COMMUNITY RESPONSES
FOR HEALTH A GAMECHANGER
FOR PRIMARY HEALTH CARE AND
UNIVERSAL HEALTH COVERAGE

72nd World Health Assembly Advocacy Brief

This brief- by the Free Space Process and the Partnership to Inspire, Transform and Connect the HIV Response (PITCH) - advocates for the recognition, inclusion and resourcing of community-based and led responses for health. It outlines what such responses are, why they matter – in the context of primary health care and universal health coverage - and what they need.

This brief advocates for the recognition, inclusion and resourcing of community-based and led responses for health. It outlines what such responses are, why they matter – in the context of primary health care and universal health coverage - and what they need.

This brief also sets out recommendations for strong and unambiguous commitments to community responses for health to be made in the decision points, declarations and accountability frameworks of key, global health processes in 2019. These include the 72nd World Health Assembly and the United Nations High-Level Political Forum on Sustainable Development and High-Level Meeting on universal health coverage. In the lead-up to and proceedings of such fora, it is recom-mended that Member States and other stakeholders should:

1. Articulate an unambiguous and strong **commitment** to community-led and based responses as essential to the prioritisation

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of primary health care, achievement of universal health cove-rage and acceleration of progress across all of the SDGs.

2. Recognise and support the full diversity of **human resources** required for community-based and led responses for health - that extends beyond Community Health Workers to include a wide range of community implementers, stakeholders and partners.

3. **Resource** community-based and led responses for health - through fair and sustainable national financing for pri-mary health care and universal health coverage, combined with on-going donor support to fill strategic gaps.

4. Ensure the structured and meaningful **engagement** of those involved in community-based and led responses in all key mechanisms

and processes for health, including the development of plans and packages to deliver universal health coverage.

This also calls for the fulfilment of existing commitments to community-based and led responses for health. For example, the 13th General Programme of Work of the World Health Organization (WHO) sets out an approach to communicable diseases that focuses on those most marginalised, expands community engagement and positions community-based service delivery, health promotion and disease prevention as central to all three objectives of universal health coverage[1]. The Global Action Plan for Healthy Lives and Well-Being for All – coordinated by WHO and uniting twelve global health and development agencies – identifies community and civil society engagement as one of its seven accelerators for progress on the health-related Sustainable Development Goals (SDGs)[2].

? **What are community responses for health?**

Community responses for health are the combination of actions taken by, in and with communities[3] to prevent and address health problems, and to ensure people's wellbeing[4].

Community responses for health are designed, led and implemented by community groups and members (including those living with and directly affected by health conditions), as well as other types of civil society organisations. Community-based and led responses for health are multi-dimensional. They combine[5]:

1. **Community-based and led service delivery,** such as initiatives with and by communities to: conduct treatment literacy among people with TB; provide home-based counseling for women experiencing gender-based violence; or distribute Antiretroviral drugs for people living with and/or at risk for HIV.

2. **Advocacy, campaigning and participation in accountability,** such as initiatives with and by communities to: advocate for the

reform of laws that criminalise vulnerable populations or perpetuate harmful gender norms; monitor national disease prevention and treatment programmes; and engage in governance and decision-making bodies for local health programmes.

3. **Participatory, community-based research and monitoring,** such as initiatives with and by communities to: research the social determinants of health for excluded communities; track the scale of drug stock-outs in local health clinics; and analyse the barriers to health services for marginalised young people.

4. **Community financing,** such as initiatives with and by communities to: advocate for health funding from diverse national and international sources; implement onward granting to community projects; and mobilise financial, technical and in-kind resources from local stakeholders.

