

COMMUNITY RESPONSES FOR HEALTH:

Issues and ideas for collaborative action



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PITCH Partnership to Inspire, Transform
and Connect the HIV response

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PART 1: INTRODUCTION

1.1. What is this discussion paper?

This discussion paper aims to explore current issues and potential future collaborations concerning community responses for health. It is based on an understanding that such responses are an integral part of comprehensive, resilient and sustainable systems for health. They are multi-dimensional, such as combining community-based service delivery with roles in advocacy, monitoring and governance. They bring significant value-added – often being more responsive and innovative than other aspects of health services and having unique reach and scale. Community responses are essential to demanding, shaping, providing and improving health interventions that are person-

centered, accessible, cost-effective and accountable.

They have a particularly crucial role in reducing health inequity - ensuring 'no one left behind' (including those who are vulnerable and marginalised) and, ultimately, improving health outcomes for all.

Yet, in practice – within many fields of health and among many key stakeholders and institutions - community responses remain poorly understood, acknowledged and/or resourced. This is due to multiple reasons. These range from the dominance of bio-medical, government-led and facility-based approaches for health to the lack of common language on this area within community responses themselves. This scenario is of particular concern within the current generation of frameworks and architecture for global health.

Community responses should be recognised as intrinsic, not an optional extra, to achieving all of the Sustainable Development Goals (SDGs). This includes Goal 3 (ensure healthy lives and promote well-being for all at all ages), including its targets to end AIDS, tuberculosis (TB) and malaria and to achieve universal health coverage¹. Yet, there appears to be limited collective momentum – in

terms of a coordinated movement for community responses to be at the heart of relevant health debates, strategies and investments. A greater sense of urgency focus and collaboration – that cuts across health areas, sectors and institutions - is needed if community responses are not to be neglected or over-simplified within today (and tomorrow's) complex and deeply political context. As outlined in the Global Action Plan for Healthy Lives and Well-Being², coordinated by the World Health Organization (WHO), community responses lie at the heart of the greater action that is needed now in order to align, accelerate and account for progress towards the health-related SDGs [see Box 1].

This paper aims to serve as a step towards addressing the current challenges and limitations. The remainder of Part 1 provides further information about the development of and rationale for this resource. Part 2 outlines key issues to be discussed and clarified in relation to community responses for health. These include: how such responses are defined; what they look like in practice; what added value they bring; how they contribute to SDG 3, particularly universal health coverage; and what resources they require. Part 3 of this paper explores the types of collaborative processes - of those involved in developing this paper and other stakeholders - that might be required going forwards. It also explores ideas for materials to support such processes, such as a Global Framework on Community Responses for Health.

BOX 1: THE OPPORTUNITY OF THE SDGS AND UNIVERSAL HEALTH COVERAGE

“The inclusion of UHC in the SDGs presents an opportunity to promote a comprehensive and coherent approach to health, focusing on health systems strengthening, including at the community level. UHC realises the principle that all individuals and communities should have access to quality essential health services without suffering financial hardship. UHC cuts across all health targets and contributes to economic productivity, social stability and sustainable development - and to every individual's right to health, well-being and security.”

– Global Action Plan for Healthy Lives and Well-Being: Uniting to Accelerate Progress Towards the Health-Related SDGs

1.2. How was this discussion paper developed?

The development of this paper was supported by a Project Steering Committee. This is comprised of global civil society organisations, technical agencies and financing mechanisms involved in diverse aspects of health, particularly communicable diseases. The members are: Aidsfonds; the Free Space Process³; the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund); the International Council of AIDS Service Organisations (ICASO); Frontline AIDS ; the Joint United Nations Programme on HIV/AIDS (UNAIDS); MPact Global Action for Gay Men's Health and Rights; the Stop TB Partnership; and WHO. This paper was funded by the Partnership to Inspire, Transform and Connect the HIV Response (PITCH), a strategic partnership between Aidsfonds, Frontline AIDS and the Dutch Ministry of Foreign Affairs.

This paper was written by an Independent Consultant. It was informed by a combination of methodologies, including: interviews with members of the Project Steering Committee and selected other stakeholders⁴; a panel session at the Global Village of the 2018 International AIDS Conference⁵; and a desk review of resources - such as position papers, research reports and strategies - produced by a wide range of institutions involved in global health [see Annex 1 for selected examples]. It should be noted that, as a discussion paper, this resource includes multiple examples, such as of definitions and case studies. These aim to inform conversations and catalyse debates. They do not intend to serve as definitive versions. It should also be noted this paper is limited by the, as yet, modest scale and breadth of consultation conducted for this initiative. It is acknowledged that any type of future action in this area will need to be developed through the meaningful engagement of a wider range of stakeholders, in particular communities themselves.

Global Fund global meeting.



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The primary audience for this paper is the members of the Project Steering Committee and their constituents and partners. However, it also aims to inform and mobilise other stakeholders that are, or should, be involved in collective action on community responses for health.

1.3. Why is this discussion paper needed?

Efforts to promote community responses for health are far from new. They build on a rich history of work in this area. For example, back in 1978, the Declaration of Alma-Ata stated that achievement of 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."⁶ Forty years later, the 2018 Declaration of Astana re-envisioned "enabling and health-conducive environments in which individuals and communities are empowered and engaged in maintaining and enhancing their health and well-being."⁷

However, in recent years, the role and value of community responses for health has become the subject of increasing scrutiny and traction. This has partly been due to positive reasons, such as the growing wealth of evidence of the concrete outcomes of such approaches. As just one example, community-based engagement, literacy and distribution was key to nearly tripling the number of people living with HIV receiving Antiretroviral therapy (ART) during 2010 to 2017⁸. However, it has also been for more difficult reasons, such as the harsh reality-checks provided by health crises. One example is the Ebola outbreak in West Africa, which demonstrated the severe consequences of fragmented systems for health where communities are not supported to self-organise or to play their full role⁹.

Increased recognition of community responses for health can now be seen within the:

- **Global frameworks on health and development**
that serve as the umbrella strategies for all stakeholders at national, regional and international levels. As one example, the 2030 Agenda for Sustainable Development calls for multi-stakeholder partnerships across the SDGs, within efforts to 'leave no one behind'.¹⁰
- **International commitments on individual diseases**
that set out the priorities and targets for national governments and other stakeholders. As one example, the Global Technical Strategy and Targets for Malaria 2016-2030 cites "country ownership and leadership, with the involvement and participation of communities" as one of its principles¹¹. Meanwhile, the 2016 United Nations Political Declaration on HIV and AIDS¹² affirmed the critical role of communities in advocacy and coordination, and also committed to "expanding community-led service delivery to cover at least 30 per cent of all service delivery by 2030."¹³
- **Strategies of global institutions**
that provide leadership and guidance on health. As one example, WHO's 13th General Programme of Work commits to an approach to communicable diseases that expands community engagement and positions community-based services, health promotion and disease prevention as central to universal health coverage¹⁴. Also, WHO's Framework on Integrated People-Centred Health Services emphasises the importance of communities in health services that are coordinated around people's needs, respect their preferences, and are safe, effective, timely, affordable and of acceptable quality.¹⁵

Many of these measures not only reflect the general importance of community responses but specify that they cannot be achieved without the strong voices, empowerment, engagement and leadership of communities. A further example of this is provided by the global strategies for TB, which call for a paradigm shift from top-down efforts to control the epidemic to multi-sectoral collaboration to end it [see Box 2]. Collaboration with communities and civil society organisations is cited as a principle or pillar of both WHO's End TB Strategy¹⁶ and the Stop TB Partnership's Global Plan to End TB.¹⁷ Annex 4 summarises the ENGAGE-TB approach to strengthening the role of communities in preventing, finding and treating the (each year) four million 'missing' people with TB who are not diagnosed, treated or given high quality care.

This increased profile of community responses in global frameworks and institutional strategies is to be welcomed. It signifies important progress in the positioning of such responses within the next era of global health. However, as yet, the impact of such measures has been questionable – in terms of the scale, pace and effectiveness with which high-level commitments have been translated into tangible changes and investments. This reflects the reality of numerous and multi-level challenges. Examples of these include how to: quantify and meet the resource needs of community responses (within a constrained donor environment); 'sell' the value-added and cost-effectiveness of community responses (within a context dominated by bio-medical and facility-based approaches); and measure and demonstrate the impact of community responses (within monitoring and evaluation systems focused on quantitative results).

Challenges for community responses include those related to the space within which communities and civil society currently operate. For example, such stakeholders – particularly those that are of and/or for marginalised populations – often face low recognition by governments, limited engagement in national processes (both within and beyond health) and low access to domestic funding (an especially critical issue while donors pursue policies of sustainability and transition). They may also experience: hostile legal environments (such as that criminalise marginalised populations); bureaucratic registration processes (that limit their access to funding); and restrictive regulatory environments (such as that stipulate that health services cannot be provided by non-state actors). Such limitations often exacerbate ongoing challenges within the communities and civil society sector itself. Examples include poor coordination across different levels (local, country, regional and global) and different areas (such as communicable and non-communicable diseases).

BOX 2: THE ROLE OF COMMUNITY RESPONSES IN ENDING TB

"The beneficiaries of the End TB Strategy should also drive its implementation. Their engagement and participation will improve understanding of their perspectives, priorities, awareness, needs and expectations. A strong coalition that includes civil society organisations and communities can help by giving patients and vulnerable populations a voice and an active role; accelerating the response to the TB epidemic; improving the use of quality services; expanding investment in research and innovation; and strengthening grassroots advocacy – all essential to mainstream TB into the development agenda."

– Implementing the End TB Strategy: The Essentials, WHO

"To find and treat all people with TB and achieve the End TB Strategy milestones, countries must abandon the passive, top down disease programmes of the past. A radical new approach is required Civil society and community-based organisations must play a key role in the planning and provision of TB care by increasing awareness; active case finding; improving access to care; encouraging adherence; providing psychosocial support and reducing stigma; monitoring programmes; and facilitating community engagement in research and development..... These stakeholders – including patient-based organisations, nongovernmental organisations, faith-based organisations, youth groups and community volunteers – are fundamental partners in the drive towards better access to health and universal health coverage."

– The Paradigm Shift 2016-2020: Global Plan to End TB, Stop TB Partnership

"Challenges for community responses include those related to the space within which communities and civil society currently operate."

Yet further challenges relate to the scope and diversity of interest in and commitment to community responses for health among key stakeholders. Such engagement has sometimes struggled to extend both: throughout key institutions (such as beyond staff whose jobs focus on civil society); and across disease areas (such as beyond those traditionally associated with such responses, such as HIV).

These diverse challenges provide a strong rationale for future thinking and action on community responses for health to be collaborative. In practice, however, much of the work to date has been fragmented – conducted by individual or small groups of organisations, with a lack of shared resources and tools, such as common definitions and joint advocacy messages. This has contributed to a degree of confusion – even tension – between some key stakeholders, such as about exactly what community responses are (and are not) and the type of systems and strategies needed to support them.

“Any agreed definitions and advocacy messages should not be based on an over-simplified or one-size-fits-all approach that risks diluting, restricting or calcifying community responses, rather than celebrating their versatility, innovation and flexibility.”

The process to develop this discussion paper suggested that collaboration on community responses for health is needed now more than ever - within a dynamic context shaped by powerful trends, such as the drive towards universal health coverage and donor policies of transition and sustainability. Such trends present important opportunities for community responses, for example to re-politicise health through

a new wave of activism on equity, accountability and the right to health¹⁸. They also, however, present major threats. These include that community responses risk being subservient to, or even squeezed out of, predominantly large-scale and bio-medical approaches to health.

An important message is that, if collaboration does take place, it should not be founded on stakeholders' 'lowest common denominator'. For example, any agreed definitions and advocacy messages should not be based on an over-simplified or one-size-fits-all approach that risks diluting, restricting or calcifying community responses, rather than celebrating their versatility, innovation and flexibility.

Global Fund global meeting.



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PART 2: KEY ISSUES

2.1. How are community responses for health defined?

As the basis for future collaborative efforts on community responses for health, it will be important to have definitions that are not only clear and succinct but agreed across key stakeholders and institutions. These should be informed - but not restricted - by previously used concepts in this area. Examples include 'community action', 'community mobilisation' and 'community-based approaches'. While each of these can be useful within specific dialogues, there is a sense that the sheer number and range of terms has contributed to a degree of confusion, as well as a perception that this area of work is overly technical and complex.

