

Indigenous Women's Maternal Health and Maternal Mortality

KEY POINTS

Indigenous women die in pregnancy and childbirth more often than other women. Failure to act will render the Sustainable Development Goals (SDGs) unattainable.

It is time to make the marginalised visible. The lack of data on the health of indigenous women and adolescent girls is masking huge disparities between populations, preventing effective action to address it.

Improving the health of indigenous women and adolescent girls is achievable. It requires States to implement commitments to disaggregate data by ethnicity and age, tackle discrimination, and make health centres physically, financially, and culturally accessible.

Access to health care, including sexual and reproductive health is a basic right. States have an obligation to ensure that indigenous women and adolescent girls enjoy equal access to health services.ⁱ



“Indigenous women’s fundamental right to health must be guaranteed so that they can realise their full potential. The 2030 Agenda for Sustainable Development presents a unique opportunity to reduce health inequalities for indigenous women and mothers.”

DOCTOR MARIAM WALLET, CHAIRPERSON OF THE UNITED NATIONS, PERMANENT FORUM ON INDIGENOUS ISSUES

INDIGENOUS WOMEN’S MATERNAL HEALTH - THE FACTS

The evidence from the available data is clear—and alarming. Across the globe, indigenous women and adolescent girls experience significantly worse maternal health outcomes than majority populations. While data is limited, analysis of the available survey data from 16 low and middle-income countries across three key indicators demonstrates that indigenous women and adolescent girls are significantly less

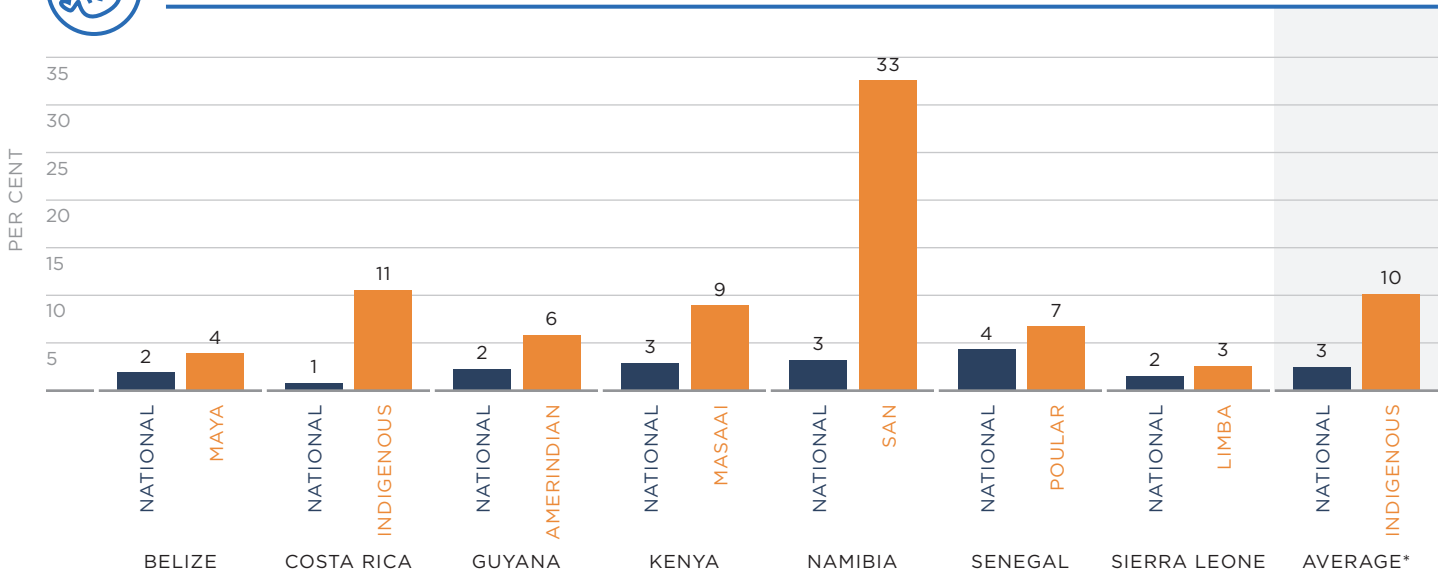
likely to benefit from services and have worse maternal health outcomes.ⁱⁱ For example, the birth rate for Amerindian adolescent girls is twice that of the general Guyanese population, Maasai women in Kenya are twice as likely to have had no antenatal care, and San women in Namibia are ten times more likely to give birth without skilled attendance.ⁱⁱⁱ