Community-based and led responses are integral – rather than 'parallel' or 'additional' - to resilient, comprehensive and sustainable *systems for health*. They complement – and fill the strategic gaps of - other sectors, including the largely bio-medical and facility-based health systems of governments.
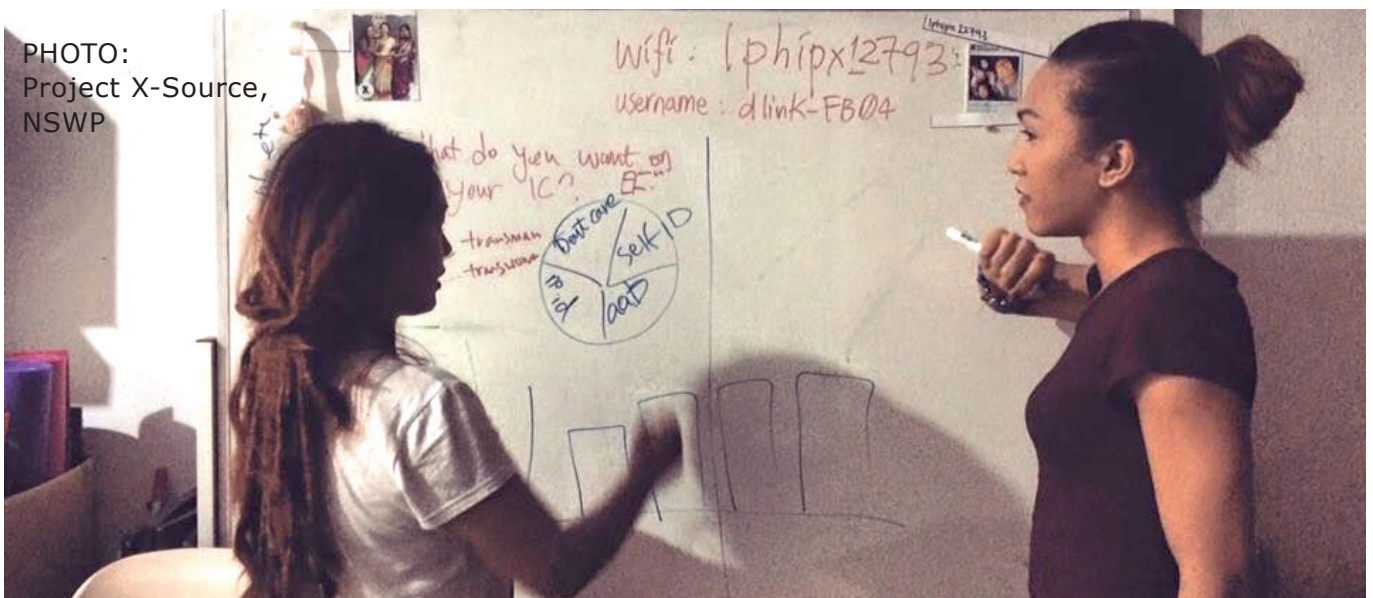
Community responses for health are dynamic – varying according to the local context, needs and resources. They are also responsive – able to identify and adapt quickly to changes in demographics (such as ageing populations) and

The interventions furthest along the spectrum - those that are most truly based in and led by communities, including those that are marginalised and excluded – play an especially important role. They complement, but are different from, interventions such as Community Health Workers – who are often part of and managed by institutionalised government systems.

contexts (such as humanitarian and emergency situations).

Community responses encompass a broad spectrum of interventions. These range: from those (to the left of the spectrum) that are that are formal, strongly linked to health and seen as part of the structured health sector; to ones (to the right) that are informal, less obviously related to health and 'under the radar'5. In the centre, there are 'overlap' interventions that are connected to the formal health sector but are within and by communities – such as the community-based delivery of prevention and treatment services.

PHOTO:
Project X-Source,
NSWP

? What do community responses for health look like?

COMMUNITY RESPONSES WITHIN THE FORMAL HEALTH SECTOR
For example:
* Community Health Workers
* Integrated Community Case Management
* Formalised local governance of health programmes

COMMUNITY RESPONSES PARTIALLY WITHIN THE FORMAL HEALTH SECTOR
For example:
* Community health education
* Community distribution of health commodities
* Home-based care

COMMUNITY RESPONSES OUTSIDE OF THE FORMAL HEALTH SECTOR
For example:
* Programmes on social determinants of health (e.g. gender equality, human rights)
* 'Under radar' services
* Community-led social accountability

Example: Finding 'missing' people with TB

In Cambodia, a community-based project in Siem Reap strengthens the relationships between people with TB, community support groups, health facilities and local authorities. A key strategy is empowerment of the Siem Reap District Network of People With or Affected by TB, whose members combine their local knowledge and their relations with other stakeholders to find 'missing' people with TB and advocate for better TB services[6].

Worldwide, community-based and led systems are vital for preventing, finding and treating the four million people who, each year, are not diagnosed, treated or given high quality care for TB. [7]

Example: Integrating health services for marginalised communities

In El Salvador, a community-led center in Sonsonate enables sex workers to access literacy lessons alongside information about alcohol and drug abuse, SRHR (including HIV prevention) and dealing with difficult clients. Through this integrated intervention, the sex workers can not only have their health needs addressed, but empower each other by reducing their social exclusion and discrimination.