As a starting point, it is useful to explore a number of foundational terms. These include:

BOX 3: DEFINITIONS OF FOUNDATIONAL TERMS RELATED TO COMMUNITY RESPONSES FOR HEALTH

Term	Example of definitions
Community	The Global Fund states that: "'Community'can be used to refer to people who are connected to each other in varied and distinct ways: People who health systems are trying to reach and whose health they aim to improve. People who are particularly affected by a given health problem. People who share particular characteristics or vulnerabilities due to gender, identity, geography, behavior, ethnicity, religion, culture or age. Groups that represent any of above communities." ¹⁹
Civil society	UNAIDS states that: "Civil society refers to the arena of un-coerced collective action around shared interests, purposes and values. It is the sphere of autonomous associations that are independent of the public and for-profit sectors and designed to advance collective interests and ideas." ²⁰
Community systems	UNAIDS and the Stop AIDS Alliance state that community systems are: "Community-led structures and mechanisms used by communities that enable community members and CBOs and groups to interact, coordinate and deliver their responses to the challenges and needs affecting their communities. Community systems can be informal and small in scale, or they can be extensive networks of organisations. Community systems should not exist in isolation; rather they should serve as a critical component of the overall system that aims to protect and promote health and human rights. These broader systems include government or public health systems (such as, public health facilities, regulatory and governance bodies, and state-employed health-care professionals)." ²¹
Community systems strengthening	UNAIDS and the Stop AIDS Alliance state that: "CSS promotes the development of informed, capable and coordinated communities and CBOs, groups and structures. In other words, it is the capacity building needed to ensure that 'community responses' can be delivered through 'community systems'. It should reach a broad range of community actors and enable them to contribute to the long-term sustainability of health and other interventions at the community level, including the creation of an enabling and responsive environment in which these contributions can be effective." ²²

Health	WHO states that: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." ²³
Health system	WHO states that a health system is: "All the activities whose primary purpose is to promote, restore and/or maintain health." ²⁴
Resilient and sustainable systems for health	The Global Fund states that: "Improved health is the result of harmonised policies, financing mechanisms and the delivery of services and other critical activities, both within and complementary to the health sector. Services and policies are developed and implemented by a variety of actors, including government or public health systems, community-based organisations and networks, nongovernmental, faith-based and private sector organisations. Together, these diverse actors constitute the broad health ecosystem that serves to protect and promote health and human rights." It also states that "Resilient and sustainable systems for health can perhaps be better understood not as static structures with communities and health systems in silos, but as evolving systems that interact and complement each other, and adapt to emerging challenges." ²⁵

In turn, these foundational terms can be used to shape an understanding of 'community responses' and, more specifically, 'community responses for health'. Currently, there is no single, agreed definition of either term. However, suggestions for the former have been provided by individual organisations [see Box 4] and there appears to be agreement on the key characteristics of the latter [see Box 5].

BOX 4: DEFINITIONS OF 'COMMUNITY RESPONSES'

Term	Examples of definitions
Community responses	<p>The World Bank states that community responses are: "The combination of actions and steps taken by communities, including the provision of goods and services, to prevent and/or address a problem to bring about social change".²⁶</p> <p>The Global Fund states that community responses are: "The means by which communities act on the challenges and needs they face."²⁷</p> <p>UNAIDS and the Stop AIDS Alliance state that, in the context of HIV, community responses are: "The collective of community-led activities in response to HIV."²⁸</p>

The process to develop this paper confirmed that, going forwards, there will be a need for a shared understanding of at least these key characteristics or, perhaps, principles. However, it also highlighted that the process to reach such consensus might not be easy – considering the differences (sometimes large, more often nuanced) of perspective among stakeholders. An example is provided by the last characteristic listed in Box 5. Some stakeholders advocate that community responses should only be understood as approaches that are implemented by community-driven/led entities (such as community-based organisations, including those run by marginalised populations). However, others argue that such responses should also incorporate approaches by more formal, established and larger-scale civil society organisations. It is noted that, in some circumstances, this debate manifests as intense competition for resources and power, such as with national and international nongovernmental organisations having preferential access to resources or being selected to 'represent' communities.

While there is broad agreement that 'communities matter', some of the associated language is contested²⁹. For example, while one person's understanding of a 'community response' might be the work of a paid Community Health Worker based

in a government centre, another's is the work of a volunteer transgender peer educator working in a community. Similarly, some of the language is perceived as political, being strongly associated with individual institutions (as with 'resilient and sustainable systems for health', used the Global Fund). Meanwhile, further challenges include that 'communities' language varies across disease areas (such as being different for malaria compared to HIV) and changes over time (such as with a growing emphasis on terms such as 'risk' and 'resilience').

A key example of differing opinions is the extent to which future work should include language around 'community systems' and 'community systems strengthening' (CSS)³⁰ [see Box 3] - concepts that have been especially important for shaping funding opportunities for community responses to HIV. CSS was the subject of a substantial framework developed by the Global Fund, first in 2010³¹ and then modified in 2014³² [see Annex 3 for its building blocks]. This benefitted from the input of civil society organisations, technical agencies and funding institutions. Now, some members of the Project Steering Committee call for the framework to be re-vitalised. Others, however, feel that this would be counterproductive, as CSS was found to be overly complex and - while often cited in strategies and grant proposals - lacked implementation. They also argue that the terminology has now moved on to focus on 'systems for health' (that incorporate community responses) and 'integrated programming' (whereby systems need to address multiple areas of health, rather than a single disease).

In conclusion, any future collaborative efforts will require a frank reflection on concepts and terminology. This should aim to ensure that any texts and messages are as clear and agreed as possible. It should also, however, be strategic - 'speaking the language' of the evolving environment and appealing to a cross-section of stakeholders, including those that, as yet, remain unconvinced of the value of community responses.

BOX 5: CHARACTERISTICS OF COMMUNITY RESPONSES FOR HEALTH

Community responses:

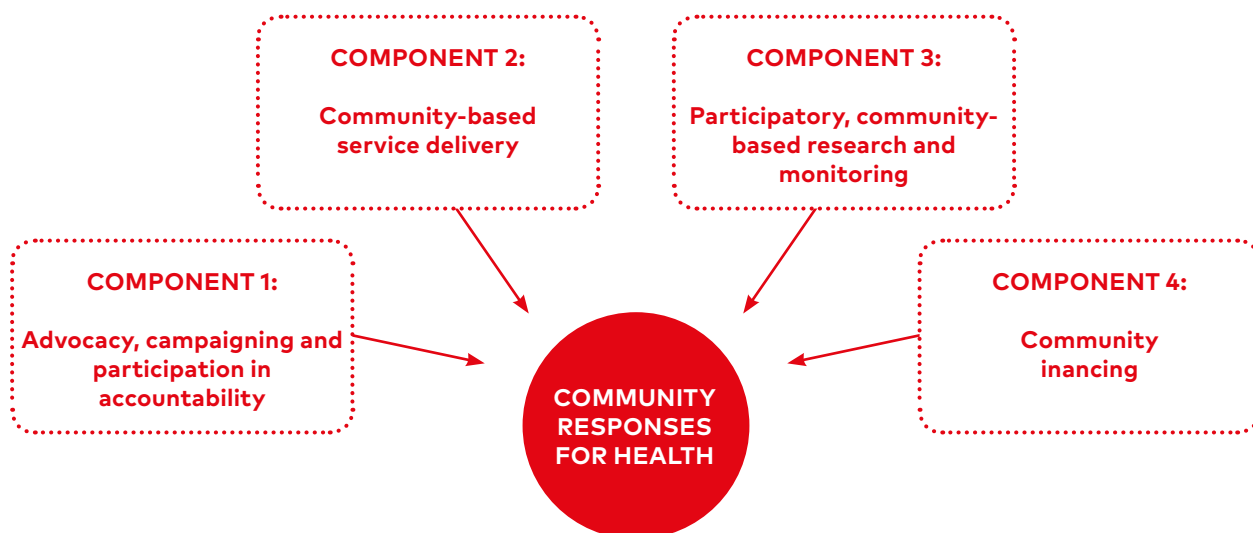
- Are essential to resilient and sustainable systems for health.
- Address the breadth of physical and mental health needs of communities.
- Are multi-dimensional, being comprised of diverse and complementary components.
- Support a wide range and diversity of people, including marginalised populations and those most directly affected by health issues.
- Are implemented by community members, groups and organisations, as well as other types of civil society organisations.

"In conclusion, any future collaborative efforts will require a frank reflection on concepts and terminology."

2.2. What do community responses for health look like?

Within future collaboration, it will be necessary to build on an agreed definition by communicating what community responses for health look like and how they contribute to systems for health.

The process to develop this paper confirmed that there is a strong desire for community responses for health to be seen as multi-dimensional. For example, they are not just about the work of Community Health Workers, the delivery of services or the distribution of commodities. While these are important, community responses incorporate more diverse and comprehensive roles, responsibilities and contributions. As suggested in a framework promoted by UNAIDS, the Stop AIDS Alliance and other organisations³³, these can be grouped under different components [see Box 6, as well as Annex 2 which gives further details about each component and examples of the activities involved]. Future work should maintain the principle that all components are valid, both individually and in combination. However, there is the potential for some components to be modified or expanded, for example to ensure that they fully reflect the nature of community responses for wider areas of health (such as immunisation and non-communicable diseases).



Box 6: The components of community responses for health

BOX 7: THE SHIFT TOWARDS SYSTEMS FOR HEALTH

“The world now needs a paradigm shift away from niche support for community systems to building comprehensive health and social support systems that can provide seamless collaboration between communities and the public and private sector.”

– Stronger Together: From Health and Community Systems to Systems for Health, UNAIDS

“Systems for health, differently from health systems, do not stop at a clinical facility but run deep into communities and can reach those who do not always go to health clinics, particularly the most vulnerable and marginalised. Systems for health focus on people, not issues and diseases.”

– Building Resilient and Sustainable Systems for Health through Global Fund Investments: Information Note, the Global Fund to Fight AIDS, Tuberculosis and Malaria

A ‘make or break’ aspect of future work will be the framing of community responses as being within resilient and sustainable systems for health. This should reflect the recent shift in mindset towards seeing community responses as integral (rather than parallel) to the health ‘ecosystems’ that cut across diverse stakeholder groups (including communities, government and private sector) and areas of health (going beyond vertical approaches to individual diseases).

These ecosystems are complex and have multiple ‘moving parts’ – with diverse health providers working synergistically and inter-dependently, adding up to a continuum of services and support for community members. Rather than talking of separate ‘community systems’ and ‘health systems’, these are now combined within the concept of ‘systems for health’ [see Box 7].

Within this framing, it may be helpful to represent community responses as a spectrum. Box 8 provides an example of this, as used in a publication by the Global Fund³⁵. Going from the left, the spectrum starts from community responses that are recognised as being related to health and incorporated into formal health systems. An example is a community health worker who is attached to a government clinic and provides regular antenatal checks and information for

pregnant women. Ending at the right-hand side, the spectrum shows services – such as related to education or economic empowerment – that may not even be recognised as health-related and are seen as being outside of formal systems. An example of this is a peer educator providing know-your-rights information to sex workers in an ‘underground’ drop-in centre, within a country where such communities are criminalised. The left-to-right progression of the spectrum can also be interpreted to show community responses that are more-to-less: included in national health and disease plans; standardised; institutionalised; centrally and government controlled; and bureaucratic.

While broadly supporting the spectrum's use as a tool, some members of the Project Steering Committee highlight that, in diverse contexts, some community responses fit in more than one of the circles and/or may move over time. Some also question the positioning of specific types of responses, such as suggesting that action on the social determinants of health should be positioned more centrally in the spectrum. Other stakeholders highlight that – wherever they are positioned and despite their daily interaction with wider health systems – community responses remain the 'poor relation' of government-run and bio-medical services, being under-planned, under-acknowledged and under-resourced. This is especially the case in disease areas that are strongly associated with the social determinants of health, such as (lower) social class, (lack of) legal protection and (restricted) political status. Health ecosystems occur within wider social and political ecosystems that are shaped by power and privilege – and within which those best placed to articulate their needs and define 'what works' (i.e. those most directly affected) often cannot do so due to being disenfranchised.

An additional issue is that those who deliver community responses are among the most disempowered cadres in the health workforce. This particularly refers to those from stigmatised populations. It also refers to women – who make up 70% of the health workforce in low and middle-income countries and face a disproportionate responsibility for healthcare roles within families, communities and health facilities.³⁶ Female health workers of all types often faced increased risk of sexual harassment and discrimination, while being under-compensated for their role.³⁷

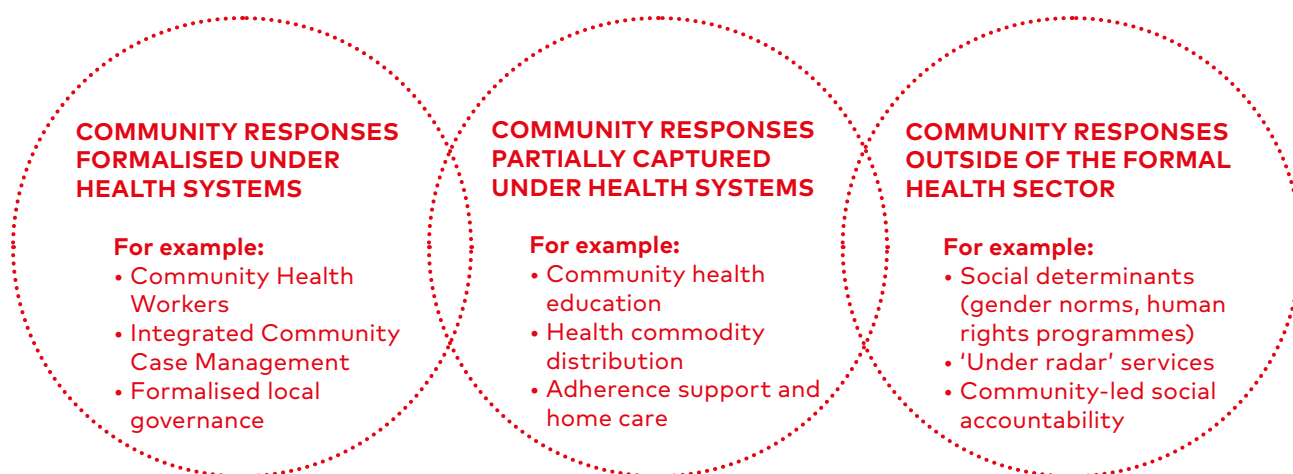
Community responses matter because, as found by the 2018 Lancet Global Commission on Health³⁸, every year, over 8 million people in low and middle-income countries die from conditions that should be treatable by systems for health. In 2015 alone, this resulted in a \$6 trillion economic loss. The Commission also notes that only one-quarter of people in such countries believe that their systems for health work well. It calls for a revolution, if health ecosystems are to reach the quality, efficacy and accountability needed to achieve the SDGs.