Figure 1 shows the disparities in antenatal care visits across a representative sample of these surveys. Indigenous women are overwhelmingly less likely to have received

antenatal care and, in most cases, the differences are very significant. Figure 2 and 3 show similar disparities in skilled birth attendance and adolescent birth rates.^{iv}



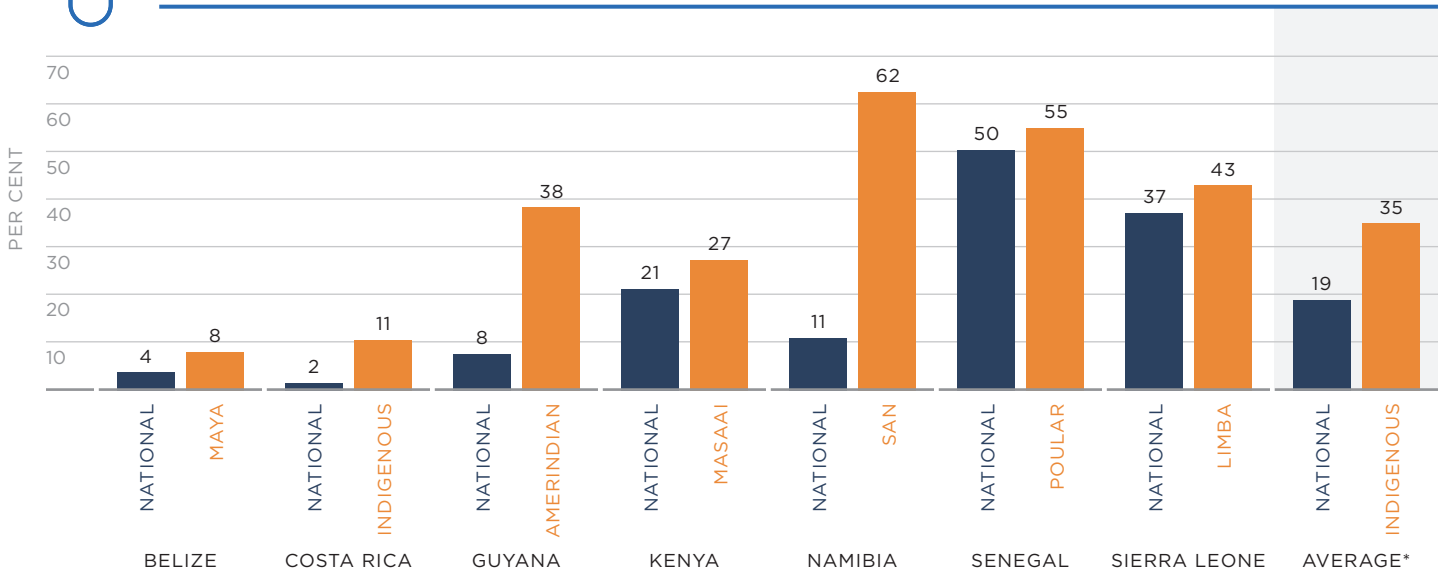
FIGURE 1. AVERAGE* PERCENTAGE OF WOMEN WHO DID NOT RECEIVE ANTENATAL CARE



*Average across all 16 countries with data combined.