Worldwide, community-based and led systems are vital for holistic support by and for marginalised groups, such as sex workers who face high levels of violence and rights abuses and have complex health and social needs.[8]

Example: Preventing malaria among vulnerable populations

In Boboye Health District, Niger, Community Health Committees distribute insecticide treated bed nets to households with young children and pregnant women, to prevent malaria. This has led to more equitable coverage and higher use of nets and, in turn, lower malaria prevalence and mortality.[9]

Worldwide, community-based and led approaches are key to increasing the distribution of insecticide treated bed nets to those most at risk, with coverage rising from 1% in 2000 to 54% in 2016.[10]

Example: Scaling up access to HIV treatment

In countries such as Kenya, Mozambique and South Africa, Antiretroviral therapy has been delivered to people living with HIV through community-based adherence clubs, distribution points and treatment groups. These models have produced higher levels of treatment adherence and retention in care, combined with lower levels of service provider costs and financial burdens for service users.[11]

Worldwide, community-based and led distribution and adherence support has been pivotal to scaling up access to treatment for people living with HIV, with levels rising from 2% in 2000 to 59% in 2017.[12]

Example: Averting and responding to Ebola crises

In the Democratic Republic of Congo, local stakeholders - such as community elders, women and networks of community-based volunteers - have raised awareness about Ebola, debunking local myths (such as about connections to witchcraft) and providing accurate facts (such as about early symptoms). They serve as an early warning system – able to spot emerging outbreaks and mobilise a response, in coordination with the government, health care workers, civil society organizations and development partners.[13]

Worldwide, community-based and led systems, based on local knowledge, are key to preparedness for health emergencies such as Ebola that, in 2014-16, caused over 11,000 deaths in West Africa.[14]

? Why do community responses for health matter?

Community responses matter because they are fundamental to health equity. They promote health as a human right (not a privilege or commodity), ensure 'no one left behind' and, in turn, improve the health outcomes for *all*. Community responses bring innovation, quality, scale and reach in a way that other sectors are unable, or unwilling, to do.

Community responses are at the heart of primary health care. The Declaration of Alma-Ata (1978) stated that achieving the highest possible level of health requires *"maximum community and individual self-reliance and participation in the planning, organisation, operation and control of primary health care."*[15] The Declaration of Astana (2018) re-iterated that healthcare requires *"enabling and health-conducive environments in which individuals and communities are empowered and engaged in maintaining and enhancing their health and well-being."* [16]

Community responses for health are essential to achieving all of the SDGs. This includes the health-related targets of SDG 3[17], including to end the HIV, TB and malaria epidemics, provide universal access to sexual and reproductive health and rights (SRHR) and achieve Universal Health Coverage[18]. However, it also includes the targets that relate to the wider determinants of health and wellbeing. These include poverty reduction, education, peace, justice and economic empowerment, as well as the elimination of all forms of violence and promotion/enforcement of non-discriminatory laws and policies.

The centrality of community responses is spelt out across many of the other key frameworks for global health. These include the: plans for collaborative action (such as the Global Action Plan for Healthy Lives and Well-being for All[19]); strategies to end individual diseases (such as the Stop TB Partnership's Global Plan to End TB[20]); and normative guidance on good practice (such as WHO's Framework on Integrated, People-Centred Health Services[21]).

Community-based and led responses are based on a rich history of experiences and lessons, including from decades of focused interventions and activism, such as for HIV and women's health. Now, such responses are critical to the next generation of action needed – in terms of approaches to health that are integrated (addressing multiple health-related issues), holistic (responding to the 'whole person') and truly universal (being available and accessible to all).

! The added value of community responses for health

Evidence-based advocacy	Accessibility of services
Connected health responses	Holistic care
Research	Governance and accountability
Behaviour change	Value for money
Health equity / leaving no one behind	Monitoring, evaluation and quality
Eliminating stigma and discrimination	Crisis aversion and response
Integrated and combined services	Sustainability

ADDED VALUE OF COMMUNITY RESPONSES

Community-based and led responses bring diverse and significant added value to a country's system for health. This includes in relation to:

Evidence-based advocacy

Identifying 'communities' real-life priorities and concerns, and using them to advocate for changes to policies, laws and resource allocations.

Connected health responses

Serving as a bridge between communities and other health services (notably by government), ensuring comprehensive and joined-up health care.

Research

Building on relations of trust with local communities to explore 'what works', such as to increase marginalised communities' uptake of health services.