BOX 9: THE NEED FOR A REVOLUTION IN HEALTH SYSTEMS

"Quality of care is worst for vulnerable groups, including the poor, the less educated, adolescents, those with stigmatised conditions, and those at the edges of health systems, such as people in prisons Quality should not be the purview of the elite or an aspiration for some distant future; it should be the DNA of all health systems."

– The Lancet Global Health Commission 2018

"It calls for a revolution, if health ecosystems are to reach the quality, efficacy and accountability needed to achieve the SDGs."



Box 8: The spectrum of community responses for health

2.3. What is the value-added of community responses for health?

The process to develop this paper confirmed that there are a growing number of evidence-based examples of the concrete and significant impact of community responses. These extend across all of the SDGs – not only Goal 3, but others, such as Goals 1 (no poverty), 5 (gender equality), 10 (reduced inequality) and 16 (peace, justice and strong institutions).

When focusing on health and, in particular, universal health coverage, it can be seen that community responses not only bring results but add value. This is because they involve interventions that fill strategic gaps in – and/or are of a higher quality or larger scale than – other aspects of systems for health.³⁹ Examples of their value-added include:

- **Value-added: Evidence-based advocacy**

Community stakeholders – such as activists and community-based organisations – can conduct unique advocacy that uses people's lived experiences to call for policy and legislative changes to improve access to and quality of health services, including for marginalised populations. Such efforts can be especially powerful when addressing issues such as human rights, funding and equitable access to medicines. As one example, within a regional grant from the Global Fund, REDTRASEX supported advocacy by national organisations of sex workers in fourteen countries in Latin America and the Caribbean. The work included monitoring national budgets and expenditure for HIV and sexual and reproductive health and rights, with the findings used to advocate for policy and funding changes to benefit the rights and needs of sex workers.⁴⁰

- **Value-added: Connected health responses**

Community responses can play a vital role in connecting different levels within health ecosystems and leveraging different stakeholders' comparative advantages to meet the needs of communities, including those that are marginalised. As one example, in Cambodia, KHANA is implementing a project in Siem Reap to strengthen relationships between people with TB, community support groups, health facilities and local authorities. A key feature is empowerment of the Siem Reap District Network of People With or Affected by TB who build on their relations with other stakeholders to find 'missing' people with TB and to conduct advocacy to demand more and better TB services.⁴¹

- **Value-added: Research**

Community responses are uniquely placed to inform the design of research initiatives and implement processes to gather evidence and data of the real needs of communities, in particular those that are marginalised. As one example, through a grant from the AIDS and Rights Alliance for Southern Africa, the Swaziland Association for Crime Prevention and the Rehabilitation of Offenders conducted the first ever study in Mbabane and Manzini on the distribution of people who use drugs (in terms of their age, gender, residence, family background and socio-economic status). The resulting population size estimates were used to improve the quality of community-based programmes, including for harm reduction.⁴²

- **Value-added: Behavior change**

Community responses can use their first-hand knowledge of local contexts and cultures to support community members to adopt health promotion measures and change harmful behavior. As one example, World Bank modeling of action on HIV indicated that increasing the number of community-based organisations (by just one group per 100,000 people) would result in a: two-fold increase in people using HIV prevention services in Nigeria; and four-fold increase in people's consistent use of condoms in Kenya.⁴³

- **Value-added: Leaving no one behind**

Community responses can use their local knowledge, reputation and networks to engage diverse communities, including those that other sectors cannot (or will not) reach. They can support people who are in remote areas or are socially marginalised, such as by providing differentiated models of care and using person-centered approaches. As one example, in Thailand, Rainbow Sky set up a community-based clinic for migrant gay men, other men who have sex with men and transgender people, all of whom face severe stigma and are not reached by mainstream health services. The clients are referred by peer educators and receive a range of services, such as screening for sexually transmitted infections and counseling and testing for HIV.⁴⁴

- **Value-added: Stigma reduction**

Community responses can build on their relationship with local communities and their knowledge of local cultures to increase accurate understanding about health issues and marginalised populations and, in turn, to contribute to stigma reduction. As one example, in Samrong, Cambodia, improved TB treatment outcomes have been achieved through interventions by health volunteers, some of whom have had TB themselves. The volunteers seek out new suspected TB patients and organise village gatherings to teach people about the disease and its prevention. This approach has not only improved community members' access to TB services but raised awareness and fought stigma about the disease.⁴⁵

- **Value-added: Integrated and combined services**

Community responses can provide packages of healthcare that address more than one area of health (such as both communicable and non-communicable diseases) and more than one type of need (such as both health and socio-economic). This not only provides more comprehensive support but saves the time and resources of both individuals and systems for health. As one example, in Afghanistan, female community health nurses provide a package of services to women and girls - addressing malaria, TB and maternal and child health, all in one go. This approach is especially important as it makes maximum use of the programme's time with the women and girls who are not able to attend other health services unless escorted by a male family member.⁴⁶

- **Value-added: Gender equality**

Community responses can provide services that not only address the immediate health needs of community members, but the 'bigger picture' determinants (such as gender and legal status) that are the underlying causes of vulnerability and ill-health. As one example, in Youna, Gambia, where communities are dominated by patriarchy and polygamy, peer educators use dramas to encourage men to engage in community health discussions. These focus on the role of men in providing moral and financial support to women to go for intermittent preventive treatment of malaria in pregnancy and to access insecticide-treated bed nets. The results have included a three-fold increase in the use of nets.⁴⁷

BOX 10: SUPPORTING MARGINALISED POPULATIONS

"The inclusion of UHC in the SDGs presents an opportunity to promote a comprehensive and coherent approach to health, focusing on health systems strengthening, including at the community level. UHC realizes the principle that all individuals and communities should have access to quality essential health services without suffering financial hardship. UHC cuts across all health targets and contributes to economic productivity, social stability and sustainable development - and to every individual's right to health, well-being and security."

– Global Action Plan for Healthy Lives and Well-Being: Uniting to Accelerate Progress Towards the Health-Related SDGs

- **Value-added: Accessibility of services**

Community responses can implement health and other interventions that are more accessible, flexible and tailored to the specific needs of local people. This, in turn, enables interventions to achieve better outcomes, in terms of both scale and quality. As one example, in South Africa task-shifting to community-based health centres led to 81% of people living with HIV accessing ART and staying alive, compared to 67.2% of those supported in hospitals. Similarly, in Malawi, 95.5% of people supported by Community Health Workers accessed ART and stayed alive, compared to 75.8% of those who lacked such support.⁴⁸
- **Value-added: Scale of reach**

Community responses can use their location and relations with communities to influence and engage large numbers of people in health interventions, linking with other health stakeholders to achieve scaled-up results. In Eswatini, the Maximising ART for Better Health Prevention and Zero New HIV Infections programme supported 16 local community-based organisations. Its work included training 5,761 Rural Health Motivators and Community Based Volunteers to expand their door-to-door visits to incorporate mobilising people for HIV testing and motivating people living with HIV to adhere to their treatment. It also included: training 98 traditional leaders and 12 political leaders; facilitating Demand Creation Community Dialogues in 220 communities; and providing rights literacy among people living with HIV. The programme contributed to Eswatini achieving: its highest ever level of HIV testing (over 250,000 people in a year, compared to 120,000 previously); almost nationwide access to ART; and reduced numbers of people living with HIV being lost to follow up.⁴⁹
- **Value-added: Holistic care**

Community responses can – in combination with other aspects of systems for health – ensure that community members receive comprehensive support that addresses them as whole people (with multi-faceted lives and needs) rather than just medical 'patients' or 'cases'. As one example, in El Salvador, at a community center in Sonsonate, sex workers can receive literacy lessons alongside information about alcohol and drug abuse, HIV and dealing with difficult clients. This intervention not only helps HIV prevention but empowers the sex workers by reducing their social exclusion and discrimination.⁵⁰
- **Value-added: Governance and accountability**

Community responses can play a unique role in monitoring the challenges and impact of health services in communities and, in turn, holding stakeholders to account to improve their performance. As one example, in Uganda, community groups and civil society organisations involved in malaria have engaged in the Global Fund's Country Coordinating Mechanism through bodies such as the Malaria Childhood Illness NGO Network Secretariat. This has enabled people working at the local level (such as volunteers and members of community groups) to monitor the implementation of national Global Fund programmes by providing data and feedback directly from affected communities, in turn helping to hold the government to account for its results.⁵¹
- **Value-added: Value for money**

Community responses can provide activities and services that make maximum use of community infrastructure and expertise and are comparatively cost-efficient and cost-effective. As one example, in Sub-Saharan Africa, Médecins Sans Frontières supported community-based delivery of ART to people living with HIV through adherence clubs, community ART distribution points and community ART groups. These models led to lower service provider costs and reduced financial burdens for patients. They also improved treatment adherence and retention in care.⁵²

- **Value-added: Monitoring, evaluation and quality**

Community responses can play a hands-on role in monitoring the availability, accessibility, acceptability, affordability and quality of health services and advocating for actions to achieve improvements. As one example, in Maharashtra, India, successive surveys found that the process and results of community-based monitoring of health facilities led to the quality of health services being assessed as 'good' by 48%, 61% and then 66% of community members.⁵³

- **Value added: Crisis aversion and response**

Community responses can operate in a flexible way, being reactive to evolving opportunities and challenges. In particular, they can play a life-saving role by providing early warning of emerging problems - preventing, or ensuring a prompt reaction to, health crises. They can also play a critical role in emergency situations (for example natural disaster or political unrest), when other stakeholders might become dis-engaged. As one example, in the Mekong region (Cambodia, Laos, Myanmar, Thailand and Vietnam), over 20,000 village and mobile workers - who are members of communities in malaria hot spots - are equipped with the knowledge and resources to promote malaria prevention, as well as to provide testing and treatment. The workers report any cases that they find to the government, enabling health professionals to follow-up and preventing isolated cases from becoming outbreaks.⁵⁴

- **Value added: Sustainability**

Community responses can support long-lasting and sustainable responses to health for individuals and communities, such as by working through local structures, building community capacity and empowering local stakeholders. As one example, in Algeria, El-Hayet, an organisation for people living with HIV, combined life skills education with economic empowerment for women and girls. It provided training in microcredit for 177 participants, with many going on to set up their own businesses or to work in the private sector. The participants reported gaining better access to HIV treatment and other health services due to their increased knowledge and financial resources (which enabled them to attend the hospital). They also reported a sense of new hope, due to a feeling of contributing to society.⁵⁵

Many of the examples cited above are drawn from the field of HIV that, for many reasons (including the dedication of activists and urgent nature of the response), is one of the most well documented areas of global health. For example, a World Bank study of HIV service delivery provided robust evidence of how community-based efforts are the "cornerstone" of action on the disease and play a major role in increasing people's uptake of services and, in turn, in decreasing incidence.⁵⁶

However, within future efforts, it will be critical to articulate why community responses bring value-added across the whole, current remit, environment and architecture of global health. This includes in terms of different: types of diseases (including non-communicable diseases); areas of healthcare (such as immunisation); and determinants of health (such as gender equality).

It should also be noted that the examples cited here do not address humanitarian contexts. However, community responses are equally indispensable within challenging operating environments where, for example, community groups often serve as first responders. The 2016 World Humanitarian Summit affirmed that: "People affected by crises should be at the heart of humanitarian action ... affected communities, their organisations and their communities should be recognised as the primary agents of their preparedness, response and recovery."

2.4. How do community responses for health support SDG3, particularly universal health coverage?

It will be essential for future collaboration on community responses for health to be informed by, and responsive to, the evolving architecture of global health and development. This especially refers to the SDGs⁵⁷, notably Goal 3 and Target 3.8 (universal health coverage). WHO defines the latter as a state whereby “all people and communities can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship.”⁵⁸ The objectives of universal health coverage are: 1. Equity in access to health services - everyone who needs services should get them, not only those who can pay for them; 2. The quality of health services should be good enough to improve the health of those receiving services; and 3. People should be protected against financial-risk, ensuring that the cost of using services does not put people at risk of financial harm.⁵⁹

BOX 11: THE OPPORTUNITIES OF UNIVERSAL HEALTH COVERAGE

“The inclusion of UHC in the SDGs presents an opportunity to promote a comprehensive and coherent approach to health, focusing on health systems strengthening, including at the community level. UHC realizes the principle that all individuals and communities should have access to quality essential health services without suffering financial hardship. UHC cuts across all health targets and contributes to economic productivity, social stability and sustainable development - and to every individual's right to health, well-being and security.”

