## **OHCHR report on ‘SDGs and the Right to Health’ – submission from Health Poverty Action**

Health Poverty Action is an international development organisation committed to addressing the full range of factors that impact on health and poverty. We work to strengthen health systems in 14 countries worldwide, specialising in hard to reach environments and working with marginalised groups. This means we often work with indigenous peoples and other cultural and ethnic minorities.

Health Poverty Action welcomes the opportunity to provide this submission to the OHCHR’s report on the contributions of the right to health framework to the effective implementation and achievement of the health-related Sustainable Development Goals. Our submission comprises four areas of concern:

* Culturally appropriate health systems
* Data disaggregation
* The Right to Health, Universal Health Coverage, and structural determinants of health
* Access to medicines

### **(i) Culturally appropriate health systems**

As the HRC Resolution recognises, indigenous people are one of the groups that face particular challenges, and intersecting forms of discrimination, in relation to their enjoyment of the right to health. Health Poverty Action has extensive experience in addressing these challenges through our work in providing maternal health and other health-related services to woman and girls from indigenous, and other cultural and ethnic minority, groups.

Mainstream health services may be inaccessible to minority groups for a range of reasons. Ethnic minorities face practical barriers to development. They are more likely to live in the most remote places, lack transport and have higher rates of poverty than mainstream groups. These practical barriers are compounded by cultural ones. These include:

*Language*: Minority groups often have a different first language to that of the mainstream population. Failure to accommodate this presents key barriers to health education, building trust and communicating with health staff, and accessing health information, particularly on sensitive topics.

*Discrimination*: Many minority groups report being discriminated against patronised or treated harshly by health workers when engaging with health services.

*Alternative concepts of health*: Many indigenous communities have a different concept of health to mainstream social groups. Often this does not focus on the individual, but is a holistic concept which encompasses the collective well-being of their community and ecosystem. This leads to alternative approaches to dealing with illness. Many indigenous communities will initially seek traditional healing, before ‘other’ (western) treatment when advised to by a healer. Often a pragmatic combination of traditional and ‘western’ approaches to health and well-being is used.

*Inappropriate services*: These are a significant obstacles to improving the maternal health of indigenous women. For example, Mayan women in Guatemala, and other indigenous women in Latin America, usually give birth in a crouching position. The woman supports herself with a rope strung from the rafters or in the arms of her spouse. Instead of painkillers, a woman is also helped by putting her braided hair between her teeth and biting down on it. Health clinics often refuse to accommodate these practices and instead force women to adapt to mainstream practices such as wearing hospital gowns, giving birth lying down, and involving male doctors. This – in conjunction with issues of language and discrimination – can make giving birth a frightening and humiliating experience for many women. Further, the lack of recognition of Traditional Birth Attendants (TBAs) - a pivotal role which in many communities goes far beyond antenatal and postnatal care - and poor cooperation between health authorities and TBAs can make many women reluctant to attend health services.

*Migration*: Mobile and migrant populations are often composed of different ethnic groups and a mix of various minority and majority groups. Migratory status is by nature transient. A group which would be the mainstream ethnic group in their area of origin becomes a minority group as a result of the migratory activity. Such groups require specific approaches are the basis of their migrant status at a given time.

*Lack of participation*: A key reason for the above barriers is the systematic exclusion of minority groups in the design and delivery of health systems.

Based on our experience in addressing these barriers, Health Poverty Action has developed a set of key principles for the provision of culturally appropriate health services:

**Enabling participation and community feedback**

The inclusion of marginalised communities in the design, delivery and development of services is vital. One method we have found useful to facilitate this is through participatory methods such as community conversations – a transformational participatory methodology which engages diverse members of communities in interactive discussions to consider sensitive issues. The method draws the community’s attention and focus to the issue, and facilitates exchange of various views. Other examples we have effectively used include establishing specific feedback mechanisms, such as Village Health Support Groups or Community Health committees to collate feedback from communities and act as a formal liaison between communities and health authorities.

**Appropriate communication**

The provision of health information and education material in relevant languages is essential to ensure information is understood. However this is not the only reason. In some cases ethnic monitories may not speak the dominant language. In other cases they may understand and speak it, but being forced to communicate in their non-native language can pose a barrier to building trust, especially when discussing sensitive topics. Where communities have oral traditions, health information using pictorial material may be relevant alongside other means of transmitting health messages, such as drama, songs and radio.

**Culturally appropriate services**

HPA has piloted and advocated for health systems that combine modern medicine with positive local practices, especially with regard to birthing. This can include adapting existing health services to incorporate appropriate elements of indigenous cultural and spiritual beliefs; introducing key interlocutors such as traditional birth attendants to assist with births; or, in some cases the provision of complementary services, for example birth waiting homes.

