workers.⁶

A call to action

While challenges exist around the collection and analysis of ethnically disaggregated data, we argue that these can and must be overcome – by raising awareness of the benefits for effective policy-making, sharing good practice and building technical expertise to strengthen existing country-level mechanisms to collect and analyse data.

As the international community enters the final stages of the 15 year effort to meet the goals set at the Millennium, and meanwhile looks ahead to what comes next, steps must be taken to ensure that all data that monitors progress towards international poverty and health goals is disaggregated by ethnicity. In particular, the indicators set to measure progress in the post-2015 framework must be broken down by ethnic and cultural group. In the short term,

the Independent Expert Review Group and those involved in implementing the Every Woman Every Child strategy must also promote such disaggregation for maternal and child health.

As we outline, a strong precedent would be set if the world's major international health surveys were routinely to break down health data by ethnicity and to make sure that the findings are published.

The measures we set out would provide credible information to assess the effectiveness of health interventions and to feed into national and international mechanisms to hold governments, multilateral organisations and other donors to account.

It is crucial to act now to ensure that the barriers to good health of some of the world's most vulnerable people are removed.

Cultural and ethnic barriers to women exercising their right to maternal health

Discrimination – Women from marginalised ethnic or cultural groups such as indigenous peoples and pastoralists face multiple layers of discrimination based on being poor, female, and indigenous or from an ethnic or cultural minority. Women from these communities who attempt to access health care may be talked down to or treated harshly by health workers – and these experiences subsequently discourage them from accessing skilled health care when they are pregnant and in need of help.

Cultural barriers – Many indigenous people and those from ethnic minorities do not speak the language spoken by the majority of the population in their countries, which means they often do not understand health care workers and have difficulty communicating with them. Health care may be provided in a setting and in ways that are totally foreign to these women, such as asking them to wear a hospital gown or involving male doctors in delivery. This makes the experience frightening and humiliating, and puts many women off seeking the help that they need.

Access to health care – Indigenous and pastoralist women often lack access to health centres because the centres are based too far away and transport to them is difficult, or because the centres charge fees they cannot afford to pay. These barriers of course affect other remote communities as well.

Harmful practices – In some communities, certain practices can cause pregnant women harm or even death. For example, in some parts of Ethiopia, if a woman falls pregnant outside of marriage her abdomen may be heavily massaged to induce an abortion. Coupled with a lack of access to health care, these sorts of practices can result in death or serious injury.

Lack of voice – Indigenous and pastoralist women often lack a voice and this manifests itself in different ways – from being able to make decisions about their own health or about spending money, to having a political voice at the local, regional or national level. Without a voice, changes will not be made to address the issue of women dying unnecessarily before, during, or just after childbirth.

2. Why disaggregation by ethnicity matters

Identifying variations in health outcomes

A detailed breakdown of health data enables researchers to identify the variations in health outcomes experienced by different socio-economic groups, including ethnic groups. The data may reveal consistently poor health outcomes for individual ethnic groups, for example, or it may show that some groups have advantages in one area but not another.

Adding a variable such as gender into the analysis can reveal the combined effects of gender and ethnicity for particular health outcomes, with the potential to shine a light on the interaction of two forms of social exclusion. For example, being both a woman and from an indigenous community might confer a greater health disadvantage than being an indigenous male, or being a woman of a more advantaged ethnic group.

A tool for improving health

At a national level the limited amount of disaggregation of data that is carried out often reflects the fact that most countries have not traditionally prioritised equality in health coverage or outcomes. However, there is strong evidence that the detailed breakdown of data by particular variables can help improve the design and evaluation of health programmes and policy, and can support country-level advocacy on health issues.

For instance, research carried out in Bangladesh in 1982 revealed that the mortality rate for girls was up to 21 times higher than for boys, depending on the educational level of their parents. Civil society groups then used the data as a spur to action. They campaigned for women's rights, enrolled girls in schools, and increased access to health care. By 1996 the mortality gap had significantly reduced, in part because of these activities. Similarly, adding the collection of health data to a nationwide household survey on living conditions in Chile (CASEN or *Encuesta de Caracterización Socioeconómica Nacional*) resulted in policy reforms to address health inequities.⁷

Most health surveys, whether national or international, collect and break down data according to factors such as age, gender, wealth quintile, and geographic

location. While the value of breaking down health data by gender is particularly widely recognised, the disaggregation of health statistics by ethnicity is hugely important for equity. However, most surveys do not yet undertake disaggregation in this way.

Proponents

There are many authoritative supporters of the disaggregation of health data by ethnicity. A commitment to obtaining information about the health of indigenous people was made by the World Health Assembly (WHA) back in 2001. The Assembly resolved to:

collaborate with partners in health and development for protection and promotion of the right of the world's indigenous people to enjoyment of the highest attainable standard of health as set out in the WHO Constitution, including through the use of accurate and up-to-date information on indigenous health status.⁸

A decade on, the World Health Organization (WHO) says:

Statistical data on the health status of indigenous peoples is scarce. This is especially notable for indigenous peoples in Africa, Asia and eastern Europe. To bridge this information gap, it is important that data is disaggregated based on variables relevant to indigenous peoples such as ethnicity, cultural and tribal affiliation, language and/or geography.⁹

It notes that with improved data, action can then be taken to ensure access to culturally appropriate health care, as well as safe water, housing and health-related education.