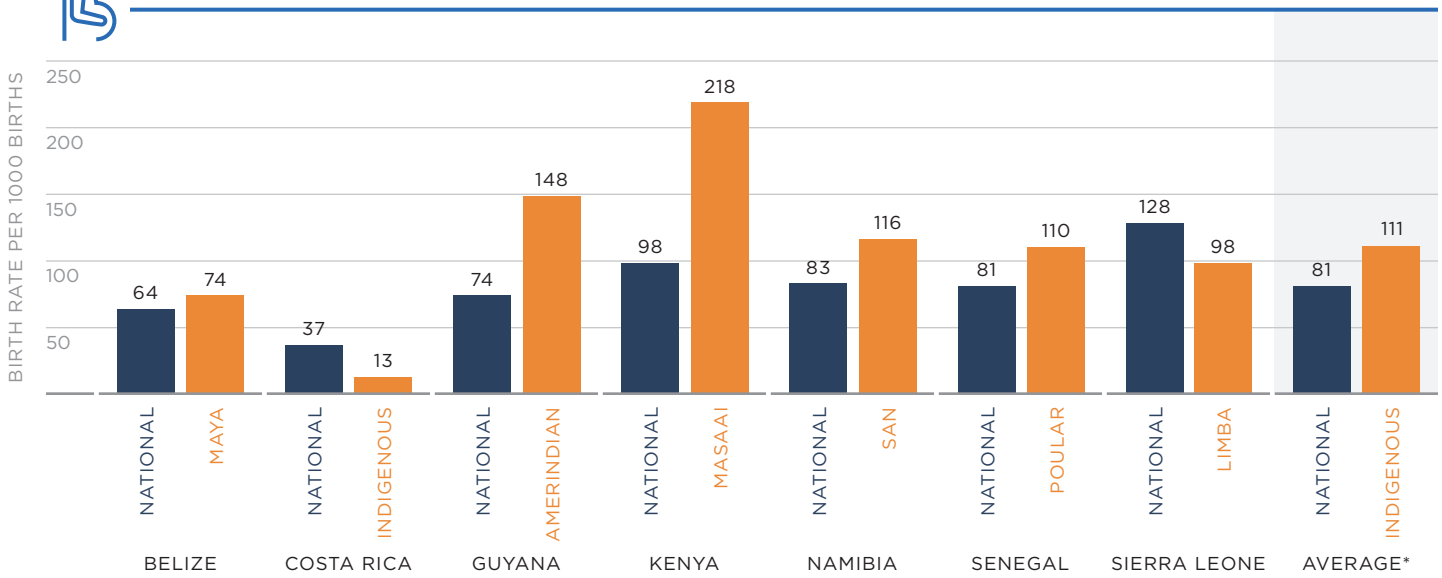
FIGURE 2. AVERAGE* PERCENTAGE OF WOMEN WHO DID NOT RECEIVE SKILLED ATTENDANCE AT BIRTH



*Average across all 16 countries with data combined.



FIGURE 3.
AVERAGE* ADOLESCENT BIRTH RATE PER 1000 BIRTHS



*Average across all 16 countries with data combined.

Other national surveys tell the same story. India's National Family Health Survey 2015-16 found that 46% of indigenous women and adolescent girls had had at least four antenatal care visits, compared to 61% of Hindu women and adolescent girls.^v Guatemala's National Survey of Mother and Child Health 2014-15 found that only 50.3% of indigenous women and adolescent girls had skilled birth attendance, compared to 82.1% of non-indigenous women.^{vi}

The situation regarding maternal mortality is equally disturbing. A study of ten populations carried out by the *Lancet-Lowitja* Institute Global Collaboration found that whilst the extent of the disparities varied considerably, indigenous populations consistently had higher maternal mortality rates.^{vii}

In both Panama and Russia indigenous women are approximately six times more likely to die in childbirth than the non-indigenous population.

The discrimination experienced by indigenous women and adolescent girls extends to industrialised countries. In Australia, Aboriginal and Torres Strait Islander women were less likely to attend an antenatal visit during the first trimester,^{viii} had an adolescent birth rate nearly five times as high as the general population^{ix} and, according to the *Lancet-Lowitja* study, were more than twice as likely to die as a result of pregnancy and childbirth.