– Global Action Plan for Healthy Lives and Well-Being: Uniting to Accelerate Progress Towards the Health-Related SDGs

A success factor for any future collaboration will be to emphatically position community responses as essential - rather than a distraction or addition - to all of these objectives.

An equally important ‘success factor’ is to position community responses as central to the strategies needed to achieve universal health coverage. Key examples of these are: integrated health services (that cut across different disease areas and sectors); people-centred healthcare (that moves beyond supply and ‘expert’-driven models to ones focused on people, needs and accountability); and community engagement. WHO’s definitions of these are provided in Box 12.⁶⁰ It will also be vital, to secure recognition of the full roles, ranges and impacts of community responses - not just the more formalised aspects (such as Community Health Workers and others illustrated on the left of the spectrum in Box 8), but ones related to areas such as advocacy and accountability.

BOX 12: WHO DEFINITIONS OF INTEGRATED, PEOPLE-CENTRED AND COMMUNITY ENGAGED HEALTH SERVICES

The Framework on Integrated, People-Centered Health Services provides the following definitions:

Integrated health services: Health services that are managed and delivered so that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation and palliative care services, coordinated across the different levels and sites of care within and beyond the health sector, and according to their needs throughout the life course.

People-centered care: An approach to care that consciously adopts individuals’, carers’, families’ and communities’ perspectives as participants in, and beneficiaries of, trusted health systems that are organised around the comprehensive needs of people rather than individual diseases and respects social preferences. People-centered care also requires that patients have the education and support they need to make decisions and participate in their own care and that carers can attain maximal function within a supportive working environment. People-centered care is broader than patient and person-centered care,

encompassing not only clinical encounters, but also including attention to the health of people in their communities and their crucial role in shaping health policy and health services.

The Community Engagement Framework for Quality, People-Centred and Resilient Health Services provides the following definition:

Community engagement: A process of developing relationships that enable stakeholders to work together to address health-related issues and promote well-being to achieve positive health impact and outcomes.⁶¹

The Framework recognises that there are multiple entry points and linkages between health systems and communities. These include settings (such as clinics, hospitals and health posts); public health functions and cadres of staff (such as surveillance staff and Community Health Workers); and consultative and accountability mechanisms (such as policy development forums and human rights bodies). Health systems can engage directly with communities through face-to-face interaction. Engagement can also occur indirectly through the systematic consideration and incorporation of the perspectives and needs of patients and service users, their families and local communities, throughout all stages of health service planning, design, implementation and evaluation.

A further essential step is to reiterate that universal health coverage should be truly universal. This will require emphasising that services and packages developed by countries should meet the health promotion, prevention and treatment needs of everyone, whatever the political and policy environment. This includes, in the context of 90-90-90 type targets - where the 10% (who are often those most marginalised and can only be reached through community responses) risk being left behind. It requires shifting the focus from numbers and targets, and towards putting people first. It also requires recognition of the on-going, specific needs of individual diseases. Universal health coverage policies and programmes should not be so 'blanket' or 'standard' that they neglect, for example, the severe and on-going stigma and discrimination associated with HIV.

As one stakeholder articulated, the SDGs' principle of 'leave no one behind' provides unprecedented "political currency" with which to advocate for community responses as, very often, the only components of systems for health that can reach affected populations and conduct essential, high quality interventions. However, other stakeholders are concerned that, at present, there is a lack of knowledge and interest among community stakeholders to engage in universal health coverage processes within countries. Many such stakeholders are unaware that these processes are going on and/or do not realise their significance.

In future collaboration, it will be critical to use the 'hooks' provided by key agreements and processes related to SDG3 and universal health coverage as entry points to advocacy. Key examples include:

- **Transforming Our World:**

The 2030 Agenda for Sustainable Development. This commits to goals directly and indirectly related to health, and mandates multi-stakeholder partnerships and a 'leave no one behind' approach.

- **Global Action Plan for Healthy Lives and Well-Being:**

Uniting to Accelerate Progress Towards the Health-Related SDGs⁶². This identifies 'community and civil society engagement' as an accelerator for the Accelerate strategic approach, with three priorities (expanding political space for civil society, increasing resources for civil society and enhancing meaningful civil society engagement for improved institutional governance).

- **Declaration of Astanta:**

From Alma Ata Towards UHC and SDGs. This commits to involving individuals, families, communities and civil society in developing and implementing primary health care policies and plans, as well as in holding public and private sectors to account.⁶³

All these processes have related action plans or roadmaps that outline opportunities for engagement and influence in 2019 and beyond, such as through country level reviews and international High-Level Meetings.

While maximising such opportunities, a frank understanding is also required of the challenges - even threats - that the universal health coverage agenda brings to communities and civil society. For example, in March 2018, a 40-participant meeting of civil society leaders – convened by WHO, and focusing on Hepatitis, HIV, TB and reproductive health – highlighted major concerns about diluting the progress made under disease-specific programmes, much of which has been due to community responses.⁶⁴ They also emphasised the need for universal health coverage to not result in the diversion of funding from community responses. Meanwhile, a position statement by APCASO and the Global Fund Advocates Network (GFAN) Asia Pacific⁶⁵ identifies a similar set of challenges and, in response, calls for the implementation of universal health coverage to be based on a set of principles. These are that it: is people-centred; is equitable and rights affirming; meaningfully engages communities and civil society; is effectively and sustainably financed; and has accountability mechanisms.⁶⁶ The statement also emphasises the importance of communities and civil society being full and respected partners in the implementation of universal health coverage within countries. This will require meaningful engagement in all relevant processes, from the development of national plans to the setting of budgets [see Box 13].

Community inputs are especially vital for developing the packages of essential and integrated services required to deliver on universal health coverage. Such packages should not be overly generic or solely based on cost-effectiveness and scalability. Instead, they should respond to the real and differentiated needs of communities, including those that are marginalised. Community stakeholders – alongside others, including governments - have an important role in ensuring that such packages are appropriately planned, costed, resourced and implemented within systems for health, with a clear articulation of the role of community responses throughout. Such stakeholders also have a vital role in implementing integrated and differentiated healthcare that meets the holistic needs of community members and has a beneficial impact on them as ‘whole people’. As argued by The Lancet Global Health Commission⁶⁷, universal health coverage should be about high-quality health care and systems for health which are measured by what matters most to people (such as competent care and positive outcomes), rather than traditional metrics (such as the number of medicines distributed).

BOX 13: THE POSITIONING OF COMMUNITY RESPONSES IN UNIVERSAL HEALTH CARE

“Communities have a huge stake on if and how UHC is implemented and achieved. Simply put, it is our health and lives at stake. As such, we dream of a UHC where we are equal partners of government and development partners in designing, implementing, budgeting for, and reviewing health policies and plans that affect us.

Community and civil society mobilisation and advocacy; community-based service provision; community outreach; community-based monitoring of policy, programme and service effectiveness; community-led research are all essential in achieving the right kind of UHC – one that reaches and responds to the needs of hard to reach communities. They are the only way to scale up health programmes and services at the level necessary, and to keep costs sustainable.

We want a UHC that considers community and civil society participation as an essential element of health programme and policy planning, decision-making, and implementation. Such involvement needs to be meaningful, sufficiently resourced, legally enabled, and include key and vulnerable populations.”

– The UHC That We Want, APCASO and GFAN Asia Pacific

“Community inputs are especially vital for developing the packages of essential and integrated services required to deliver on universal health coverage.”

Packages for universal health coverage should not only look at services but address the upstream root causes of people's health problems. It will be important to develop practical models that show what universal health coverage can look like in practice, including in terms of the role of community responses and how they complement others. Such models can build on the successes of community responses to date. For example, community groups that have successfully engaged in HIV – including for marginalised populations – have gained processes, relationships and experience that can now be capitalised on for wider health programming to contribute to universal health coverage.

BOX 14: THE RELATIONSHIP BETWEEN COMMUNITY RESPONSES AND UNIVERSAL HEALTH COVERAGE

“A clear commitment to ‘leaving no-one behind’ must be applied to all communities. Reaching marginalised communities requires partnership and collaboration with those affected communities and with broader civil society. We need to ensure community perspectives inform our understanding of essential packages of services, commodities and interventions; we need to work with communities to better understand who is being left behind and how to ensure universal health coverage can address disparities and gaps; we need to recognise and support the role of communities in service delivery and in strengthening broader health systems; we need to do more to enable your advocacy and activism efforts, to support universal health coverage and to increase access to essential medicines and health commodities.”

– Dr Tedros Adhanom Ghebreyesus, Director General, WHO

“In our increasingly globalised world, the fabric of global health security rests on resilient communities. Everywhere, whether in remote villages or crowded cities, resilient communities are ultimately made up of people who enjoy their basic human rights: to live in dignity, free from fear and

free from want. UHC is a cornerstone of these rights and the right to health, with protection against financial hardship at its heart. Therefore UHC must be more than a technical exercise. UHC is, and must be, about realising rights and redistributing opportunity. And, as such, it is inherently political - it is about addressing entrenched power structures and tackling disempowerment, marginalisation, and exclusion.”

– Michel Sidibé, Executive Director, UNAID

“Universal health coverage ... and health security will not be attainable without the involvement of communities. They are essential to designing effective interventions, to implementing and evaluating the robustness and quality of health services, to creating demand for services and to reaching those who do not always go to health clinics – in particular the vulnerable and marginalised. They are also essential in health promotion, prevention, fostering healthy behaviors and can reduce the demands on the health system. Systems for health that involve the community will always be the first to identify, report and respond to emerging health threats.”

– Building Resilient and Sustainable Systems for Health through Global Fund Investments: Information Note, the Global Fund to Fight AIDS, Tuberculosis and Malaria

2.5. What are the resource needs of community responses for health?

It will be crucial for future work on community responses for health to address the issue of resourcing. This should be based on the principle that such responses are not 'free' or 'cheap alternatives' and, instead, require adequate, appropriate and sustainable investment.

Action in this area should also be based on an understanding that resourcing refers not only to money, but other types of support, such as technical assistance, human resources and capacity building. However, it should be acknowledged that, within the current environment, funding is an increasing concern - even crisis - for many involved in community responses. This is especially the case in contexts where donors are

implementing policies of transition and sustainability, with the withdrawal of their support from middle-income countries and accompany pressure for increased domestic investment. Here, there are major concerns as to whether financing by national governments will meet either the scale or nature of resource needs for community responses. These concerns reflect experience of countries, in practice, being reluctant to support community responses, especially those that target marginalised and/or criminalised communities and may be perceived as politically sensitive. They also reflect the presence of legal and financial obstacles that, for example, do not permit governments to contract non-state health providers.⁶⁸

It is suggested that this element of future collaboration will need to address two aspects:

How to categorise and quantify resource needs

Future work will need to address the type of resources that are needed by community responses for health, and at what scale. This could build on past efforts, such as the Global Fund's CSS Framework and Modular Framework (for grant proposals) that breaks down community responses for HIV, TB and malaria into definable, measurable and fundable activities that can be resourced within countries' applications for disease-specific or health systems grants [see Annex 3].

Future efforts should highlight that, in fact, responses to major epidemics (such as HIV, TB and malaria) – including the aspects by and for communities - require increased investment. As an example, UNAIDS estimates that, to achieve the Fast Track targets for the response to HIV (mandated by the 2016 United Nations Political Declaration on HIV and AIDS), investment in community mobilisation will need to rise three-fold in low and middle-income countries, from 1% of the total resources in 2014 to 3% by 2020.⁶⁹ Furthermore, community-based delivery of ART will need to grow to 3.8% of the total investment, while

funding for action on social enablers (including work related to advocacy, political mobilisation, law and policy reform, human rights and stigma reduction) will need to reach 6%. As a further example, the Global Plan to End TB cites how advocacy, community engagement and community strengthening will require a \$2.3 billion investment over 2016-2020 (representing 4% of the total).⁷⁰

BOX 15: THE IMPORTANCE OF FUNDING COMMUNITY RESPONSES

"The most important change that could facilitate integrating community engagement in UHC is proper funding for engagement interventions, supported by mechanisms of governance that allow for transparency, accountability and representation. Resources will need to be redistributed and channeled into community engagement as a cross-cutting technical area to support the generation of evidence for strong policy recommendations. Given the increasing demands being made on health systems around the world, investing in community engagement makes sense as it supports services and systems to maximise available resources. Donors and researchers should support the small investments needed to develop community engagement, which is critical to the future of public health and success of UHC."

– Universal Health Coverage and Community Engagement, Asiya Odugleh-Kolev, WHO, and John Parrish-Sprowl, Global Health Communication Center, in Bulletin of World Health Organisation, 2018

"Future efforts should highlight that, in fact, responses to major epidemics (such as HIV, TB and malaria) – including the aspects by and for communities - require increased investment."

According to the United Nations Sustainable Solutions Network, an additional \$69-89 billion is needed every year to achieve the health-related SDGs.⁷¹ However, an analysis by Stenberg et al. (based on a more ambitious approach incorporating a larger health workforce, emergency risk management and non-communicable diseases) suggests that the true figure is more like \$371 billion per year for low and middle-income countries.⁷²

Some members of the Project Steering Committee call for a tone of urgency in this area – in recognition that, despite growing acknowledgement of their role, many community groups and civil society organisations face severe financial hardship that threatens their sustainability, even existence. For example, a UNAIDS survey of over 480 community-based organisations found that 40% reported that their funding had decreased, while two thirds expected that it would be flat-lined or reduced in the future.⁷³ Such a harsh financial environment inevitably impacts on services. In the same survey, 89% of those who reported a decrease in their funding had already had to scale down their work.