The United Nations' 'State of the World's Indigenous Peoples Report, 2010' highlights that the absence of such data inevitably acts as a brake on the effectiveness of health interventions. It states:

...because indigenous peoples are essentially invisible in the data collection of many international agencies and in most national censuses, the disparities in their health situation as compared to other groups continue to be obscured.

The lack of data means ongoing shortcomings in plans, programmes and policies that seek to improve global health including efforts to achieve the MDGs, which are based on averages instead of disaggregated data.¹⁰



Similarly, the Pan American Health Organization notes that:

the lack of vital statistics or breakdown by ethnic groups, gender, and age makes the generation of policies and managerial processes based on evidence more difficult, which, in turn, jeopardizes the formulation of priorities and appropriate monitoring and evaluation systems for indigenous populations.¹¹

It goes on:

Currently, the assessment of progress toward the MDGs is based on averages but not disaggregated data; the progress (or lack thereof) of indigenous populations is, therefore, lost in the calculations.

Another supportive voice is the UK Department for International Development. Its current 'Framework for Results' for improving reproductive, maternal and newborn health states:

Disaggregated data, that tracks changes in the lives of poor and marginalised groups, is important. Analysis of who has poor reproductive, maternal and newborn health, and why, is critical.¹²

It comments that 'inequality in access and use is markedly greater for reproductive, maternal and newborn interventions than for other health interventions'. It further notes that stigma and discrimination can exclude women and girls from services, and can significantly affect the quality of the health care they receive.¹³

3. Current practices in the collection of health data

Data capture at the national level

Almost every country has some form of health information system, often collecting information through national statistics bodies and ministries of health. However, in many cases these systems do not function well.

In the world's poorest countries, vital registration data (the registration of births and deaths) and health services data are either lacking, or are highly unrepresentative of the most excluded communities, such as indigenous groups and other marginalised ethnic and cultural groups.¹⁴ Where health information is captured, it can often be recorded inaccurately. A further complication is that non-state providers are the main source of health care in many countries and integrating data from public and private health care providers is often a serious challenge.

What often drives the timing and content of data capture at a national level are the reporting requirements of donors – tracking the prevalence of particular infections or in monitoring the uptake of immunisation programmes, for example. The short term demands of different donors can mean health information is fragmented, undermining the establishment of central, unified national systems.

Initiatives such as the Health Metrics Network, set up in 2005 and based at the WHO, demonstrate recognition of the scale of the problem. The Network aims to galvanise international efforts to improve health information by providing technical and financial support.

International surveys

There are two main international surveys that collect data on health in middle- and low-income countries. These are considered to be more robust than national data from developing countries.

The Demographic and Health Survey (DHS) – A household survey funded by USAID, which has been carried out in over 85 countries since 1984. The standard survey is repeated every five years, with sample sizes usually between 5,000 and 30,000 households. Data may be collected by public or private bodies – often national statistics agencies, Ministries of Health or family planning organisations.

The Multiple Indicator Cluster Survey (MICS) – Funded by UNICEF, this household survey began in 1995 and has been carried out every five years in up to 65 countries. It involves a household survey, a women's survey and a survey of children under five.¹⁵ A fourth round is currently underway, and surveys will now be carried out every three years. MICS surveys are usually carried out by government organisations, supported by UNICEF and other partners.

UNICEF and the DHS programme are considered authorities in the field of health data collection. They work together to make sure that the data are comparable across countries, to harmonise the questions asked, and to avoid any duplication of effort.

Both surveys cover a range of health and socio-economic statistics, including child and maternal health, as well as several other Millennium Development Goal (MDG) indicators.¹⁶ As a result the MICS and DHS have become important sources of data for monitoring the progress towards the MDGs.

Data is mainly disaggregated by:

- region
- sex
- educational background
- wealth
- rural or urban residence.

Both the MICS and DHS provide governments with the option to include questions on ethnicity, or to use proxy measures such as religion or language. In the MICS most governments have chosen not to do this.¹⁷ In the third round of MICS (2005-6), just 17 countries collected data disaggregated by ethnicity, language and/or religion out of a total of more than 50 countries.¹⁸

For example:

- Ethnicity data was collected by countries including Gambia, Vietnam and Guyana. It is worth noting, however, that Vietnam only provided the options of 'Kinh/ Chinese' or 'Other'.
- Sierra Leone collected data on the religion of the head of the household, but not data on language or ethnicity.
- Laos collected data on the language of the head of the household, but not religion or ethnicity.

The DHS survey varies from one country to another in whether or not ethnicity is recorded. A 2009 research paper found that 55 of the 77 countries covered by that point had included an 'ethnic' variable.¹⁹ However, whether or not data on ethnicity is collected, the published reports often fail to make use of it to break down health indicators by ethnicity. For example:

- Ethiopia's 2011 survey included questions on ethnicity and religion, but did not use these in its analysis of health outcomes (see case study below).
- In Namibia the 2006-7 DHS survey reports on the proportion of Khoe-San speakers in the population in a section on population characteristics, but it does not analyse language against any health indicators. (See case study on page 19).
- Rwanda's 2005 survey collected information about respondents' religion, but only used this to analyse data on circumcision.