Behaviour change

Using understanding of the local society and culture to support individuals to make and sustain behaviour change, such as for disease prevention.

Health equity / leaving no one behind

Ensuring social inclusion, with health services that are accessible for all community members, including those that are marginalized and criminalised, and that have complex health needs.

Eliminating stigma and discrimination

Understanding and tackling the stigma and discrimination associated with specific: health conditions (such as HIV and TB); issues (such as sexual orientation, gender identity and expression, and sex characteristics (SOGIESC)); and populations (such as sex workers and people who use drugs).

Integrated and combined services

Delivering integrated packages that combine attention to different health issues, and cut across prevention, care, support and treatment.

Gender equality

Understanding and addressing the gendered power dynamics and inequalities that limit access to health for community members, including women and girls.

Accessibility of services

Ensuring that health services are physically, socially and financially accessible to local communities, including those excluded by other providers.

Scale of reach

Having the connections and infrastructure to reach large numbers of community members, including those that are geographically or socially isolated.

Holistic care

Providing innovative and tailored health interventions to address the 'whole person', rather than using a 'one size fits all' or disease-specific approach.

Governance and accountability

Bringing communities' experiences and issues to the governance mechanisms of health services, and holding stakeholders to account.

Value for money

Providing interventions that are cost-effective, affordable and sustainable – maximising local resources and minimising out-of-pocket expenses.

Monitoring, evaluation and quality

facilitating community-based monitoring, whereby programme quality and impact can be identified, learned from and improved.
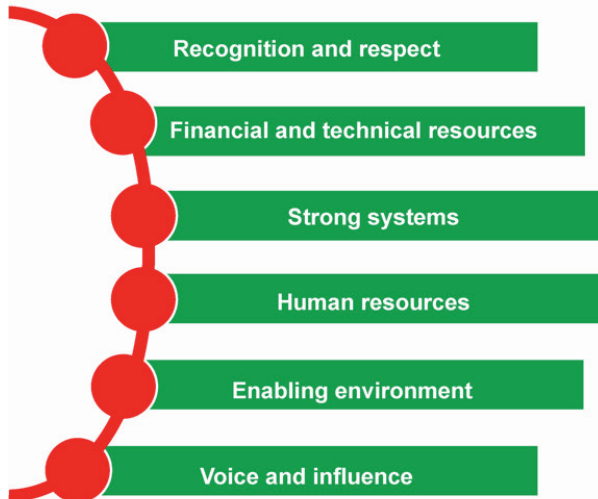
Crisis aversion and response

Identifying emerging health problems and being 'first responders' within coordinated and localised[22] responses to humanitarian emergencies.

? What do community responses for health need?

To play their full role in primary health care and universal health coverage – and maximise their unique contribution to health equity, rights and outcomes – community responses need:

THE NEEDS OF COMMUNITY RESPONSES FOR HEALTH

- Recognition and respect
- Financial and technical resources
- Strong systems
- Human resources
- Enabling environment
- Voice and influence

- **Recognition and respect:** Communities need to be understood as essential partners in countries' systems for health. Their unparalleled experience, evidence and expertise should be formally acknowledged – such as in plans and packages for universal health coverage - as a critical complement to other stakeholders, including the government and private sector.

- **Financial and technical resources:** Community responses for health need an appropriate quantity and quality of resources. This includes adequate and sustainable funding. Communities need to be allocated resources within national budgets, including as larger proportions of government expenditure is targeted to health. They also require on-going support from international sources, including in contexts where donors are implementing policies of transition. Here, international funding remains vital to fill strategic gaps – especially in responses for excluded and marginalised groups, which governments may be unable or unwilling to finance. Meanwhile, in all contexts, community responses also need access to technical resources, such as normative guidance and capacity building on good practice approaches.

- **Strong systems:** Community responses do not 'just happen', but need effective, efficient and resourced systems. For example, to fulfil their role, community-led and based groups need opportunities to: strengthen their financial and administrative processes; conduct effective planning; access resources; develop monitoring systems; create alliances; build their leadership; and engage in advocacy[23].

- **Human resources:** Community responses also require human resources that include, but go beyond, the conventional and widely recognised role of Community Health Workers. All types of stakeholders in community responses – from peer educators to home-based care volunteers - should be recognised as part of a country's health workforce and receive appropriate technical support (such as opportunities for training) and financial remuneration.