It is important to appreciate these variations and their causes as a means of implementing appropriate health interventions, to tackle inequality, and to prevent maternal deaths among indigenous women and adolescent girls. The 2030 Agenda for Sustainable Development commits States to meet all targets 'for all nations and peoples and for all segments of society,' and to undertake the necessary level of data disaggregation to monitor progress in ensuring that no one is left behind.^x Yet progress in meeting the commitment to gather fully disaggregated data is uncertain. There are clearly challenges in disaggregating data, but if the SDGs are to be met, they must be overcome.

WHERE IS THE DATA?

The statistics above provide compelling evidence of the need to document, understand, and address the exclusion experienced by indigenous women and adolescent girls. However, the data currently available is far from comprehensive. Of the 90 national and sub-national surveys conducted under the last two rounds of the Multiple Indicator Cluster Surveys (MICS) and Demographic Health Surveys (DHS), only 43 included a question on ethnicity and only 27 of the published reports included an analysis based on ethnicity.^{xi} Although unreliable and not recommended in most cases, some additional insight may be possible through using language or region as 'proxies' for ethnicity where disaggregated data does not exist.^{xii} As a result of this lack of data, the experiences of the most marginalised—including indigenous peoples and those who experience intersectional discrimination and exclusion on the basis of other characteristics (e.g. poverty and disability) remain largely invisible.

Failure to adequately disaggregate data is explained, in part, by sensitivities. There have been historical instances of governments using census data (including data on ethnicity and religion) to identify populations for pursuing policies of assimilation or even persecution. And there remain some areas where the political or security situation will not allow for safe collection and publication of data disaggregated on the basis of ethnicity. However, provided

that the appropriate safeguards are in place, the benefits of collecting and disaggregating data on the basis of ethnicity in the vast majority of countries are clear. In addition to these sensitivities, there are also the challenges of generating sufficiently large sample sizes. Nevertheless, in many cases, the lack of data is due to poor functioning of the information system, or the low priority attached to collecting such data.

States that have collected and published detailed data disaggregated by ethnicity are to be commended, and their efforts should be welcomed as progress towards resolving disparities and improving access to services and better outcomes for all.

“The Permanent Forum strongly recommend [...] the disaggregation of data on the basis of indigenous identifiers/ethnicity and the full and effective participation of indigenous peoples in developing and monitoring national action plans and in all processes relating to the follow-up to and review of the implementation of the Sustainable Development Goals”.^{xiii}

PERMANENT FORUM ON INDIGENOUS ISSUES REPORT

WHY ARE INDIGENOUS WOMEN LEFT BEHIND?

Indigenous women and adolescent girls face considerable barriers to accessing medical treatment, despite typically experiencing higher health risks. While some of these may involve direct discrimination, the reasons are also grounded in a wide range of social, economic, political, cultural and geographical factors.^{xiv} These factors intersect with and impact upon the experiences of indigenous women and

adolescent girls in varied and complex ways. Figure 4 shows some of the key subjective experiences of indigenous women and many of the wider factors that contribute to poorer access to health services and outcomes. It should be noted that these are not 'either/or' distinctions, but should rather be understood as different points along a 'services-structural' continuum.

“ I would be happy to give birth in hospital if it were not for the way they talk to us.