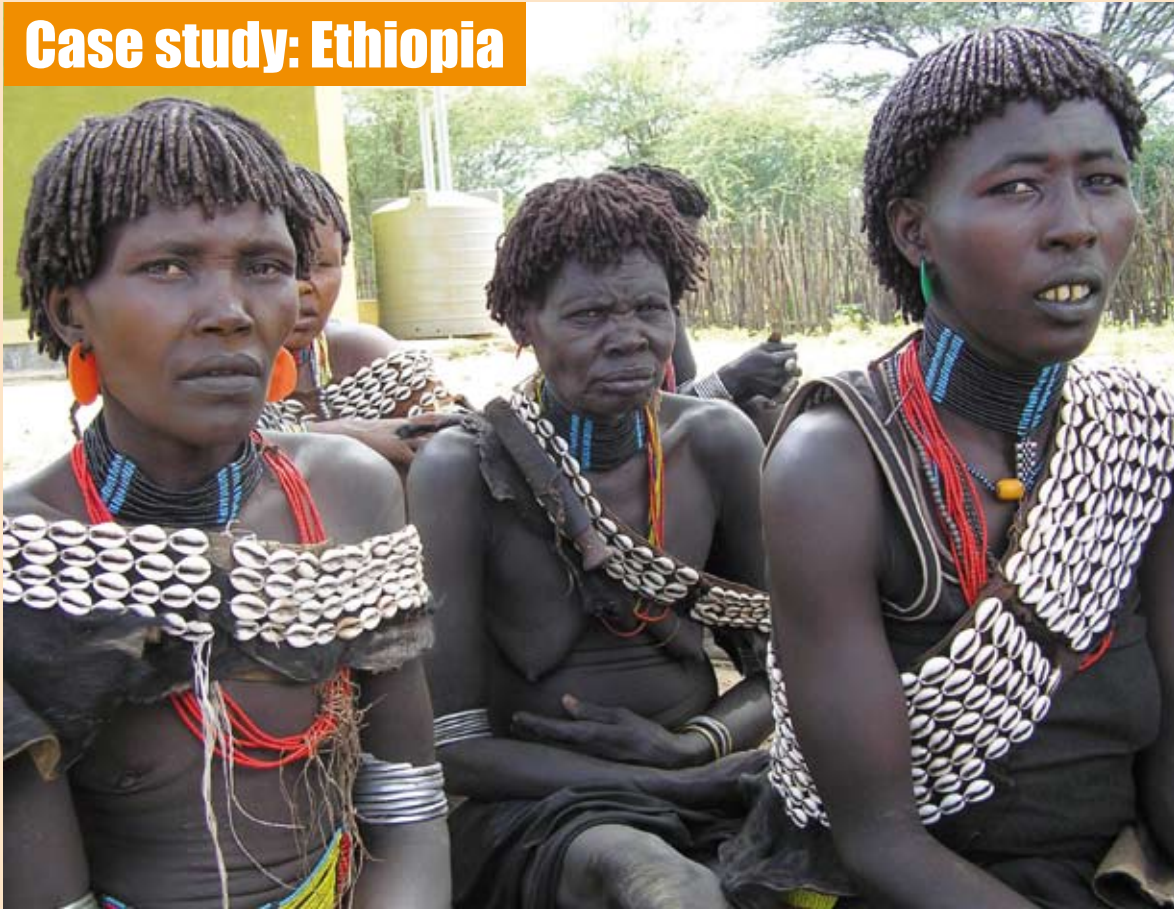
In each of these cases, the data collected on ethnicity is, at least to an extent, being wasted. It could instead be analysed to see how health outcomes vary by ethnicity.

Proxy measures

Region or language can be proxy measures of ethnicity for researchers trying to examine the health outcomes of indigenous or marginalised ethnic groups. While this is an improvement on aggregate data there are certain problems. For example, a language once closely related to a particular ethnic identity may be in decline following the urbanisation of a community, or it may fall out of use if the marginalised group associate it with discrimination and stigma. Likewise, region may not be a useful proxy if ethnic groups are widely scattered amongst the majority population.

Another issue is that smaller communities may find that the only category available to record their status is the one labelled 'Other' – once again concealing the disparities in health outcomes between different ethnic communities. Nevertheless, any survey design would have to take practicality into account. A participatory process would help to identify which categories surveys should capture, and donors should encourage the inclusion of particularly marginalised groups to guard against their continued invisibility.

Case study: Ethiopia



Analysis of health data shows that maternal and child health indicators vary considerably by region. This suggests differing access according to ethnic and cultural group which should be more accurately monitored.

Ethiopia has one of the world's highest maternal mortality ratios – alongside one of the world's lowest health spending per person.²⁰ The statistics are stark. Across the country as a whole, 676 mothers die for every 100,000 live births. About 9 out of 10 births are not attended by skilled health workers.²¹ But these averages obscure significant variations within the population, such as among cultural minorities like pastoralists. The country is home to more than 80 ethnic groups, which vary in population size from more than 26 million people to fewer than 100.²²

There are approximately 12-15 million people belonging to 29 different ethnic groups in the pastoral regions of Ethiopia.²³ Ethiopia's pastoralists are dependent on nomadic livestock production, and their lifestyle means they are often isolated from government services and support. Many pastoralist groups have low social status due to their distinct cultures and traditions.