- **Enabling environment:** Community responses require a social, political and legal environment in which they can operate openly and effectively. This includes the removal of policies, laws and social norms that violate the rights of community members, including those – such as sex workers, people who use drugs and lesbian, gay, bisexual, trans and intersex (LGBTI) people – who are most marginalized and vulnerable to health conditions. It also includes the provision of a structural environment in which community groups and civil society organizations can register, function and access resources freely and safely.

- **Voice and influence:** Those involved in community responses need opportunities to state their needs and have their opinions heard within health governance at all levels (local, national, regional and global). Beyond a 'seat at the table', they require meaningful engagement – whereby they can influence decision-making on policies and resources. They also need to have the opportunities and safe spaces within which to hold others – including the government – to account for their performance on health.

PHOTO:
Global Fund
Meeting, NSWP

RECOMMENDATIONS

The following recommendations are made to representatives of Member States and other key stakeholders – such as donors, global health agencies, civil society organisations and communities - engaged in the lead-up to and proceedings of key decision-making fora on global health in 2019. These include:

72nd World Health Assembly, Geneva, 20-28 May [24] which includes agenda items on the 2030 Agenda for Sustainable Development[25], Universal Health Coverage[26], human resources for health[27] and public health emergencies preparedness and responses[28].

High Level Political Forum on Sustainable Development, New York, 9-18 July[29] which has a theme of 'Empowering People and Ensuring Inclusiveness and Equality' and includes reviews of SDGs 10 (reduced inequalities) and 17 (partnership).

United Nations High-Level Meeting on Universal Health Coverage, New York, 23 September[30] which has a theme of 'Moving Together to Build a Healthier World' and will result in a Political Declaration on universal health coverage setting out Member States' commitments and accountabilities.
It is recommended that - within ambitious decision points, declarations and resource allocations at these events – Member States and other key stakeholders:

1. Articulate an unambiguous and strong commitment to community-led and based responses as essential to the prioritisation of primary health care, achievement of universal health coverage and acceleration of progress across all of the SDGs.

Community-based and led responses should be understood and stated as being at the heart of primary health care – the priority and foundational strategy required for Universal Health Coverage and progress across all of the SDGs. Such responses should be recognised as bringing unique added value to prevention, care, support and treatment interventions for health and wellbeing. This includes in terms of: promoting the right to health; ensuring health equity ('leaving no one behind', including those most marginalized and vulnerable); reaching scale; providing person-centered services; ensuring high quality; facilitating and delivering integrated programmes; responding to emergencies; and providing value for money.

2. Recognise and support the full diversity of human resources required for community-based and led responses for health - that extends beyond Community Health Workers to include a wide range of community implementers, stakeholders and partners.

Examples of such human resources include: community groups; community health volunteers; community health committees; prevention and outreach workers; traditional leaders; religious leaders; community centres; and peer supporters, such as prevention providers, outreach workers and peer educators (including those living with and directly affected by health conditions).

3. Resource community-based and led responses for health - through fair and sustainable national financing for primary health care and universal health coverage, combined with on-going donor support to fill strategic gaps.

Community-based and led responses should - rather than be viewed as 'cheap' or 'free' - receive adequate and appropriate funding. This includes through fair and equitable domestic systems (such as of insurance and taxation) developed to finance universal health coverage, combined with responsible policies and on-going support from international donors. The latter is required to fill strategic gaps, particularly in contexts where governments cannot or will not fund community responses, in particular for those who are marginalised and criminalised.

4. Ensure the structured and meaningful engagement of those involved in community-based and led responses in all key mechanisms and processes for health, including the development of plans and packages to deliver universal health coverage.

The multi-sectoral efforts required to prioritise primary health care and deliver universal health coverage must actively involve the unique experiences, lessons and insights of those involved in community-based and led responses. Such engagement should be institutionalised and meaningful – enabling such stakeholders to participate freely and safely, and to concretely influence decision-making and resource allocation.

5. Agree a strong and transparent accountability framework for universal health coverage – enabling communities to hold Member States to account, including on prioritising primary health care, 'leaving no one behind' and resourcing community-based and led responses.

Decision-points and commitments – notably the Political Declaration on Universal Health Coverage - should be accompanied by strong and transparent accountability frameworks. These should cite measurable targets and indicators, through which all relevant stakeholders – including communities – can hold Member States to account for their performance, including in relation to prioritising primary health care, 'leaving no one behind' and resourcing community responses for health.