**Forging links between communities and formal services**

This as an important part of building trust between communities and health services, and encouraging referrals. It can involve working with interlocutors who are trusted by communities and can play a key role in engaging both with communities and health services. In many places we have found that Traditional Birth Attendants (TBAs) are ideally placed to fill this role. TBAs play a major role in maternal health across the world. Their longstanding role and status in communities mean they are present in remote locations, respected by the people they serve and provide important practical and emotional support for women. The WHO recommends collaboration between skilled birth attendants and TBAs in order to provide an ‘unbroken chain of care between the community and the health system’ as an interim step of a longer-term plan for training and providing sufficient skilled attendants. We have found that training and supporting TBAs to work as ‘link workers’ between health facilities and women in communities can be a highly successful way of bridging the gaps with formal health services.

### **(ii) Data disaggregation**

There is one further principle that we consider essential for the provision of health services that address the barriers experienced by indigenous people and other minority populations: the data that is collected regarding the utilisation of health services must be disaggregated on the basis of ethnicity. Without this disaggregation, it is impossible to know the scale of the exclusion experienced by minority groups - and therefore also impossible to design and implement the required measures to address that exclusion, or to monitor progress. The recognition of this issue in the Resolution is therefore most welcome.

The fundamental importance of disaggregation data across a wide range of disadvantaged groups is enshrined within the SDGs agenda – but the current approaches of governments, donors and intergovernmental institutions fail to live up to this commitment. For example, the two main international surveys that monitor maternal health are the UNICEF-funded Multiple Indicator Cluster Surveys (MICS), and the USAID-funded Demographic and Health Survey (DHS). However, only a minority of the published national and sub-national surveys conducted under the last two MICS rounds included analysis of maternity related services on the basis of ethnicity; and none of the DHS surveys included this level of analysis.

A forthcoming UNFPA, UNWomen, UNICEF factsheet highlights the challenge of disaggregated data, and calls for the following three steps:

*National governments* should consult indigenous communities about the best ways to collect, analyse and report such data – and act on the advice that they receive.

*International institutions, donors and NGOs* should promote ethnically disaggregated data in their own reporting mechanisms.

*International household survey programmes, and donors supporting the surveys at the country level*should use their influence to improve the collection, analysis and publication of ethnically disaggregated data.

### **(iii) The Right to Health, Universal Health Coverage, and the structural determinants of health**

The Resolution recognises the central importance of the pursuit of Universal Health Coverage (UHC) in the context of the right to health and the SDGs. While of course supporting the objective of ensuring that all people have access to the health services they need without the risk of financial hardship when paying for them, Health Poverty Action does have reservations about the extent to which approaches to achieving UHC can satisfy the requirements entailed by the right to health. The first of these reservations is that – by definition, and/or in practice – the (debate about the) pursuit of UHC does not encompass all of the policies and practices that are relevant to the right to health. For example, while the right to health explicitly includes rights relating to the underlying determinants of health (such as access to safe water, sanitation, food, housing, etc), debates around UHC tend to be more narrowly focused health care services. And in the context of the principles for culturally appropriate health services discussed above, a further concern is that UHC debates and approaches are less clear on the principles of participatory decision-making and prioritising vulnerable and marginalised groups than is required by the obligations entailed by the right to health.[[1]](#footnote-1)

Our second concern about the ‘UHC agenda’ is more fundamental. Numerous recent studies - including a recent WHO study[[2]](#footnote-2) - have highlighted the huge gap between how much money poor- and middle-income countries will be able to spend on health services (even in the most optimistic scenarios), and the level of expenditure necessary to achieve UHC. The only way that these countries will have any chance of bridging this gap is if rich and powerful countries take action to address the structural determinants of poverty, inequality, and health injustice. Examples of structural determinants that were identified by the WHO Commission on the Social Determinants of Health included inequitable trade policies, reversal of capital flows, debt burden, and the impact of EU export subsidies. A recent analysis of the impact of structural factors such as these on the economies of the 48 countries comprising ‘sub-Saharan Africa’ found that these countries are in fact net creditors to the rest of the world, to the tune of $41.3 billion (in 2015).[[3]](#footnote-3)Action to address these structural determinants therefore needs to be central element in any global strategy to achieve UHC – and, of course, to satisfy the obligations entailed by the right to health.

### **(iv) Access to medicines**

Health Poverty Action strongly endorses the concerns expressed in the Resolution about lack of access to medicines for a large proportion of the world’s population. One third of people in the Global South are denied access to essential medicines.[[4]](#footnote-4) Whilst it is predominantly wealthy countries and international financial institutions who advocate trade liberalisation, when it comes to intellectual property, they tend to support the opposite – for increased government intervention. This is due to the influence of forces such as the pharmaceutical industry who advocate for stronger patent protection for their drugs to keep prices high to fund research and boost profits. In 2014 1.5 million people died from TB.[[5]](#footnote-5) A course of treatment for some forms of the disease can cost up to US$ 250,000.[[6]](#footnote-6) These high prices mean governments and patients can afford fewer drugs, and in many instances the poor are not able to afford them at all.