Obstacles to accessing health care

Pastoralist communities face particular obstacles in accessing health care and other public services. Local health facilities are often under-resourced, lacking trained health workers, adequate supplies, and safe water, while the absence of public and private transport systems can make it difficult or impossible for pregnant women to reach these facilities in the first place. In maternal healthcare these factors can be a question of life or death. A complicated labour, a haemorrhage or an unsafe abortion, for example, can be fatal. With little contact with formal health services, misconceptions about vital health issues, such as how HIV can spread, are common.

Large parts of the country experience chronic and periodic food insecurity, worsened in recent years by hikes in food and fertiliser prices. Across the country around a third of under-fives are judged to be malnourished.²⁴ In addition many pastoralists have found their livelihoods under pressure because development initiatives and systems of land-use planning have failed to take full account of the needs of nomadic pastoralists.

Recent years have seen some positive steps, however, with comprehensive development interventions for pastoral communities being funded by the government and by donors such as USAID, focusing on the water sector and on livestock development for example. Pastoralist needs are better reflected in Ethiopia's most recent World Bank Poverty Reduction Strategy Paper. The Government of Ethiopia has established the Ministry of Federal Affairs (MoFA), which deals with the emerging regions, of which the pastoral regions are key. Furthermore, government development policies and programmes have started to be sensitive to pastoralism. The new Pastoral Development Policy and the establishment of a Pastoral Affairs Standing Committee (PASC) within the House of Peoples Representatives of the Ethiopian Parliament are among the positive indications that the government is paying attention to pastoralism.

In terms of health services, the Federal Ministry of Health has taken some measures to provide prioritised and specialised services to pastoralist communities, with a specific Pastoralist Director responsible for Health Promotion and Disease Prevention. Furthermore, political representation is improving. Regions with large pastoralist populations are increasingly seeing pastoralists achieving positions at higher government levels as a result of the government's decentralisation programme.²⁵

The 2011 Demographic Health Survey²⁶

Ethiopia's Demographic Health Survey of 2011 included questions on respondents' ethnicity: an overview of the nine major ethnic groups plus a broad 'other' category is given at the start of the survey, but ethnicity is only collected for the background data, it is not used in the analysis. Data is not collected on whether respondents are pastoralists or not. The full data was disaggregated on the basis of age, region, education, wealth quintile, sex, and rural or urban residence.

However, with pastoralists concentrated in particular regions, such as Afar and Somali, the breakdown of health data by regions and sub-regions can provide a useful picture of the health situation of pastoralists. The 2011 DHS data indicates that maternal health and other socio-economic indicators vary more by region than by any other characteristic, such as wealth quintile or education level.

For example:

	Women's use of any form of contraception	Under five mortality rate (deaths per 1000 live births)
National average	29%	88
Afar region	9.5%	127
Somali region	4%	122

These rough proxies for concentrated pastoralist populations highlight major variations and indicate that disaggregation of existing and future DHS data on the basis of major ethnic/ cultural groups (including pastoralists) would offer critically important material for formulating equitable health policy. Such data could provide valuable insights into the circumstances of each group and could inform more targeted efforts to address their particular health needs.

Case study: Laos



Breaking down health data by linguistic group has revealed important variations in the health care accessed by pregnant women.

Laos is one of the world's least developed countries, situated between Thailand and Vietnam in South East Asia. Despite a fall in numbers of people living in poverty, around two thirds of its people live on under \$2 per day²⁷ and inequality has risen over the past ten years.²⁸

Although Laos seems set to meet some of the Millennium Development Goals, it is unlikely to reach targets on improving maternal health.²⁹ Its maternal mortality rate remains one of the highest in South East Asia despite some progress. Around a quarter of women do not seek antenatal care, and only 37 per cent of deliveries were taking place with a trained birth attendant when surveyed in 2011.³⁰

Ethnic diversity

Laos is incredibly diverse. Its 2005 national census categorised the population into 49 distinct ethnic groups, but there are over 240 distinct ethno-linguistic groups in the country altogether. The ethnic Lao comprise 55 per cent of the total population and dominate the country both politically and economically. Ethnic Lao live mainly in the lowlands while most ethnic minorities live in the remote highland areas, where they experience major health and social challenges.

Aggregate national statistics – such as for skilled attendance during childbirth and for maternal mortality – conceal the significantly higher health risks faced by women from ethnic minority groups during pregnancy and childbirth. For example in the southern Attapeu province, home to many ethnic minority groups, only 15 per cent of births are attended by a skilled professional compared to the national average of 37 per cent, and less than half of women have at least one antenatal visit, compared to 71% nationally.³¹ Remote villages often become cut off during the rainy season, preventing women in these areas from reaching health clinics and meaning they often give birth in unsafe conditions without skilled birth attendants. Villagers also have insufficient food for over half the year, affecting women and children's nutrition and thus their wider health. Cultural differences also mean that many women from ethnic groups are reluctant to access formal health services.