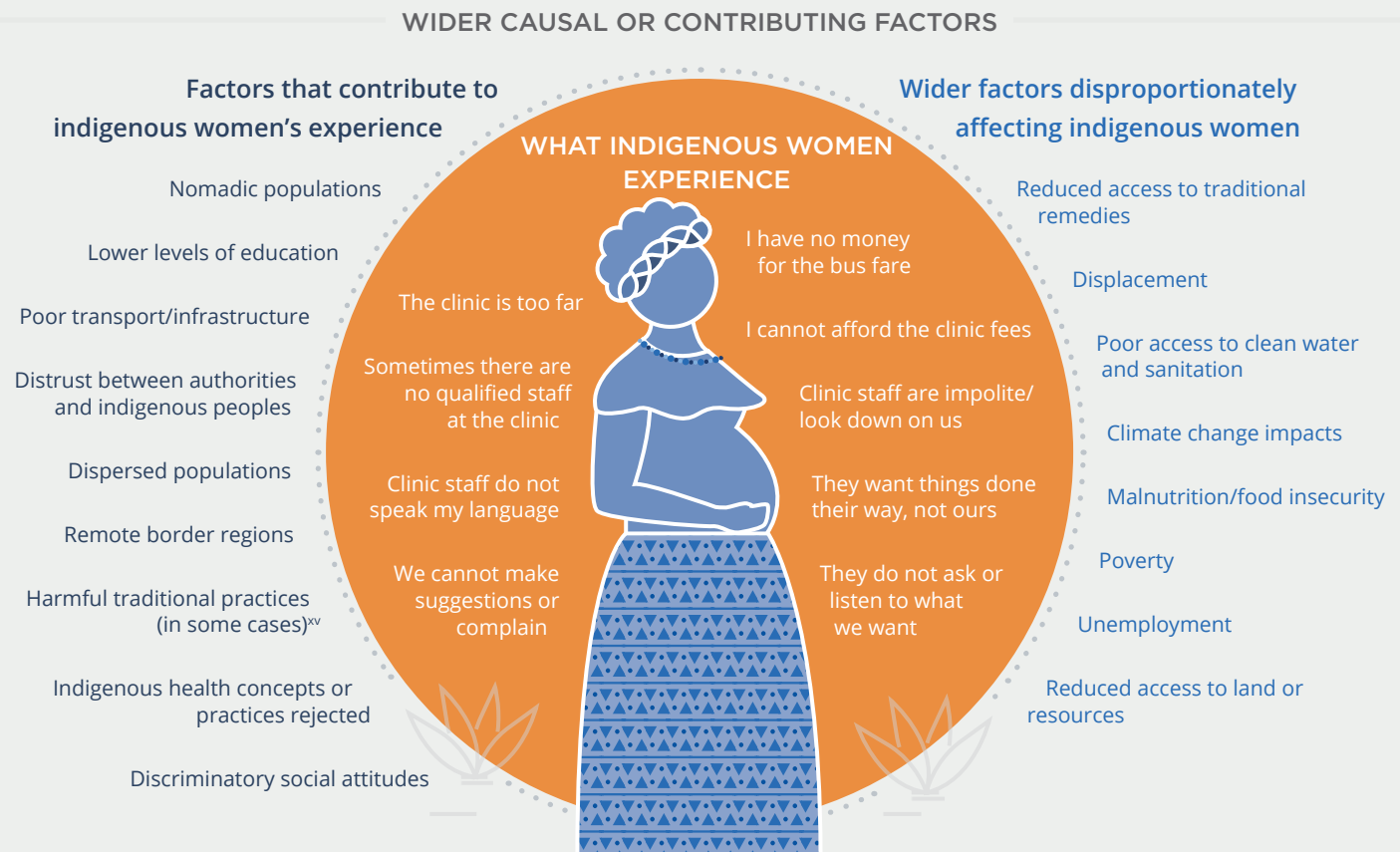
INDIGENOUS COMMUNITY MEMBER, NICARAGUA.

Indigenous women are not a homogenous group and intersecting and multiple forms of discrimination on the basis of factors such as disability, age, location and sexual orientation and gender identity, also affect the experiences of individual women and patterns of experiences.

BOX 1. Comments from an indigenous woman with a disability from Mexico (unpublished interview, conducted for the purposes of this fact sheet)

“Doctors and midwives do not have training on how to care for a woman with a disability before, during, and after pregnancy. There is no previous and informed consultation about the procedure that will be carried out at the time of delivery, so that an indigenous woman with a disability cannot give an opinion on what the most appropriate position in which to be able to give birth may be. The lack of policies for our social group has negative impacts, there is little participation in decision making in shaping public policies and services are not inclusive for everyone.”