The categorisation and quantification of resource needs can be especially challenging in disease areas where the role of community responses has traditionally been less recognised and, in turn, less financially articulated and budgeted for. This is illustrated in Box 16, with an extract from a declaration by the first-ever global civil society coalition for malaria elimination.

BOX 16: ADDRESSING THE RESOURCE NEEDS FOR COMMUNITY RESPONSES TO MALARIA

"Civil society recognises the diversity and capacity of community-based organisations on one hand, and the challenges facing donor institutions in providing appropriate funding mechanisms that ensure results and accountability, on the other. Most grassroots community and civil society organisations lack access to funding opportunities despite being best placed to reach the most marginalised and vulnerable groups. Funding civil society initiatives at all levels, including the most local, represents a strategic investment contributing to appropriate and effective service delivery, advocacy, and people driven surveillance and response We call on national governments, international institutions, bilateral and multilateral donors to prioritise and increase funding allocations for community-driven community and civil society initiatives."

– Global Civil Society for Malaria Elimination (CS4ME) Declaration, Malaria World Congress 2018

How best to provide for resource needs

Future collaborative action will also need to address how the resource needs of community responses for health can best be met. This should start by acknowledging the often-negative past experiences of community stakeholders in accessing, utilising and reporting on funding. For example, an analysis for Funders Concerned About AIDS⁷⁴ characterised funding for community responses to HIV from external sources as "sporadic, limited, and hampered by a number of challenges related to the nature of the community sector, attitudes to AIDS and those affected, and the systems of funders". Examples of the first set of challenges (concerning the community sector) include that there is often a vast number and range of civil society organizations that lack coordination. Examples of the latter set of challenges (concerning the systems of donors) include that there can be complex processes to access resources (that are skewed towards higher capacity organizations); onerous monitoring requirements; limited core funding; and limited funding for advocacy. The analysis highlighted the need for donors to not simply resource community responses, but do this in the right way.

Beyond the practices of donors, stakeholders interviewed for this paper highlighted the presence of numerous structural and sectoral barriers to the effective resourcing of community responses. Examples include legal obstacles to registration; regulatory frameworks that prohibit the delivery of health services by non-state actors; competition among community actors; poor or non-existent sub-national health plans and budgets (that incorporate community responses); and low awareness, adoption and resourcing of packages of differentiated health care.

In addition, where funding opportunities are available for community responses, there can be low levels of uptake. This is due to a wide range of issues, including the prioritisation of other areas by national stakeholders and poor coordination of community responses. For example, the Global Fund's Technical Review Panel has

"For example, the Global Fund's Technical Review Panel has expressed concern that a large proportion of Concept Notes from countries do not include funding for CSS."

expressed concern that a large proportion of Concept Notes from countries do not include funding for CSS or, where incorporated, such work is in the 'above allocation' category and, therefore, unlikely to get resourced.⁷⁵

As noted, an acute resourcing challenge is presented by donor policies of transition and sustainability. This is particularly the case in middle-income countries where community responses - especially by and for marginalised groups - have often been dependent on external resources. Here, domestic financing is likely to be very limited and/or to come with 'strings attached' [see Box 17]. In such contexts, community groups and civil society organisations already report the threat of closure or severe cutbacks to their health operations, in particular those for marginalised populations. This highlights the need for 'responsible transitions' where the legal and policy environment is considered (alongside a country's economic income) and communities are meaningfully engaged at all stages of planning and decision-making.

BOX 17: THE IMPACT OF TRANSITION AND SUSTAINABILITY POLICIES ON COMMUNITY RESPONSES FOR HEALTH

"There is a painful awareness among communities in countries whose economies are growing that donors are pulling out and abandoning them – or, as it is commonly-termed, 'transitioning'. This process is driven by the criteria donors have laid out for eligibility and demonstrated by the actual level of disbursements going to some countries. But communities know that growing economies do not equal growing domestic support for communities in the HIV response The gradual process of 'transition', or divestment of donors, will mean a slow death of the community response, away from the headlines and without emergency actions. In this process, the scope of community programmes will diminish, organizations will rely more and more on volunteer time and resources, and their reach and impact will be mitigated, but they may still exist for some time. This process is often compounded by histories of long-term underfunding for community organizations, limiting their capacity to respond to the changing context."

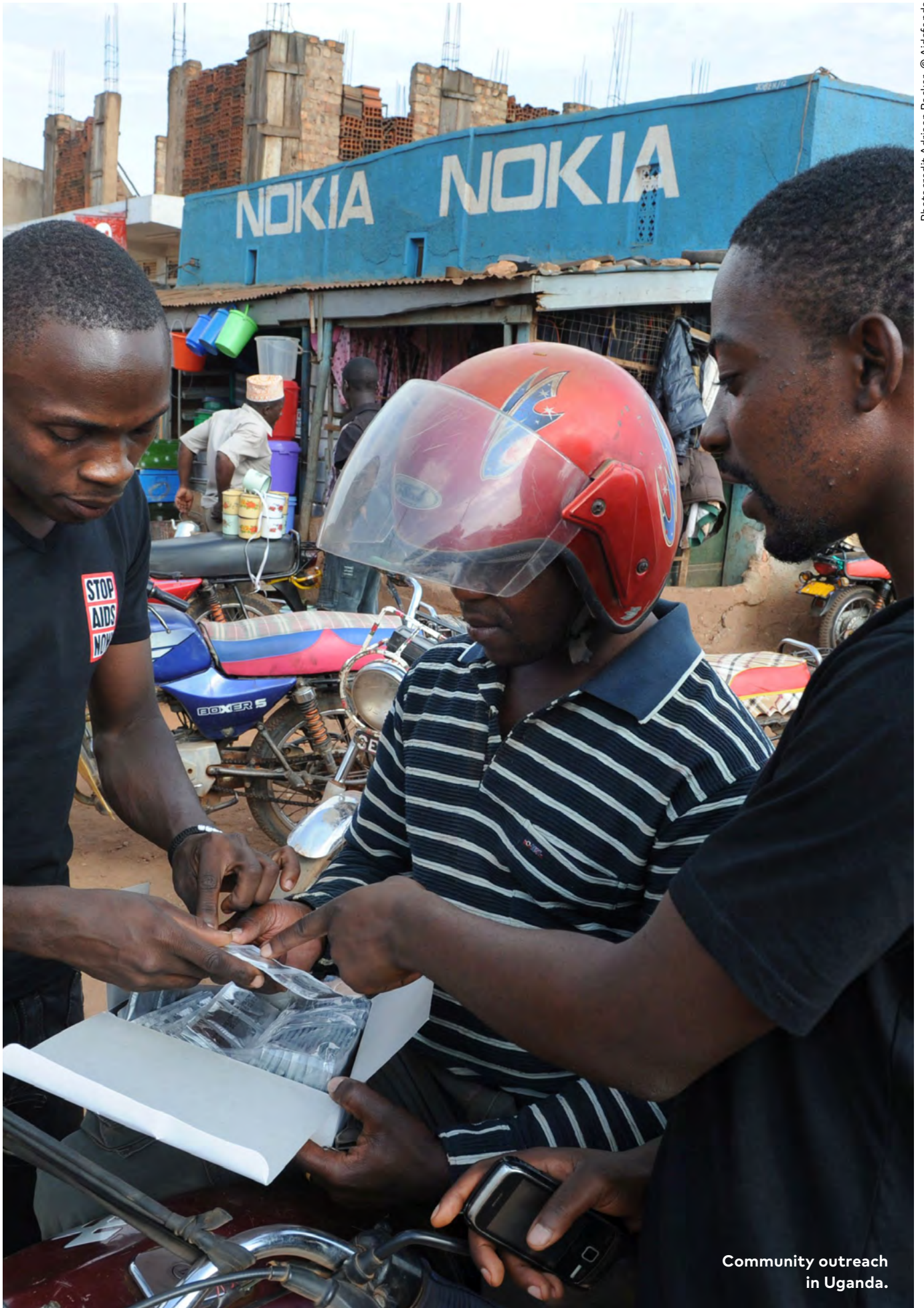
– The Central Role of Community Action in Contributing to Achieving the 2030 Agenda and SDG 3

Concerns about transition and sustainability policies have been especially articulated within the governance and policy-making mechanisms of the Global Fund, as well as of the President's Emergency Fund for AIDS Relief (PEPFAR) (the largest bilateral donor for HIV). Within such forums, multiple civil society stakeholders have evidenced and advocated on the very real threat that transition poses to community responses to HIV, TB and malaria – at a time when the role of such responses is more important than ever, in terms of ending epidemics and achieving the SDGs.

The resourcing of community responses is also especially challenging in countries with a shrinking space for civil society where, for example, organisations face an increasing number of bureaucratic obstacles to their registration and function, as well as increased exclusion from national processes. For example, a study by the Eastern Africa National Networks of AIDS Service Organisations (EANNASO)⁷⁶ found that, as measured against the World Bank's Worldwide Governance Indicators⁷⁷, civil society priorities were less likely to be included in Global Fund Concept Notes in countries with lower levels of freedom of association and expression. A report by the NGO Delegation to the Programme Coordinating Board of UNAIDS highlighted how, when governments do fund communities and civil society, they tend to primarily resource service delivery, with little support for areas such as advocacy on human rights, community mobilisation and community monitoring.⁷⁸

Within future efforts, it will be increasingly important to document and learn from successful and/or interesting examples of resourcing as they occur. For example, UNAIDS produced a study of six diverse countries⁷⁹

(Argentina, Brazil, India, Malawi, Malaysia and the Republic of Moldova) where governments have supported community responses to HIV either through direct allocations from national budgets or through inclusion in Global Fund applications. Meanwhile, some stakeholders urge that, to address the need for increased investment, community responses should also be maximising recent efforts towards self-sustainability – such as through innovative financing and social enterprise - in order to become less reliant on international or government resources.



Community outreach
in Uganda.

PART 3: IDEAS FOR FUTURE COLLABORATION

3.1. What type of collaborative action is needed on community responses for health?

The process to develop this paper identified a strong interest among the Project Steering Committee and external stakeholders in some type of collaborative action to mobilise greater recognition, support and investment in community responses for health. If successful, such collaboration could:

- **Increase clarity and consensus on the meaning, value and principles of community responses for health**
 - enhancing shared understanding, reducing confusion and providing firm foundations for joint work.
- **Re-frame community responses for health**
 - bringing the subject up-to-date and utilising the strongest evidence and messages available to engage strategically within key global frameworks, notably the SDGs and universal health coverage.
- **Re-invigorate advocacy on community responses for health**
 - building on past work, while catalysing renewed momentum among key stakeholders and institutions for a larger and more diverse movement of support. The latter could cut across different types of stakeholder groups, disease types and health interventions.
- **Leverage existing processes of relevance to community responses for health**
 - using and complementing ongoing and emerging processes at different levels. Examples include: national-level planning and budgeting processes for universal health coverage; Voluntary National Reviews of the SDGs; United Nations High Level Meetings (such as on HIV, TB and universal Health Care); and Universal Periodic Reviews.

Such collaboration will require work:

- **Between diverse sectors and institutions,**
 - such as with people, organisations and institutions that have not previously worked together breaking out of their silos (such as of sectors or specific diseases) and finding common ground and forging new partnerships.
- **Across different disease areas,**
 - such as stakeholders from communicable, non-communicable and other disease areas.
- **By individual institutions,**
 - such as to leverage the unique reach and influence that specific organizations bring to collective action on this area. For example, WHO is recognised to have a crucial convening and influencing role in relation to governments and Ministries of Health. Meanwhile, regional and global key populations networks are recognised to be vital for mobilising support and buy-in among marginalised communities.

- **Within individual institutions,**
such as by building support across different departments, notably beyond staff that work most directly with civil society.
- **At different levels,**
such as by not only mobilising commitment and action among communities themselves, but also, for example, among national governments, regional offices of technical institutions and global offices of donors.

The discussions to inform this paper also highlighted potential challenges for future collaboration. These include the need to overcome a sense of fatigue among some stakeholders, such as those who have undertaken years of work on CSS for HIV, TB and malaria, with limited results. They also include the need to recognise that, beneath agreement on high-level messages about community responses to health, institutions may have significant differences in terms of interpretations and priorities. There is a fear that, in practice, collaboration will 'only go so far' before it becomes too slow or difficult.

A further key challenge is that different areas of health are at different stages in their incorporation of community responses. For example, principles that were hard-fought for - but are now commonplace - within action on HIV (such as human rights-based approaches and civil society engagement in decision-making) are comparatively under-developed in some other areas.⁸⁰ As such, there is a sensitive balance to be achieved - between using past lessons to leverage new commitment, and supporting health sectors to learn for themselves and not feel dominated by others.