Disaggregation of health data by language

The 2006 Multiple Indicator Cluster Survey (MICS)³² is the only survey so far to have collected health data on ethnicity in Laos and to break that data down by language. The survey was conducted by Lao government departments in collaboration with UNICEF and was the third MICS survey to be carried out. For the first time it asked households questions on language, ethnic group and religion.

However the survey results were only disaggregated by language, with the mother tongue of the household head used as a proxy indicator for ethnicity. Respondents were classified into four language groups: Lao, Hmong, Khmou and 'other'. The three principal language categories are based on the three largest ethnic groups.³³ The 'other' group (making up 12 per cent of the respondents) included smaller and more marginalised ethnic minority groups.

The MICS results show dramatic differences between maternal health indicators for women from different ethno-linguistic groupings:

Language spoken by head of household	Receive antenatal care	Give birth in a health facility
Lao	49%	27%
Khmou	32%	8%
Hmong	10%	6%
'Other'	18%	4%

Another striking contrast is shown in the data collected on whether women give birth with a trained birth attendant:

Language spoken by head of household	Give birth with assistance of skilled personnel
Lao	32%
'Other'	5%

The variations across linguistic groups can be compared to variations across wealth quintiles. For example, looking at who receives antenatal care, the MICS suggests that women from households where the head speaks Hmong are significantly worse off than even those from the poorest wealth quintile, where 16 per cent receive antenatal care.

For many of the indicators, the worst performing group is that where the household head speaks 'other' languages. This would suggest that ethnicity is a stronger marker of marginalisation than educational background, region, wealth quintile and rural or urban residence.

What could be improved?

Further disaggregation within the 'other' languages group could clearly offer more specific insights into the health challenges faced by women from different ethnic groups. But the use of the mother tongue of the head of the household is only a proxy. Future surveys could explore more precise ways to identify respondents' ethnic group, while taking care to ensure that data is collected and broken down in such a way that comparisons over time will become possible.

4. Overcoming the barriers to obtaining and using ethnically disaggregated data

Several overlapping factors help to explain why breaking down health data by ethnicity is yet to become the norm. These include the lack of capacity at a country level, reluctance from decision-makers, and issues around the right to self-identification and the right to privacy.

Each of these challenges can be addressed or mitigated if the right support and safeguards are put into place. An important step is to ensure that people from indigenous and other marginalised ethnic and cultural groups are themselves fully involved at each stage in the collection, analysis and dissemination of the information.

4.1 Capacity and methodological challenges

The basic information needed to measure and address health inequalities is reliable, long term and representative data which can link health indicators with other indicators, such as socio-economic group, ethnicity, gender or geographical area. Many countries simply do not have this data.³⁴ As noted above (Section 3), national health information systems may be seriously hampered by a failure to prioritise vital registration systems, and by limited capacity and fragmented information. This can mean that basic health information is often incomplete, of low quality or out of date.

Limited technical expertise at a national level can also be a barrier to carrying out health surveys. In-depth training in survey design, delivery and analysis is essential for statisticians, researchers and decision-makers.

Specific technical challenges when carrying out data collection relating to ethnicity can compound the situation. These include:

- How to identify the most appropriate categories to provide as options, so that the smallest and most marginalised groups are not restricted to the category of 'other'.
- How should 'ethnic group' be defined? And if only one category is permitted for ethnic identity, how should people of mixed parentage respond?
- How to obtain representative and accurate data if the sample size is small and ethnic minority populations are small and scattered. Problems of sample size must be addressed in the survey structure to make sure that there are a meaningful number of responses from different ethnic groups - but enlarging the sample size to obtain meaningful data can be costly.
- How to formulate questions which will be appropriate in the family and social contexts of marginalised indigenous or ethnic or cultural communities, when these may differ from the profile of the rest of the population.

A more practical obstacle is that ethnic minorities may live in areas of conflict, or even war, or areas which are inaccessible for periods of the year, making data collection difficult or impossible.

Once collected, it is vital that the capacity then exists to digest the implications of any findings and turn them into concrete action. Policy makers need the skills to understand the complex and interlocking factors behind the differing health outcomes of different ethnic groups and to develop strategies to address inequalities. Furthermore, countries need to have the capacity to repeat health surveys regularly in order to build up sufficient longitudinal data to identify trends and to monitor the impact of health interventions.

Addressing these challenges

International institutions, donors and NGOs have a central role to play in encouraging the ethnic disaggregation of health data in particular, and in strengthening health information systems more broadly.

The routine breakdown of health data by ethnicity in the published MICS and DHS surveys would be particularly influential since these two surveys are important drivers for health data collection in the developing world. There is a clear role for the funders of these surveys to encourage ethnic disaggregation to become the norm.



Other areas in which donors have a role to play include:

- Encouraging and supporting countries in their efforts to disaggregate data by ethnicity through sharing good practice and supporting the development of technical skills at a national level.
- Providing long term support for the establishment of unified, reliable national health information systems, while harmonising their own reporting requirements to avoid fragmentation of information.
- Pushing for internationally coordinated efforts to promote the ethnic disaggregation of health data.