FIGURE 4. WHY DO INDIGENOUS WOMEN HAVE WORSE MATERNAL HEALTH OUTCOMES?



WHAT NEEDS TO BE DONE?

Whilst there has been progress in addressing indigenous peoples' marginalization,^{xvi} much greater efforts are needed to tackle disparities between them and majority populations across all sectors. Specifically, the following measures are recommended to ensure that indigenous women and adolescent girls are not left behind in the pursuit of the SDGs:

1. Disaggregate data. Health and other data to monitor SDG progress must be disaggregated by a range of categories, including ethnicity, using the principles of data protection, self-identification, participation of indigenous and other marginalised ethnic and cultural groups, and the independence of official statistics. Specifically:

- » National governments must consult indigenous communities about the best ways to collect, analyse, and report such data in line with the commitments of the 2030 Agenda for Sustainable Development, and train officials to do so. Data must be analysed and form the basis of interventions to address disparities.
- » International institutions, donors and Non-Governmental Organizations (NGOs) must include requirements for disaggregation by ethnicity in their own reporting mechanisms as standard.
- » National statistical offices and line ministries should be strongly encouraged to collect, analyse, and disseminate data collected by ethnic categories in all appropriate surveys at country level (including DHS and MICS).

Disaggregated statistics are a starting point. They will clearly show where disparities exist for needed action. To this extent, policy makers also need to understand WHY indigenous women in their countries have higher maternal mortality. And then they need to ACT to address the barriers. Every maternal death should be fully investigated and as part of this, the ethnicity of the woman should always be recorded. Analysis of this data will reveal trends and patterns of factors that have contributed to indigenous women's deaths.

“Failure to collect health data disaggregated by ethnicity, self-identified indigenous status or cultural identity can conceal deep inequities. [...] Such data should address issues such as gender, socioeconomic status and disability, as data focused purely on indigenous status does not fully capture the composite rights of indigenous peoples who are marginalized owing to other aspects of their identity.”^{xvii}

UN SPECIAL RAPPORTEUR ON THE RIGHT TO HEALTH



Above: Global Leaders' Meeting on Gender Equality and Women's Empowerment: A Commitment to Action © UN Women/Ryan Brown

2. Take positive action. Where indigenous maternal mortality is higher than national levels, States must fulfil their duty to take positive action to address this through:

- » Participatory and inclusive action research at national, regional and local levels to identify what barriers are preventing indigenous women, particularly adolescent girls from benefitting fully from health services, and implementing programmes to address them.



Perhaps the most urgent call of all is to remove the cloak of invisibility from the shoulders of indigenous peoples.

LANCET EDITOR, RICHARD HORTON^{xviii}

- » Participatory inclusion audits or reviews of maternal and adolescent health policies and action plans to gather views on how they meet the needs of, or exclude, indigenous women and adolescent girls.
- » Allocating appropriate budgets to identify and address socio-cultural and other barriers and monitor the impact of measures taken.
- » Incorporating an intercultural approach to sexual and reproductive health (SRH) services to guarantee culturally appropriate health services and medical staff with intercultural competencies.
- » Ongoing participatory processes, at the national and community levels, to gather indigenous women and adolescent girls' views on services, including the use of complaint mechanisms for indigenous women and their families and encourage the use of these mechanisms.

3. In situations of conflict:

- » Where there is conflict or distrust between indigenous communities and the State, trusted third parties (such as inter-governmental organisations (IGOs) and NGOs) may be useful agents for providing services and mediators for rebuilding trust over time.
- » In conflict affected regions, IGOs and NGOs who provide SRH services to women and adolescent girls must ensure that indigenous women's and adolescent girls' needs are fully appreciated and factored into service provision plans.