Provisions in trade agreements include patent protections which restrict access to cheaper, generic medicines. In the US, the Food and Drug Administration reports that the cost of a generic drug is 80 to 85 percent lower than the brand name product.[[7]](#footnote-7) The Agreement on Trade-Related Aspects of Intellectual Property (TRIPS) introduced in 1995 is binding on all members of the World Trade Organization. TRIPS establish a common set of global standards to protect intellectual property including 20 years patent protection, and shielding test data against ‘unfair commercial use’. The result is that a patent can give the originator company a market monopoly for 20 years, allowing it to push up prices and stifle competition. The balance between the interests of pharmaceutical companies who hold the patents and the people who rely on the medicines are severely skewed.

The group of Least Developed Countries have pushed to be exempt from enforcing patent protection on pharmaceutical products required under the TRIPS Agreement, but opposition from the USA resulted in an extension to the deadline rather than full exemption.

In addition, despite TRIPS flexibilities being a legal and legitimate means to protect the right to health, some pharmaceutical companies have previously been exposed trying to prevent their application.[[8]](#footnote-8) The USA and European countries have pushed for even stricter intellectual property rights than those under TRIPS[[9]](#footnote-9) in so called TRIPS plus agreements[[10]](#footnote-10) which introduce additional measures such as extension of patents, and data exclusivity provisions giving companies exclusive rights not to reveal data on drug safety and efficacy.[[11]](#footnote-11)

1. For a fuller discussion of the extent to which UHC approaches can and cannot satisfy right to health requirements, see this WHO paper: <http://apps.who.int/iris/bitstream/10665/199548/1/9789241509770_eng.pdf?ua=1>. [↑](#footnote-ref-1)
2. [http://www.thelancet.com/journals/langlo/article/PIIS2214-109X(17)30263-2/fulltext](https://urldefense.proofpoint.com/v2/url?u=http-3A__www.thelancet.com_journals_langlo_article_PIIS2214-2D109X-2817-2930263-2D2_fulltext&d=DwMGaQ&c=euGZstcaTDllvimEN8b7jXrwqOf-v5A_CdpgnVfiiMM&r=UyrnjtBcWO9Py7gT8Qn0GMgJdPu-TOTf3fE_7jPNbnI&m=-e4rB6p0XIecRJ0hhHCd9QDMkOo3nEEKrXr4onLZRmU&s=xB1ljxsvdteKAM2NuJZ3cJWZ5VWmwqV1ZOMFMYsa4Xs&e=). [↑](#footnote-ref-2)
3. [https://www.healthpovertyaction.org/wp/wp-content/uploads/2014/07/Honest-Accounts-2017-1.pdf](https://urldefense.proofpoint.com/v2/url?u=https-3A__www.healthpovertyaction.org_wp_wp-2Dcontent_uploads_2014_07_Honest-2DAccounts-2D2017-2D1.pdf&d=DwMGaQ&c=euGZstcaTDllvimEN8b7jXrwqOf-v5A_CdpgnVfiiMM&r=UyrnjtBcWO9Py7gT8Qn0GMgJdPu-TOTf3fE_7jPNbnI&m=-e4rB6p0XIecRJ0hhHCd9QDMkOo3nEEKrXr4onLZRmU&s=FYfRW4sJCSAhzJxV-SqeufXv3AKgl-yM3uZz_wmsf3s&e=).  [↑](#footnote-ref-3)
4. WHO, Trade, foreign policy, diplomacy and health <http://www.who.int/trade/glossary/story002/en/>. [↑](#footnote-ref-4)
5. WHO Media Centre, Tuberculosis Fact sheet N°104 Updated October 2015 http://www.who.int/mediacentre/factsheets/ fs104/en/. [↑](#footnote-ref-5)
6. Trade Justice Movement, September 2015, TTIPing Away the Ladder: How the EU-US trade deal could undermine the Sustainable Development Goals. http://www.tjm.org.uk/documents/TTIPing\_Away\_the\_Ladder.pdf. [↑](#footnote-ref-6)
7. U.S. Food and Drug Administration, Facts about Generic Drugs http://www.fda.gov/drugs/resourcesforyou/consumers/buyingusingmedicinesafely/understandinggenericdrugs/ ucm167991.htm#\_ftn3The. [↑](#footnote-ref-7)
8. STOPAIDS condemn pharmagate plot, stopaids.org.uk/stopaids- protest-mercks-london-hq/. [↑](#footnote-ref-8)
9. Médecins Sans Frontières, TRIPS, TRIPS Plus and Doha <http://www.msfaccess.org/content/trips-trips-plus-and-doha>. [↑](#footnote-ref-9)
10. Bridging the divide: global governance of trade and health, Lee, Kelley et al. The Lancet , Volume 373 , Issue 9661 , 416 – 422 [http://www.thelancet.com/journals/lancet/article/PIIS01406736(08)61776-6/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS01406736%2808%2961776-6/fulltext). [↑](#footnote-ref-10)
11. Médecins Sans Frontières, TRIPS, TRIPS Plus and Doha http://www.msfaccess.org/content/trips-trips-plus-and-doha. [↑](#footnote-ref-11)