When carrying out surveys, involving marginalised communities themselves in all stages of the survey design, data collection, analysis and dissemination is crucial for obtaining accurate and appropriate information. For example, targeted qualitative research with members of a marginalised group, drawing on local expertise, can be useful at the

initial stage to inform survey design and to address problems of sample size.³⁵ Members of the community can also be employed to carry out the data collection in the most appropriate language.

At a national level, the strengthening of national health information systems overall is essential if vital events in a person's health are to be monitored across all sections of society. Important measures for governments to take, supported by development partners, include: having comprehensive vital registration systems, integrating several sources of data (e.g. censuses, household surveys), and ensuring that there are the human resources and institutional capacities to support data gathering systems. In particular, high quality record-keeping needs to become a routine part of health workers' roles. Once the accuracy of data has been improved, technology holds the potential to assist and speed up data gathering from the community level up.

4.2 Reluctance from decision-makers

It is clear that there are occasions, such as in some DHS surveys (see page 11 above), when ethnically disaggregated data is collected but not then used in the published analysis. In other instances the information is simply not captured at all by national health information systems or surveys.

Governments may resist the collection or publication of data broken down by ethnicity for a variety of reasons. Some may argue that the different health outcomes of different ethnic groups can be attributed to class or regional disparities, and that other forms of disaggregation are unnecessary. Some may wish to avoid any research which may reflect badly on their policies.

For many there is a concern that research drawing attention to ethnic, religious or linguistic differences will confirm negative stereotypes or fuel ethnic tension. In ethnically diverse states, a high premium may be placed on national unity.³⁶ States which have experienced major ethnic conflict, such as Rwanda, can be reluctant to draw attention to differences between ethnic groups and may resist the collection of data relating to ethnic origin.³⁷

In regions of extreme ethnic tension, such concerns have some validity, not least because of historic examples of the misuse of such data. Where tensions are high, the use of proxies (such as language, geographic location, or religion) may be preferable to direct collection of ethnic data.

Contributing to this context may be weak public consciousness and demand for such data. Indigenous and other marginalised cultural and ethnic groups – and in particular women from these groups – often have little or no voice in government and in policy-making, meaning that too few questions are raised about the factors contributing to their health outcomes.

Addressing these challenges

Anxieties about ethnic tensions may be understandable in particular contexts, but the refusal to acknowledge the social and economic differences between ethnic groups can all too often reinforce the cycle of exclusion and marginalisation. Without accurate and broken down data, governments cannot identify health policy failings and take measures to address them.

Building awareness of the potential benefits of breaking down data is essential for stimulating action by governments. It can also influence social attitudes. For example, the ethnic disaggregation of data from censuses and household surveys over many decades in Brazil is considered to have prompted changes in social awareness of discrimination.³⁸

Indeed, obtaining authoritative data which is broken down by ethnicity can help improve national unity by providing a sound basis for responding to criticisms or rumours of ethnic bias in government policy – for example, countering scare-mongering by extremist political groups.

At the same time, civil society groups have a role to play in boosting public demand for disaggregated information among marginalised communities. Raising awareness of how the availability of data can feed into better health interventions for their communities holds the potential to increase public pressure on decision-makers and put the needs of marginalised groups in the spotlight.

Case study: Namibia's marginalised San people



The lack of available data on the marginalised San people is holding back efforts to address their particular health needs.

Namibia's 31,000 semi-nomadic indigenous San (formerly called 'Bushmen') experience significantly worse health outcomes in comparison to the rest of the population.³⁹ Many San are trapped in a cycle of poverty and poor health.

Being a mobile group, scattered in remote areas, the San population cannot be reached with conventional service models, and the cost of reaching them is necessarily much higher than the majority population. They have little representation in government and often feel they have little or no say in public services such as health. Many distrust public health services because they are provided by other ethnic groups who they feel discriminate against them.

Published health surveys do not provide information about health outcomes by ethnic group in Namibia. Health data collected by the government does not include information about ethnicity, and while Namibia's 2005 Demographic Health Survey (DHS) obtained the requisite information to make a sophisticated analysis of language groups, like the San, against health indicators, it did not publish this information.

Continued over...

Disparities in health outcomes

From the evidence that exists there appear to be significant disparities between regions and ethnic groups, despite the government's relatively high spending on health per head.⁴⁰ For example, while Namibia's German-speaking population has a life expectancy of 79 years, the San's is 52.⁴¹ The San's Human Development Index is just one third of the rest of the population.⁴²

The concentration of San people is highest in Tsumkwe Constituency, Otjozondjupa Region, where the San face high levels of HIV/ AIDS, TB and malaria. Crowded living conditions and sleeping without insecticide treated nets contribute to these. The proportion of San people living with HIV/ AIDS who are taking anti-retroviral drugs is low, and the uptake of treatment to prevent mother to child transmission lags behind the rest of the country. The long treatment period for TB is a particular challenge for the mobile San population; deadly drug-resistant strains of TB have spread as a result of the regular failure of sufferers to complete their treatment.

Faced with such severe health challenges, the availability of health data broken down by ethnic and cultural group would be a huge step forward. It would establish a solid basis for groups to advocate for health policies and programmes to address their particular and severe needs, and could inform the selection of the most appropriate interventions by government.