BOX 2. Examples of successful approaches

Maya Mothers and Children project, Guatemala

Health Poverty Action's 'Maya Mothers and Children' project sought to improve maternal and newborn health for indigenous people in the Totonicapán and Quetzaltenango departments of Guatemala by increasing community participation and ownership of services. A central focus of the project was to promote and support greater community participation in the local health commissions that monitor health authorities and facilities. The increased participation of mothers, community leaders, and traditional birth attendants (TBAs) resulted in improvements including TBAs gaining telephone access to Ministry of Health staff in emergencies, and changes in service hours to adapt to community needs. In terms of the direct impact on indigenous women's maternal health, the project saw, for example, a 72% increase in newborn health check-ups over a one-year period; and, in one of the largest districts, Santa Lucia la Reforma, an increase in the proportion of births taking place in Ministry of Health facilities from 19% to 30% over two years.

Baka Young Mothers project, Republic of Congo

In the Republic of Congo, UNFPA partnered with Médecins d'Afrique to increase access to SRH services for indigenous Baka women. As part of the "First time Young Mother" initiative in the department of Sangha, a series of initiatives were piloted from April to June 2017. These included workshops for health providers on the specific needs of indigenous women, training community volunteers to liaise with pregnant women to inform them of their rights to maternal health services and encourage them to go to the health clinics, training traditional birth attendants on biomedical practices to enable them to practice in the medical institutions, and distributing clothing kits, including soap, to the pregnant indigenous women for their antenatal visits (so that they were able to arrive washed and wearing clean clothes and did not feel embarrassed when visiting the clinics). As a result of these interventions, the number of women receiving antenatal care and giving births in the health clinics and hospital in the district increased dramatically. In the first quarter of 2017, 10 women received antenatal care and 11 women gave birth in a medical facility. In the third quarter, 112 women received antenatal care and 38 gave birth in a medical facility.

ENDNOTES

The authors would like to recognise the valuable contributions of the Health Poverty Action and Minority Rights Group International to this fact sheet.

This fact sheet was developed following a recommendation of the UN Permanent Forum on Indigenous Issues at its fifteenth session in which the Forum urged “Member States and funds, programmes and specialized agencies of the United Nations system to implement action to reduce maternal mortality among indigenous women. The Forum recommends that the United Nations Population Fund, the United Nations Children's Fund and the United Nations Entity for Gender Equality and the Empowerment of Women publish a fact sheet, in collaboration with the Forum, on indigenous women's maternal mortality and maternal health, with the aim of reducing maternal mortality and promoting sexual and reproductive health.” (Paragraph 38, Report of the UN Permanent Forum on Indigenous Issues, fifteenth session of 9-20 May 2016).

- i The right to health, including sexual and reproductive health has been recognized by numerous human rights treaty bodies, including the Committee on Economic Social and Cultural Rights in its General Comment no. 22 (2016) and the Committee on the Elimination of Discrimination Against Women in its General Comment no. 24 (1999). The right of indigenous women and adolescent girls to enjoy equal access to health services is specifically emphasised in article 24 of the United Nations Declaration on the Rights of Indigenous Peoples and by the Committee of the Rights of the Child in its General Comment no. 11 (2009).
- ii The countries are: Belize, Costa Rica, Ethiopia, Gambia, Guyana, Indonesia, Kenya, Laos, Mexico, Namibia, Nepal, Pakistan, Senegal, Sierra Leone, Suriname, Vietnam. See note ‘xi’ below for an explanation of why these countries provide the basis for the analysis.
- iii The adolescent birth rate is defined as the number of births to women aged 15-19 years during the three-year period preceding the survey divided by the average number of women aged 15-19 years during the same period, expressed per 1,000 women. The statistics relating to receipt of antenatal care, and to skilled birth attendance, are both based on the experience of women aged 15-49 years who had had a live birth in the two years preceding the survey.
- iv For more information about any community listed in these tables or concerning indigenous peoples in any country listed in these tables, see <http://www.minorityrights.org/directory/>.
- v <http://rchiips.org/nfhs/pdf/nfhs4/india.pdf>.
- vi VI Encuesta Nacional de Salud Materno Infantil, ENSMI 2014-2015, Informe de Indicadores Básicos, Guatemala, noviembre 2015.
- vii Indigenous and tribal people's health (The *Lancet*-Lowitja Institute Global Collaboration): a population study, *The Lancet*, Vol. 388, 2016: [http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(16\)00345-7.pdf](http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(16)00345-7.pdf).
- viii <https://www.pmc.gov.au/sites/default/files/publications/indigenous/Health-Performance-Framework-2014/tier-3-health-system-performance/301-antenatal-care.html>.
- ix <http://www.healthinfonet.ecu.edu.au/population-groups/women/reviews/our-review>.
- x See paragraph 4 of the Declaration.
- xi The two main sources of data on maternal health in low and middle-income countries are the Multiple Indicator Cluster Surveys (MICS), funded by UNICEF, and the Demographic and Health Surveys (DHS), funded by USAID. The figures in this paragraph relate to surveys undertaken under the two most recent rounds of the MICS (rounds 4 and 5) for which survey reports have been published in English, French, Spanish or Portuguese (the only surveys reports not included are the two that were published in Arabic). DHS surveys do sometimes include questions relating to ethnicity, but the published reports do not contain analysis on the basis of this data in relation to maternal health or adolescent birth rates.