There is also the fundamental question of 'What should we actually do?', in terms of what collaboration might look like and what type of action is most likely to make a difference. Examples of suggested ideas for collaborative efforts are:

- **Designing an Advocacy Roadmap on Community Responses for Health (outlining key messages, sources of evidence and advocacy opportunities)**
- **Fostering Champions for Community Responses for Health - with individuals who mobilise and coordinate action in their organisation or sector**
- **Developing a Charter on Community Responses for Health that outlines the shared, core principles of such approaches**
- **Developing a Global Framework on Community Responses for Health (outlining the definitions, value-added and resource needs of community responses)**
- **Producing a set of practical 'how to ...' resources on community responses for health (such as on 'how to advocate for the inclusion of community responses in national planning for universal health coverage')**
- **Devising social media campaigns on community responses for health, based on creative and appealing messages to mobilise broad-based engagement**
- **Compiling an evidence bank that, in one place, brings together - and provides easy access to - high quality data, research and case studies in support of community responses for health.**
- **Developing a set of case studies or models that - based on real life examples - show how community responses fit within health ecosystems, complement the work of others and bring added-value, such as to universal health coverage.**

These reflect that: on the one hand, there is an eagerness to learn from the successes of similar collaborations to date; yet, on the other, there is strong interest in developing approaches that are new and different. For example, the latter might involve - rather than focusing on the production of hard-copy materials - channeling most of the time and effort into building a bottom-up social movement that maximises social media.

While the exact nature of future collaboration is not yet clear, there appears to be some agreement on the characteristics and success factors for such efforts. These include:

- **Urgency:**
Collaboration will need to have a sense of urgency, rather than 'business as usual'. It will need to articulate that community responses need support now if the SDGs are to be achieved and no one is to be left behind.
- **Ambition:**
Collaboration must articulate that more investment is needed if community responses are to fulfill their potential role, such as within ending individual diseases and achieving universal health coverage.
- **Buy-in:**
Collaboration will need to actively involve – or, at the very least, have the stated support of – key sectors and institutions involved across global health, with representatives strongly owning the 'asks'. The sectors and institutions should range from communities themselves to global, normative agencies.

BOX 18: WHO GLOBAL STRATEGY ON PEOPLE-CENTERED HEALTH SERVICES

STRATEGIC GOAL 1: Empowering and engaging people

Empowering and engaging people is about providing the opportunity, skills and resources that people need to be articulate and empowered users of health services. It is also about reaching the underserved and marginalised groups of the population in order to guarantee universal access to services. This goal seeks to unlock community and individual resources for action at all levels. It aims at empowering individuals to make effective decisions about their own health and at enabling communities to become actively engaged in coproducing healthy environments, providing care services in partnership with the health sector and other sectors, and contributing to healthy public policy.

- **Cross-health:**
Collaboration will need to speak to diverse areas of health, including both communicable and non-communicable diseases. This is partly to reap the benefits of cross-health collaboration, but also to avoid the perception of efforts being driven by a single disease area.

- **Targeted:**
Collaboration will need to have clear targets, such as with defined audiences for advocacy actions and clear, tailored 'asks'.

- **Non-divisive:**
Collaboration should be based on a collaborative approach, such as recognising the value of all components of health ecosystems, rather than, for example, 'pitching' community systems against health systems.

- **Strategic:**
Collaboration should make maximum, strategic use of all existing processes (such as reviews of the SDGs and consultations for universal health coverage) and 'hooks' (such as commitments made in policies). A key example of the latter is the WHO Global Strategy on

Integrated People-Centered Health Services 2016-20 that explicitly, as its first goal, mandates empowerment and engagement of people [see Box 18].

- **Person-centered:**
Collaboration will, ultimately, need to be about people – in terms of remaining focused on ensuring comprehensive and appropriate support for community members. It should not become overly technical or academic.

As indicated by the last characteristic, any type of collaborative efforts will need to bring community responses to life and give them a human face – showing how, within resilient and sustainable systems for health, they are vital for helping real people with real health problems. Within collaborative initiatives, case studies and patient/healthcare journeys should be used to illustrate the role of community responses, such as within integrated health care and universal health coverage.

3.2. What type of products could support collaborative action on community responses for health?

The development of this paper also found that, to support collaborative action on community responses to health, it might be useful to produce individual or sets of materials. Examples of these are listed in Box 18. A specific option discussed by the Project Steering Committee is to develop some type of Global Framework on Community Responses for Health. This guidance would be informed and owned by a range of institutions involved in diverse diseases areas. As summarised in Box 19, it could serve to: document shared definitions related to community responses; explain the value-added of such responses; frame such responses as essential to the SDGs and universal health coverage; and advocate for the necessary resources. A Global Framework could also include recommendations for key stakeholders and institutions – such as national governments, private sector, donors, financing mechanisms, technical agencies, communities and civil society - on actions to promote and invest in community responses. The recommendations should be as specific and practical as possible, without being prescriptive, reductionist or overly simplifying the range of community responses.

It is hoped that, if widely owned and used, a Global Framework could serve as the foundations of a rallying cry – being used by and mobilising different types of stakeholders at national, regional and international levels [see Box 20 for examples].

BOX 19: POTENTIAL CONTENTS OF A GLOBAL FRAMEWORK ON COMMUNITY RESPONSES FOR HEALTH

1. Introduction	Why have a Global Framework on Community Responses for Health? Explaining what the Global Framework is, why it was developed and how it should and shouldn't be used.
2. Definition	What are community responses for health? Providing a clear description of the range of community responses for health and other key terms (such as communities and resilient and sustainable systems for health) and outlining their key characteristics
3. Practice	What do community response for health look like? Explaining the multi-dimensional nature of community responses and illustrating what they can look like for real people (including marginalised communities) across diverse areas of health.
4. Value-added	What do community responses bring to resilient and sustainable systems for health? Articulating the value-added of community responses within resilient and sustainable systems for health, alongside other health providers.
5. Strategy	How do community responses for health enable universal health coverage? Articulating the essential role of community responses within the type, scale and breadth of actions needed to achieve SDG3, notably universal health coverage.
6. Resources	What resources do community responses for health need and what are the best mechanisms to deliver them? Outlining the types and scale of resource needs for community responses and how to deliver them, including in the context of donor transition and sustainability and increased dependence on domestic financing.
7. Actions	What can be done to support community responses for health? Providing recommendations for action by key stakeholders (such as donors, national governments and communities) to support community responses for health.

BOX 20: USING A GLOBAL FRAMEWORK OR GUIDANCE TO PROMOTE COMMUNITY RESPONSES FOR HEALTH

A Global Framework on Community Responses for Health could be used by key stakeholders to support a range of planning, strategising, investment and advocacy initiatives. For example:

National governments could use a Global Framework to:

- Support a leadership role - championing, promoting and resourcing community responses for health.
- Articulate the role of community responses for health within national strategies and reviews, such as on the SDGs and universal health coverage.
- Quantify the resource needs for community responses for health and integrate them into the design and monitoring of national budgets.
- Inform the review of national policies and laws that limit the role of community responses for health, especially in relation to marginalised communities.
- Donors and financing mechanisms could use a Global Framework to:
 - Shape the criteria and remit of funding channels, making them more appropriate to the type and scale of needs for community responses.
 - Inform the review of funding processes to identify how to make them more accessible to communities, including for less formalised health interventions.
 - Leverage a shared understanding among funding recipients of the diverse nature of community responses for health (that goes beyond Community Health Workers).

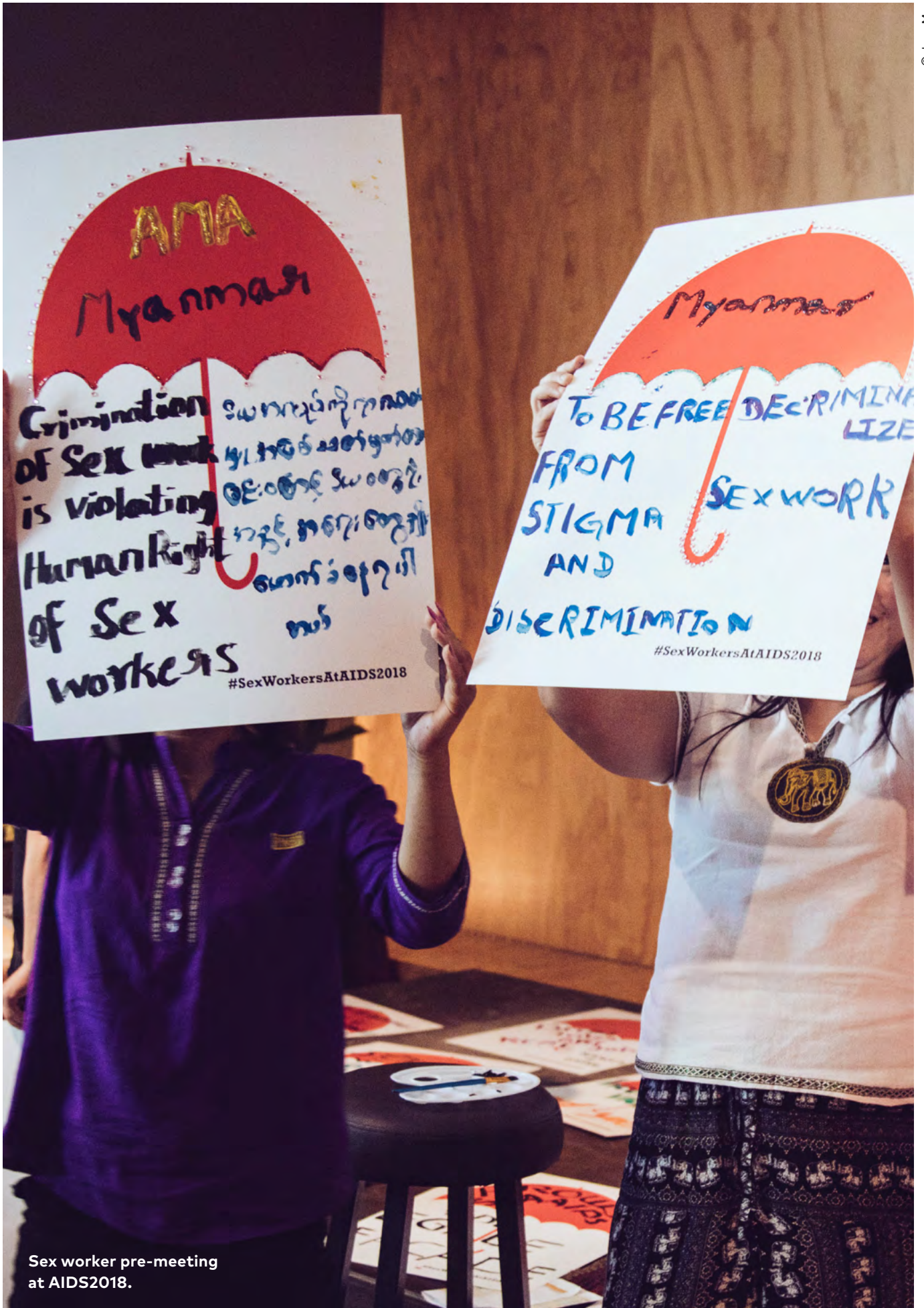
Communities and civil society could use a Global Framework to:

- Strengthen messaging and consensus across communities and civil society sectors on the unique role and importance of community responses for health, in particular for marginalised populations.
- Collectively advocate to national, regional and international policymakers for the engagement of and investment in community responses within all levels of strategising and planning on the SDGs and universal health coverage.
- Inform additional evidence collection and research on the impact of community responses for health, particularly within the rollout of universal health coverage
- Technical agencies could use a Global Framework to:
 - Build consensus within and across health-related agencies on the importance of community responses and the need for supportive policies and investment.
 - Provide options to national governments on what policy and programmatic steps could be taken to support community responses for health.
 - Adapt or develop technical guidelines and tools to translate commitment to community responses for health into costed strategies and programmes.

The process to develop a Global Framework or some other type of guidance on community responses for health could build on work conducted to date, such as relating to CSS in the fields of HIV, TB and malaria. It could also maximise existing resources produced in diverse areas of health. One of the extensive number of examples is the Community, Rights and Gender Integrated Toolkit developed by the Stop TB Partnership to support national-level stakeholders in their design of TB programmes.

An essential question is how a Global Framework – and similar resources to support collaborative action – would be informed and developed, in terms of the consultation processes used and the sectors and stakeholders engaged. To ensure validity, there is a strong call for communities – including marginalised populations - to be at the heart of the development journey. This requires a genuinely meaningful process, with communities having the opportunity to articulate their understanding of the meaning and value-added of community responses, as well as to set out their needs, including for investment. In short, a Framework needs to be designed with and by communities, not for them. It also, however, requires the endorsement of key international institutions that – by providing normative guidance, facilitating international political processes and allocating resources – have significant influence, in particular on national governments. Key examples of such institutions cited by stakeholders interviewed for this project are WHO, the Global Fund, PEPFAR and the World Bank.

It should be noted that some stakeholders warn against developing a Global Framework – fearing that it would involve lengthy negotiation and consensus building that culminates in a document that just 'sits on the shelf'. Instead, they argue that emphasis should be placed on the process for collaboration – in terms of how principles and messages will be agreed and then how advocacy opportunities (that maximise different stakeholders' reach and influence) will be mapped out.



Sex worker pre-meeting at AIDS2018.

PART 4: CONCLUSIONS

As introduced, this discussion paper was based on an initial set of interviews and preliminary desk review that focused on the organisations involved in the Project Steering Committee and selected additional stakeholders. It aimed to summarise key issues concerning community responses for health and to explore ideas and options for future collaboration.