Sarah Zungu is a senior counsellor in Tsumkwe. She understands the importance of health services that are culturally appropriate as she has seen the rates of HIV and TB drop since health professionals began speaking San languages. She is pleased to see more San people training as nurses.

4.3 Respecting the principles of self-identification and privacy

The principle of self identification, as defined by the UN, says that individuals have a right to assert their own identity, and that states should not impose identities on the individual. This provides a solid basis for protecting the rights of marginalised groups.

The implication of this for data collection, however, is that it can result in the under-reporting of ethnicity on a small or large scale. In societies where discrimination and prejudice continue to be rife, it is not surprising to learn that many people from indigenous or marginalised ethnic groups can be reluctant to identify themselves with a particular ethnic identity (see case study from Guatemala, page 22). Marginalised groups may fear that their personal data will be misused for racist or exclusionary policies. This is a particular problem when majority groups dominate the machinery of the state.

A further challenge is that identities can be fluid. A person from an indigenous or marginalised ethnic group may reassess their sense of identity over time, reducing the accuracy of longitudinal surveys.

Legal restrictions and the right to privacy must also be taken into account. How states hold and use data varies considerably, but the right to privacy is often understood to mean that individuals have a right to know what data is held about them and how it is disclosed, with implications for data collection.

Addressing these challenges

Steps to mitigate these obstacles include:

- Setting up outreach programmes to sensitise communities to the benefits of self-identification and of disaggregated data. These can counter any fear or mistrust by explaining how the information will or will not be used.⁴³
- Involving marginalised groups themselves at all stages in the design, conduct, analysis and dissemination of health surveys, including decisions about what data should be collected and how it should be broken down.
- Ensuring surveys are carried out in a manner and language that is appropriate to the community, ideally with data collected by trained members of the community.
- Ensuring that individual data is kept anonymous within the aggregate health data, so that it cannot be linked to an identifiable person (although this may be difficult in very small communities).
- The development of international legal standards to protect individual privacy which can be applied in countries where current safeguards are insufficient.⁴⁴

Alongside these measures, concerted efforts to reduce prejudice and discrimination are likely to affect how individuals choose to identify themselves. This will further improve the accuracy of health data when broken down by ethnic group.



Case study: Guatemala

Persistent racial stigma appears to be resulting in the under-reporting of indigenous identity.

Guatemala is one of the world's most unequal countries. Although classified as a middle-income country, this obscures the reality that the richest 20 per cent of the population enjoy 61 per cent of total income, while the poorest 20 per cent share just 3 per cent of total income.⁴⁵

Official census reports claim that only 41 per cent of the country is now indigenous, despite greater fertility rates among indigenous populations. The statistics are contentious, however, with activists asserting that indigenous groups actually form a majority of the population. One explanation is that more and more ethnically indigenous people no longer identify themselves with Maya culture, out of a wish to avoid the social, political and economic marginalisation that indigenous groups have historically experienced.

Ethnic discrimination and poverty

Whatever the exact figures, these groups, such as the Maya Mam and Maya K'iche', are among the most marginalised groups in Guatemalan society, both because of endemic discrimination and because of their rural location. In the wake of Guatemala's devastating civil war, and following the global economic crisis of recent years, more than half the population are now believed to be living below the poverty line.⁴⁶ However the poverty rate is even higher among the indigenous Maya population, with around 73 per cent considered to be living in poverty.⁴⁷ The rate of chronic malnutrition among indigenous children under five is approaching twice that of non-Maya children.⁴⁸

There has been some progress, however. The Indigenous Parliamentary Forum provides a national voice for the Maya people, representing their concerns in the Parliament and calling on the international community to focus on development that is *with* (rather than merely for) indigenous people. But the use of basic services reflects persistent marginalisation, with Maya people having lower school attendance, for example, especially among rural girls. A 2006 survey found that indigenous women of fertile age were more than three times as likely to be illiterate compared to the non-indigenous population.⁴⁹

Maternal health

Measuring progress against many of the Millennium Development Goals (MDGs) in Guatemala is hampered by a lack of information. However it is clear that MDG 5 on maternal health will not be met if progress continues at the same rate, and evidence suggests that indigenous groups fare significantly worse than the non-indigenous population. The estimated maternal mortality rate in 2000 was 153 per 100,000 live births, but the figure for the indigenous population was three times higher than for the non-indigenous population.⁵⁰ Regular access to health services is a major obstacle for many indigenous women, and the physical distance to health centres is made worse by the lack of roads or poorly maintained dirt roads. This is compounded by the fact that public health expenditure is among the lowest in the region at around 1.9 per cent of GDP.⁵¹

‘It’s difficult to get to [health services], there’s no money, and they’re far away.’

Father-in-law of a woman who died during childbirth

Good practice: Ethnic disaggregation of health data

Given the significant disparities between the health outcomes of different ethnic groups, it is promising that the 2008-09 Maternal and Child Health Survey, conducted by the National Statistics Institute, disaggregated data by ethnicity.