The analysis of the experience of indigenous women and girls presented in this fact sheet only includes data from 8 of the 27 MICS reports that included analysis on the basis of ethnicity. This is because data relating to ethnicity does not always translate into data about indigeneity. There are two reasons for this: (i) disaggregation may be too broad (such as providing a binary breakdown between the majority ethnic group, and ‘other’); (ii) there may not be a straightforward correspondence between ethnicity and an indigenous population—for example, where ethnicity data relates only to communities identifying as ethnic, religious or linguistic minorities.

For the purposes of this fact sheet, the published statistics from these 8 surveys was supplemented by independent primary analysis of the data from a further 8 surveys. For more detailed explanation and analysis of the relevant data, see [accompanying web-page forthcoming].
- xii Proxies almost inevitably involve guesswork or assumptions, or reliance on statistics that may be in dispute or not up to date. Geographical proxies ignore indigenous peoples’ migrations away from traditional lands to cities, and may also fail to take account of in-migration into traditionally indigenous lands by other population groups. Whilst using language as a proxy for indigeneity is also not totally reliable, in general, despite the loss of indigenous languages and problems with the reporting of those who are multilingual, there is a closer fit in that those who identify as speaking an indigenous language are very likely to be themselves a member of an indigenous people. For this reason, we have used two languages as proxies of indigeneity (San in Namibia and Balochi speakers in Pakistan). However, we did not include any data based on geographical proxies. These reservations about the use of proxies were echoed in the *Lancet*-Lowitja study cited above, which stated that ‘caution is required in the use of proxy measures to make inferences’.
- xiii Permanent Forum on Indigenous Issues Report on the fifteenth session (9-20 May 2016) E/2016/43-E/C.19/2016/11.
- xiv Two case studies that investigate the interplay of some of these factors in specific contexts (San in Namibia and West Papua in Indonesia) are available [accompanying web-page forthcoming].
- xv Some traditional practices (e.g. Female Genital Mutilation or early marriage) may impact on maternal and child mortality. Whilst some indigenous peoples do follow such practices, so do many non-indigenous communities. This issue has been included here not because it is necessarily more prevalent within indigenous communities, but because it can represent a real barrier for indigenous women accessing maternal healthcare. In addition, there are often sensitivities in tackling or addressing it within indigenous communities—particularly communities which feel that all or many aspects of their culture are disparaged or are threatened.
- xvi Including a range of UN declaration resolutions and initiatives.
- xvii Right to health and indigenous peoples with a focus on children and youth: <http://documents-dds-ny.un.org/doc/UNDOC/GEN/G16/177/09/PDF/G1617709.pdf>.
- xviii Horton, R., ‘Indigenous peoples: time to act now for equity and health’, *The Lancet*, vol. 367, no. 9524, 2006, pp. 1705–7.