In broad terms, it can be concluded that – among the stakeholders and institutions involved in this initiative to date – there is strong interest in moving forwards and taking collaborative action on community responses for health. This commitment reflects a shared understanding of the importance of such responses. It also reflects recognition that now is the time to act - if, for example, the role of communities is to be fully recognised and resourced within processes for the SDGs, universal health coverage, and sustainability and transition.

However, it can also, broadly, be concluded that the way forwards with this initiative may not be straightforward. There is a degree of nervousness about how smooth collaboration will, or will not, be when discussions reach a more detailed and nuanced level. There are also questions about the practicalities of collaboration, such as in terms of who should resource and coordinate the process and who should own the results.

Going forwards, it is suggested that the immediate next steps for this initiative should focus on:

1. Developing key messages and principles on community responses for health.

This should involve discussion and agreement on some basic shared messages and/or principles that can be used by a range of involved stakeholders within different types of advocacy processes and forums. The messages/principles should be as clear and simple as possible, articulating what community responses for health are, why they matter and what support they need. In time, they could form the basis of more detailed products, such as a Global Framework on Community Responses for Health or a set of case studies on community responses for health within the context of universal health coverage.

2. Developing an advocacy roadmap for community responses for health.

This should identify and sequence the major opportunities for utilising the key messages and principles within advocacy for community responses for health. It should focus on processes, events and platforms with which stakeholders can engage – individually, in combinations or as a whole. It should maximise the reach, roles and entry points of the members of the Project Steering Committee and other stakeholders, such as within national, regional and global processes related to the SDGs and universal health coverage.

The roadmap should focus on existing advocacy opportunities. However, it should also schedule check-ins for those involved in this initiative – such as to compare progress in different types of advocacy forums, make necessary adjustments (such as to the key messages and principles) and identify collective next steps.

3. Developing a wider consultation process on community responses for health.

Alongside the advocacy roadmap, a consultation process is needed to ensure more and wider inputs into – and, ultimately, ownership of - this initiative. This should be as participatory as possible, while aiming to be efficient, such as by using existing communities and civil society platforms, delegations and advisory groups. The process should:

- Prioritise consultation with communities (in particular those living with or most directly affected by health issues) and civil society stakeholders.
- Emphasise strategic collaboration with mechanisms related to universal health coverage, notably UHC2030 and its Civil Society Engagement Mechanism.
- Strategically target other key stakeholders - such as donors, global health institutions and global health academics - to fill specific gaps, such as in technical inputs or constituency influence.

ANNEX 1: Resources on community responses for health

The process to develop this discussion paper identified a significant number of useful resources relating to community responses for health. The following are examples:

Role of community responses for health:

1. Uncovering 'Community': Challenging an Elusive Concept in Development and Disaster Related Work, Alexandra Titz, Terry Cannon and Fred Krüger, Societies Journal, 31 August 2018. www.researchgate.net/publication/327352202
[Uncovering 'Community' Challenging an Elusive Concept in Development and Disaster Related Work](#)
2. The Crucial Role of Communities: Strengthening Responses to HIV, Tuberculosis and Malaria, the Global Fund to Fight AIDS, Tuberculosis and Malaria, April 2018. www.theglobalfund.org/media/7263/publication_communityresponses_focuson_en.pdf?u=636583505110000000
3. Community Systems Strengthening Framework: Revised Edition, the Global Fund to Fight AIDS, Tuberculosis and Malaria, February 2014. www.theglobalfund.org/media/6428/core_css_framework_en.pdf?u=636637834640000000
4. Maximising Impact by Strengthening Community Systems and Responses, the Global Fund to Fight AIDS, Tuberculosis and Malaria, November 2016. www.theglobalfund.org/media/4790/core_communitysystems_technicalbrief_en.pdf
5. Community Systems Strengthening and Key Populations: A Policy Discussion Paper, MPact, 2013. www.clac.cab/portfolio-item/community-systems-strengthening-and-key-populations
6. Independent Multi-Country Review of Community Engagement in Grant Making and Implementation Processes, CLAC, 2017. www.nswp.org/sites/nswp.org/files/Community%20Engagement%20in%20Grant%20Making%2C%20MSMGF%2C%20NSWP%20-%202017.pdf
7. Small Grants Case Studies 2013-2015: Catalysing HIV, TB and Human Rights Advocacy in Southern and East Africa, ARASA. www.arasa.info/files/9115/0341/3814/GRANT_REPORT_FULL_FINAL_3.pdf
8. Stronger Together: From Health and Community Systems to Systems for Health, UNAIDS, 2016. www.unaids.org/sites/default/files/media_asset/JC2788_stronger_together_en.pdf
9. Invest in Advocacy: Community Participation in Accountability is Key to Ending the Aids Epidemic, UNAIDS, 2016. www.unaids.org/sites/default/files/media_asset/JC2830_invest_in_advocacy_en.pdf
10. Communities Deliver: The Critical Role of Communities in Reaching Global Targets to End the AIDS Epidemic, UNAIDS and Stop AIDS Alliance, 2015. www.unaids.org/sites/default/files/media_asset/UNAIDS_JC2725_CommunitiesDeliver_en.pdf
11. UNAIDS Guidance for Partnerships with Civil Society, Including People Living with HIV and Key Populations, UNAIDS, 2011. www.unaids.org/sites/default/files/media_asset/JC2236_guidance_partnership_civilsociety_en_0.pdf
12. Statement of Action to Enhance the Engagement of Communities, Non-Governmental and Other Civil Society Organisations in the Implementation of the End TB Strategy: Outcome of a WHO Consultation Meeting, Addis Ababa, Ethiopia, WHO, 2015. www.who.int/tb/publications/2015/statement-of-action/en/
13. Community Engagement in Tuberculosis: Fact Sheet, WHO, 2017. www.who.int/tb/publications/Community_Engagement_factsheet_2014corr_29may15.pdf?ua=1

14. Setting the Scene: ENGAGE-TB Approach for Integrated Community-Based TB Activities and Finding the Missing TB Cases, Haileyesus Getahun, Global TB Programme, WHO, April 2018. www.who.int/tb/features_archive/setting_the_scene_getahun_11apr18.pdf
15. Integrated Toolkit: Communities, Rights and Gender, the Stop TB Partnership. www.stoptb.org/resources/publications/
16. Global Civil Society for Malaria Elimination (CS4ME) Declaration: Malaria World Congress, CS4ME, July 2018. www.developingngo.org/wp-content/uploads/2018/07/Global-Civil-Society-for-Malaria-Elimination-Statement.pdf
17. Meaningfully Involving People Living with NCDs, What Is Being Done And Why It Matters, NCD Alliance, October 2018. ncdalliance.org/sites/default/files/resource_files/MeaningfullyInvolvingPLWNCs_Report_FINAL.pdf

Resourcing of community responses for health:

18. Investing in Community Responses: A Case for Funding Non-Service Delivery Community Actions to End AIDS, ICASO and ARASA, 2016. icaso.org/wp-content/uploads/2017/03/ICASO-Community-Report_Final-ZK-Feb-27.pdf
19. Governments Fund Communities: Six Country Experiences of Financing Community Responses Through Governmental Mechanisms, UNAIDS, 2016. www.unaids.org/sites/default/files/media_asset/JC2836_Governments-fund-communities_en.pdf
20. An Unlikely Ending: Ending AIDS By 2030 Without Sustainable Funding for the Community-Led Response: Report by the NGO Representative, UNAIDS Programme Coordinating Board, 2016. www.unaids.org/en/resources/documents/2016/PCB39_16-23
21. Building Resilient and Sustainable Systems for Health through Global Fund Investments: Information Note, the Global Fund to Fight AIDS, Tuberculosis and Malaria, May 2017. www.theglobalfund.org/media/4759/core_resilientsustainablestemsforhealth_infonote_en.pdf
22. Last Mile Funding: Improving Practice in Philanthropic Funding of Community Action on AIDS, Matt Greenall and Helen Parry for Funders Concerned About AIDS, June 2018. www.fcaids.org/wp-content/uploads/2018/11/Last-Mile-Funding-FCAA-November-2018-1.pdf

Community responses and universal health coverage:

23. The UHC that We Want: A Position Statement from the Asia-Pacific Community and Civil Society Universal Health Coverage Caucus, APCASO and GFAN AP, 2017. apcaso.org/wp-content/uploads/2017/12/v1-Final-UHC-AP-Statement-for-UHC-Forum-2017.pdf
24. Call to Action: The Central Role of Community Action in Supporting the Achievement of the Sustainable Development Goals: High Level Political Forum on Sustainable Development, 10-19 July 2017, New York, Stop AIDS Alliance, FSP and PITCH, 2017. aidsalliance.org/assets/000/003/050/call_to_action_community_action_hlpf_original.pdf?1499853171
25. Framework on Integrated, People-Centred Health Services, WHO, 15 April 2018. apps.who.int/gb/ebwha/pdf_files/WHA69/A69_39-en.pdf?ua=1&ua=1
26. WHO Community Engagement Framework for Quality, People-Centred and Resilient Health Services, WHO, 2017. apps.who.int/iris/bitstream/handle/10665/259280/WHO-HIS-SDS-2017.15-eng.pdf?sequence=1
27. Universal Health Coverage and Community Engagement, Asiya Odugleh-Kolev, WHO, and John Parrish-Sprowl, Global Health Communication Center, in Bulletin of World Health Organisation, 2018. www.who.int/bulletin/volumes/96/9/17-202382/en/

28. Universal Health Coverage: An Opportunity to Reach Key, Overlooked and Underserved Populations, Discussion Paper for Promote Health, Keep the World Safe, Serve the Vulnerable: HIV, Viral Hepatitis, Tuberculosis, Sexually Transmitted Infections and Universal Health Coverage Civil Society Meeting, prepared for WHO, March 2018.
29. Promote Health, Keep the World Safe, Serve the Vulnerable: Report of HIV, Viral Hepatitis, Tuberculosis, Sexually Transmitted Infections and Universal Health Coverage: Civil Society Meeting, WHO, March 2018.
30. High-Quality Health Systems in the Sustainable Development Goals Era: Time for a Revolution, Margaret E Kruk, Anna D Gage, Catherine Arsenault, Keely Jordan, Hannah H Leslie, Sanam Roder-DeWan, Olusoji Adeyi, Pierre Barker, Bernadette Daelmans, Svetlana V Doubova, Mike English, Ezequiel García Elorrio, Frederico Guanais, Oye Gureje, Lisa R Hirschhorn, Lixin Jiang, Edward Kelley, Ephrem Tekle Lemango, Jerker Liljestrand, Address Malata, Tanya Marchant, Malebona Precious Matsoso, John G Meara, Manoj Mohanan, Youssoupha Ndiaye, Ole F Norheim, K Srinath Reddy, Alexander K Rowe, Joshua A Salomon, Gagan Thapa, Nana A Y Twum-Danso, Muhammad Pate, The Lancet Global Health Commission, September 2018. [www.thelancet.com/journals/langlo/article/PIIS2214-109X\(18\)30386-3/fulltext](http://www.thelancet.com/journals/langlo/article/PIIS2214-109X(18)30386-3/fulltext)



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ANNEX 2: Components and activities of community responses for health

The following are from *Communities Deliver: The Critical Role of Communities in Reaching Global Targets to End the Aids Epidemic by UNAIDS and Stop AIDS Alliance, 2015*. They provide further details (from the perspective of HIV) about the four suggested components of community responses and the type of activities involved.

COMPONENT 1: ADVOCACY, CAMPAIGNING AND PARTICIPATION IN ACCOUNTABILITY

Description:

Community-based advocacy, campaigning and participation in accountability have changed the landscape of the AIDS response worldwide, and they continue to deliver key changes that enhance the well-being of individuals and their communities. They demonstrate examples of the innovative efforts of communities to negotiate the complex social and political landscapes that define the AIDS response. Community-based advocacy and campaigning have: mobilised millions of individuals; influenced policies and laws; improved access to treatment, care, support, HIV testing and other services; challenged stigma and addressed discrimination; enhanced prevention interventions; and created more enabling environments. These changes have in turn supported the achievement of better health outcomes and human rights. Attention to context is key to successful advocacy, campaigning and participation in accountability, as is a clear focus on the change that is intended and an understanding of what steps are necessary to achieve the desired outcome. Also key to advocacy success is founding actions and leveraging the expertise and knowledge of people in communities most affected.

Examples of activities:

Participation in decision-making and monitoring mechanisms:

- Resource tracking and monitoring.
- Meaningful engagement in National AIDS Councils, Country Coordinating Mechanisms, and other monitoring and coordination bodies.
- Participation in the design, implementation, monitoring and evaluation of policies and programmes, including enforcement and impact of laws.
- Securing accountability and fulfilling a watchdog role.

Advocacy and campaigning on HIV-specific issues:

- Advocacy and campaigning to improve access to services, reduce cost of treatment, overturning restrictive laws and secure funding for HIV services.

Advocacy and campaigning on broader human rights:

- Advocacy and campaigning to protect and advance gender equality, the right to health for all, and the rights of key populations, children and young people.

Campaigning across society:

- Campaigning to change attitudes, combat stigma and improve levels of HIV-related knowledge and rights literacy.