Household surveys were carried out in both rural and urban areas of every region, and the ethnic background of respondents was included. The data was also broken down by age, education level, urban or rural residence, geography and civil status. The results show significant differences in the health care accessed by indigenous and non-indigenous women. For example:

	Use of any form of contraception	Gave birth at home	Attended by a doctor or nurse during delivery
Indigenous women	40%	69%	30%
Non-indigenous women	63%	28%	70%

Data has so far been broken down in this way in specific, one-off investigations; an important development would be the systematic collection of disaggregated data across all the country’s health services. If data were disaggregated in this way it would enable much more sensitive strategic planning in public health. However the continuing stigma attached to indigenous status may result in the under-reporting of indigenous identity. Knowledge and understanding of Maya culture needs to be incorporated into the survey design, implementation and data collection, in order to boost the accuracy and usefulness of the data – ideally by involving indigenous groups, and organisations which advocate for them, at every stage in the process.

5. It's time to count

Reaching the health-related [Millennium Development] Goals is not about national averages. It is about reaching the poor, who are almost invariably the hardest to reach. This is the challenge, and the measure of success.

Margaret Chan, Director General, World Health Organisation, May 2010

Information and statistics are a powerful tool for creating a culture of accountability and for realizing human rights.

UNDP Human Development Report 2000, p. 10

It is time for the needs of women from the most marginalised ethnic communities to be placed centre stage.

The use of averages to measure progress towards targets such as MDG 5 means that gross inequalities and terrible suffering are being hidden. The lack of reliable and disaggregated health data in the poorest countries is a significant obstacle to setting priorities, measuring progress and holding decision-makers to account, with potentially catastrophic consequences for women from indigenous and marginalised ethnic groups.

Coordinated international action is urgently required to build awareness of the benefits offered by ethnically disaggregated data, to address barriers to its collection, and to put in place the technical capacity required at a national level.

Now is the time for change. International discussions on the development framework to replace the MDGs present an ideal opportunity to influence the way that data is collected and analysed. This would bring lasting benefits by highlighting the health situation of the most marginalised and vulnerable. It would furthermore facilitate the targeted and cost-effective use of future donor funds.

In the shorter-term, those involved in the Independent Expert Review Group and the Accountability Commission of the Every Woman, Every Child initiative have a vital opportunity to bring about a step change in the understanding of the maternal health outcomes experienced by marginalised groups by promoting the disaggregation of data by ethnic and cultural group.

Such data would provide the international community with credible information to monitor the effectiveness of health interventions and to hold governments, donors and institutions to account. It would provide the necessary evidence to demonstrate that investing in the health of women and children is making a difference, and help build the case for disaggregation across the measurement of international poverty and health goals. Without it, donors who emphasise measuring the results of their programmes simply will not have the right information to judge their performance and to maximise their impact.

We believe that progress away from poverty and towards better health should be enjoyed by all sections of society. It's time to count.

Recommendations:

1. To donors, international institutions and NGOs:

- All data which monitors progress towards any new post-2015 goals should be disaggregated by ethnicity. In the meantime, the indicators set to measure progress in implementing the Every Woman, Every Child Strategy must be broken down by ethnic and cultural group. Reporting against indicators must include separate reporting on equity.
- International institutions, donors and NGOs should support internationally coordinated efforts to promote the ethnic disaggregation of health data, such as through the Health Metrics Network.
- International institutions, donors and NGOs should support the strengthening of existing national level mechanisms to collect and analyse health data, by sharing good practice, providing resources, and building national level skills and expertise.
- International institutions, donors and NGOs should incorporate requirements for ethnically disaggregated data in their own reporting mechanisms, while taking care to avoid the fragmentation of health information.

2. To donors to the MCIS and DHS surveys:

- Donors to the two leading international health surveys should push for the disaggregation of health data by ethnicity to become routine.
- Donors to these two health surveys should push for indigenous and other marginalised ethnic and cultural groups to be fully involved at all stages of survey design, data collection, analysis and dissemination.

3. To the UK government:

- The UK government should champion the ethnic disaggregation of data in the post-2015 framework, including the development of indicators to be broken down by ethnic and cultural group, and reporting against equity.
- The Department for International Development (DFID) should support ethnically disaggregated data in implementing its 'Choices for Women' results framework for reproductive, maternal and newborn health. It should support countries where it works to obtain ethnically disaggregated health data by sharing good practice, providing resources, building national level skills and expertise, and by incorporating requirements for ethnically disaggregated data in its reporting mechanisms.

4. To developing country governments:

- Developing country governments should prioritise strengthening the capacity of their national health information systems, with particular emphasis on collecting and analysing ethnically disaggregated data with the full involvement of indigenous and other marginalised ethnic and cultural groups.

To find out more and to get involved in our campaign to improve the lives of Mothers on the Margins please visit:
www.healthpovertyaction.org/campaigns

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Every Mother Counts

Reporting health data by ethnicity

This report examines the lack of statistical information around the health outcomes of women from indigenous and other marginalised ethnic and cultural groups within developing countries.

Unless breaking down health data by ethnicity becomes the norm, the true health situation of some of the world's most marginalised people will continue to be dangerously concealed. There can be no more delay. It is time for the most marginalised communities to be counted.



Health Poverty Action works to strengthen poor and marginalised people in their struggle for health.

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