The Free Space Process was created to provide a safe space where networks could meet, learn from each other's work and start developing a shared agenda, and it seeks a global HIV response that sustainably and comprehensively engages diverse segments of the communities as essential drivers of the response. Its members are: MPact Global Action for Gay Men's Health & Rights; Frontline AIDS; International Network of People Who Use Drugs (INPUD); Global Network of Sex Work Projects (NSWP); HIV Young Leaders Fund; International Community of Women Living with HIV (ICW): Global Network of People Living with HIV (GNP+); International Treatment Preparedness Coalition (ITPC); ICASO; Global Action for Trans Equality (GATE); and Ecumenical Advocacy Alliance.

The Partnership to Inspire, Transform and Connect the HIV response (PITCH) enables people most affected by HIV to gain full and equal access to HIV and sexual and reproductive health services. The programme strengthens community-based organisations' capacity to uphold the rights of populations most affected by HIV by engaging in effective advocacy, generating robust evidence and developing meaningful policy solutions. PITCH is a strategic partnership between Aidsfonds, Frontline AIDS and the Dutch Ministry of Foreign Affairs.

1   World Health Organisation 13th General Programme of Work, 37th World Health Assembly, 3 April 2018.

2   The Global Action Plan for Healthy Lives and Well-Being for All; https://www.who.int/sdg/global-action-plan

3   'Community' is a widely used term that has no single or fixed definition. Broadly, communities are formed by people who are connected to each other in distinct and varied ways. Communities are diverse and dynamic. One person may be part of more than one community. Community members may be connected by living in the same area or by shared experiences, health and other challenges, living situations, culture, religion, identity or values. As defined in: Community Systems Strengthening Framework - Revised Edition, the Global Fund to Fight AIDS, Tuberculosis and Malaria, February 2014.

4   Definition is based on a number of sources, including: The Crucial Role of Communities: Strengthening Responses to HIV, Tuberculosis and Malaria, the Global Fund to Fight AIDS, Tuberculosis and Malaria, April 2018; and Communities Deliver: The Critical Role of Communities in Reaching Global Targets to End the Aids Epidemic, UNAIDS and Stop AIDS Alliance, 2015; and Increasing the Evidence on the Role of the Community In Response to HIV/AIDS, Rodriguez-Garcia R, Bonnel R, Journal of Epidemiology Community Health, October 2012.

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6   Grantee Profile: KHANA, Cambodia, Challenge Facility for Civil Society Round 8, Stop TB Partnership.

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13 Early Detection, Early Action: Preventing DRC's Ebola Outbreak From Spreading Into Nearby Uganda, IFRC, 26 January 2019; https://media.ifrc.org/ifrc/2019/01/26/early-detection-early-action-preventing-drcs-ebola-outbreak-spreading-nearby-uganda-2/; and Women Are Key In Ebola Response, WHO, 27 January 2019; https://www.who.int/news-room/facts-in-pictures/detail/women-join-hands-to-oust-ebola-from-drc

14 Community Engagement in the Ebola Response, WHO; https://www.who.int/features/2014/community-stories-ebola/en/; and 2014-2016 Ebola Outbreak in West Africa, CDC, https://www.cdc.gov/vhf/ebola/history/2014-2016-outbreak/index.html

15 Declaration of Alma-Ata, International Conference on Primary Health Care, 1978.

16 Declaration of Astana, Global Conference on Primary Healthcare, 2018.

17 'Ensure healthy lives and promote well-being for all at all ages'.

18 Sustainable Development Goal 3; https://sustainabledevelopment.un.org/sdg3

19 Towards a Global Action Plan for Healthy Lives and Well-Being for All, a joint initiative of WHO, UNAIDS, UNDP, World Bank, UNFPA, UNWOMEN, UNICEF, UNITAID, GAVI and the Global Fund to Fight AIDS, Tuberculosis and Malaria, 2018.

20 The Paradigm Shift 2016-2020: Global Plan to End TB, the Stop TB Partnership.

21 Framework on Integrated, People-Centred Health Services, WHO, April 2016.

22 The localisation agenda – which commits to changing the way humanitarian stakeholders work with and relate to national actors - was endorsed at the World Humanitarian Summit, Istanbul, 2016.

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24 Seventy-Second World Health Assembly, WHO; https://www.who.int/about/governance/world-health-assembly/seventy-second-world-health-assembly

25 Implementation of the 2030 Agenda for Sustainable Development, document A72/11, provisional agenda item 11.4 for 72nd World Health Assembly, 1 April 2019.

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