COMPONENT 2: Community-based service delivery

Description:

Community-based service delivery is an important component of the wider delivery of HIV services. Evidence shows that there is a greater impact, in terms of better access and wider coverage, with services that are community-led compared to other types of service provision. Evidence also shows that community-based service delivery has better health outcomes and can lead to the rapid scale-up of interventions through demand creation. Communities create the demand for services, but they also directly provide those services—whether they are medical interventions, social care or legal and human rights-related. Community-based services also humanise the delivery of prevention, treatment, care and support. The actions of communities in providing HIV-related services are particularly noteworthy, as they bring knowledge of the complexities and specifics of lives, rights and needs, enabling access to (and trust from) highly marginalised communities. Community-based services lend expert knowledge combined with lived experience from people living with HIV and key populations to inform and improve health systems service delivery. Given the high levels of stigma and discrimination experienced when accessing health services by people living with HIV and other key populations, the training and sensitisation of health-care providers is a critical component of community-based service delivery. Addressing health, social, psychological and economic issues, including impact mitigation, is the mainstay of most community-based services, and it is done through informal as well as formal services. Communities are diverse, and so are their needs; strong community action is defined, led, implemented and owned by communities with support from civil society, government and other stakeholders.

Examples of activities:

HIV prevention:

- Distribution of prevention commodities.
- Delivery of behaviour change interventions.
- Prevention of mother-to-child transmission related-services (linkage to care, adherence support, antiretroviral therapy delivery, home-based care).
- Services for key populations through specifically designed combination prevention services, including harm reduction and peer education.
- Integration of HIV prevention services into sexual and reproductive health and rights services.

Confidential and voluntary HIV testing and counseling:

- Testing services at the community level for the general population.
- Testing, counselling and linkage to care services for key populations.
- Peer support in accessing testing (including home testing) and counselling, and in coping with results.
- Different types of counselling.

HIV treatment:

- Antiretroviral therapy and other medicine provision and delivery.
- Treatment education.
- Treatment services for key populations.
- Services addressing co-infections, including tuberculosis and hepatitis C.
- Adherence support.

Demand creation and service uptake:

- Raise awareness of available services.
- Mobilise communities for demand creation.
- Broker access and referrals to services.

Care and support:

- Palliative care, including home-based care.
- Psychosocial support.
- Food and nutrition support.
- Care for children and families.
- Economic empowerment and income generation.

Rights and legal services:

- Programmes to reduce stigma and discrimination.
- Services to address and end gender-based violence.
- Legal services.
- Legal and human rights literacy.

Task-shifting and task-sharing:

- Community health workers.

Training and sensitisation of service providers:

- Including health-care personnel, lawmakers and law enforcement officials

ELEMENT 3: PARTICIPATORY COMMUNITY-BASED RESEARCH AND MONITORING

Description:

Community-based research is essential for ensuring that policy-makers and programme planners are well informed as to: (1) the needs of the communities that their policies and programmes are aimed to reach; and (2) the real impact, availability, accessibility, affordability, acceptability, quality and effectiveness of the services and policies they currently are (or plan to be) delivering. Beyond informing others, community-based research is also an important source of information for communities to guide services, advocacy and actions. Moreover, community-based research empowers communities to play an active role in influencing policy dialogue. Participatory community-based research is particularly impactful because it demonstrates the importance of understanding the context within which needs, rights and responses are analysed and understood. It is also a more ethical form of research since it affords communities the opportunity to participate in the research discourse, enabling them to be the subject as well as the object of enquiry. There are a range of effective approaches that have been used by communities, nearly all of which involve a participatory approach that allows for a process where the community validates results and outcomes.

The meaningful engagement of communities in research is crucial. It is well understood that engaging communities in research, including biomedical and clinical research, is essential for achieving deeper and more reliable results, including reaching a representative sample, determining the right questions to ask and ascertaining how to interpret the data. Any research that aims to investigate a community or develop new technology that will be used by a community should involve the community as a partner.

Examples of activities:

Research on human rights, stigma, and discrimination:

- Research on stigma and discrimination faced by a community or a population group.
- Research on stigma and discrimination experienced in accessing services.
- Research on gender norms and gender equality.
- Monitoring, documenting and analysing human rights violations.

Improving "know your epidemic" and "know your response":

- Research on burden of disease and HIV-related vulnerabilities for population groups and communities.
- Research on vulnerability factors to HIV for different population groups or different geographical locations.
- Research on available programmes, including treatment and prevention (for whom and how), and gaps in and barriers of access (for whom and why).
- Needs assessments (including by key populations) on priority health and social care needs, and services.
- Policy framework analysis and how it affects ability to access equitable and quality treatment, prevention, care and support.

Research on new treatment and prevention technologies:

- Participation in the research to test new technologies.
- Participation in Ethical Review Boards and in deciding what and how research should be conducted.

Research to reach key populations with community–and rights-based policies and programmes:

- Population size estimates.
- Modes of transmission-related research.
- Research on gaps and barriers to access for services and human rights.
- Needs assessments for key populations.
- Evaluating policies and programmes aimed at reaching or affecting access by key populations.

Evaluation of programmes and services.

COMPONENT 4: COMMUNITY FINANCING

Description:

Community-based financing approaches can create favourable economies of scale and leverage additional funds from relatively small investments. Many community organisations have long had vibrant fundraising elements, and many are also experienced in disbursing funds to ensure that the community organisations, in particular those working most closely with people living with HIV and marginalised populations, are not left behind. Civil society organisations undertaking this financing role have been supported by their ability to reduce transaction costs; they also can evaluate and disburse funds more rapidly, with less weighty infrastructure and often better accountability than many other large and bureaucratic organisations. Several examples show how communities are working to ensure that funds reach those in greatest need, ensuring that valuable resources are not lost in excessive transaction costs. Many CBOs have proven that they can responsibly account for funds of major donors, especially if given adequate capacity strengthening in financial management. They may also be able to provide added value in the form of technical assistance and other support services. Community financing initiatives (such as health insurance schemes) are becoming an increasingly important part of the landscape, as are efforts to reach key populations. Where state-funded social protection schemes are unable to reach certain population groups, community-based financing initiatives have stepped in to fill that gap, whether it is because state-funded schemes do not have the capacity or because there are legal or policy barriers to access for certain key populations.

Examples of activities:

- On-granting (forward granting)
- Resource mobilisation
- Community financing initiatives

ANNEX 3: Building blocks of community systems and activities for community systems strengthening

UNAIDS and the Stop AIDS Alliance suggest that community responses for health are comprised of four components: 1. Advocacy, campaigning and participation in accountability; 2. Community-based service delivery; 3. Participatory, community-based research and monitoring; and 4. Community financing. Annex 2 provides charts that detail the type of activities that, from the perspective of the response to HIV, are included in each component.

The Global Fund¹⁹ suggests that the implementation of community responses requires community systems. These are based on six building blocks:

- **Building block 1:**
Enabling environments and advocacy – including community engagement and advocacy for improving the policy, legal and governance environments, and affecting the social determinants of health.
- **Building block 2:**
Community networks, linkages, partnerships and coordination – enabling effective activities, service delivery and advocacy, maximising resources and impacts, and coordinated, collaborative working relationships.
- **Building block 3:**
Resources and capacity building – including human resources with appropriate personal, technical and organisational capacities, financing (including operational and core funding) and material resources (infrastructure, information and essential medical and other commodities and technologies).
- **Building block 4:**
Community activities and service delivery – accessible to all who need them, evidence-informed and based on community assessment of resources and needs.
- **Building block 5:**
Organisational and leadership strengthening – including management, accountability and leadership for organisations and community systems.
- **Building block 6:**
Monitoring and evaluation and planning – including M&E systems, situation assessment, evidence-building and research, learning, planning and knowledge management.

In turn, the Global Fund provides the following illustrative examples of community systems strengthening activities to fulfill the six building blocks and maximise the quality and impact of community responses:

AREA OF COMMUNITY SYSTEMS STRENGTHENING AND EXAMPLES OF ACTIVITIES

Community-based monitoring for accountability

- Development and planning of community based monitoring and documentation mechanisms.
- Design, establishment and maintenance of research plans, community-based monitoring and documentation tools and systems.
- Monitor or develop indicators to measure legal rights.
- Equipment for monitoring (e.g. relevant information technology).
- Implementation of monitoring for accountability activities (including baseline monitoring, data collection by communities, discussions with service providers, and use and appraisal of official/government data).
- Collation, centralisation and analysis of monitoring data and development of recommendations and demands for improvement.
- Publication and dissemination of community monitoring data and recommendations
- Technical support and training.
- Training for community researchers/monitors.

Advocacy for social accountability

- Planning of consensus, dialogue and advocacy work with decision makers and service providers at local and national level.
- Consultations with community members.
- Consultations with relevant government representatives.
- Development and dissemination of advocacy products/materials.
- Conduct of advocacy activities (e.g. meetings, campaigns, public advocacy events).
- Support to participation of community actors (including key populations) in local and national decision making/consultative bodies.
- Technical support and training.

Social mobilisation, building community linkages, collaboration and coordination

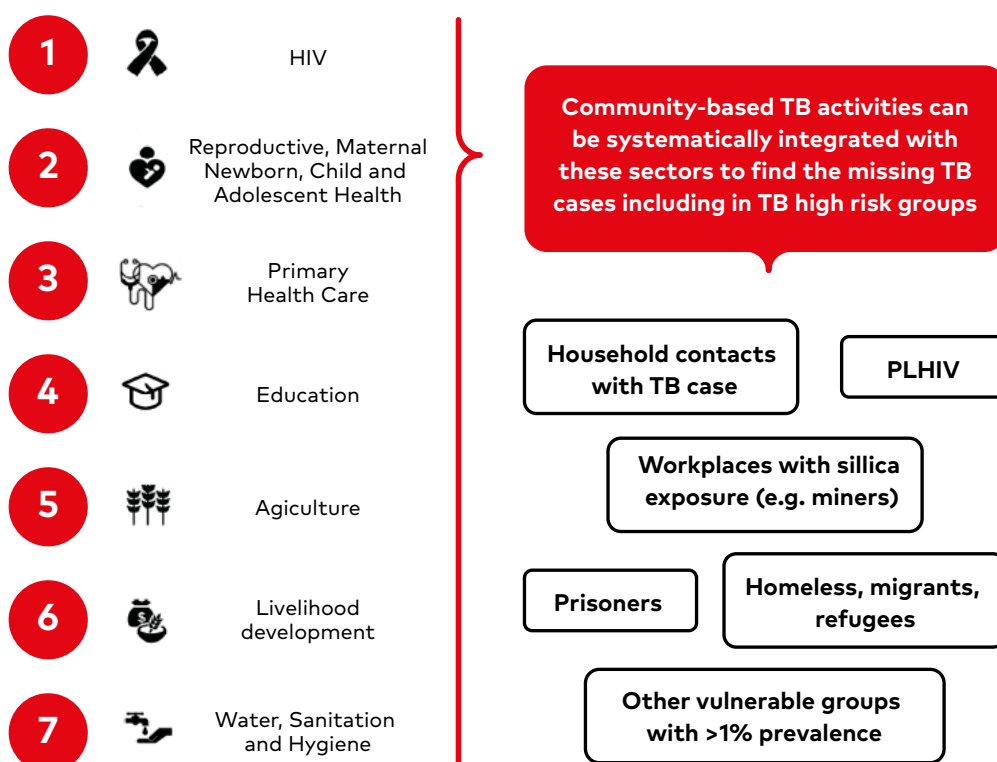
- Community/social mobilisation activities (including participatory assessments, community meetings and identification of issues, mapping of community efforts, planning).
- Support to establishment of community organisations.
- Develop and maintain coordination and joint planning mechanisms to link community actors with each other, and with other relevant actors, at local, national, regional and international levels.
- Develop and maintain referral mechanisms between different service providers, in particular between community and other sector providers, and across borders where relevant.
- Develop and support networking of community groups [on HIV, TB, malaria, health and women's], particularly of key populations, to ensure representation and advocacy at national level is effective, and for experience sharing, mentoring etc.
- Core support for participation in coordination mechanisms by community representatives (including transport/travel costs).
- Establishment of community health worker programming, strengthening, integration within the health systems and linkages with the community systems.
- Community level groups (e.g. health committees) whose mandate includes coordination and networking, identifying and responding to issues and barriers and mobilising actions, support, linking with the health system, etc.
- Awareness-raising amongst community members about their entitlements, as specified in service-provider commitments.
- Technical support and training.

Institutional capacity building, planning and leadership development in the community sector

- Assessment of needs in human resources, systems, equipment, organisational and institutional development, leadership, etc.
- Provision of resources for institutional support including legal support, support for registration etc.
- Evidence informed planning, management, and policy formulation for community systems.
- Development of systems for planning community action.
- Development and implementation of systems and policies for recruitment, supervision, motivation and support of community level workers and volunteers.
- Capacity building in leadership, project management, volunteer management and supervision, motivation.
- Professional development for community workers/volunteers not covered elsewhere, e.g. for professional ethics, human rights, stigma reduction.
- Training in special technical areas such as child protection, social protection, gender mainstreaming, working with criminalised or marginalised communities, providing integrated TB/HIV services, drug resistance, community audits such as verbal autopsy of reasons for deaths.
- Strengthening communications skills and infrastructure.
- Mentoring programs for community sector actors (including leaders and volunteers).
- Development of systems for rational, transparent and effective distribution of funds to community sector organisations within the framework of the national response and, if necessary for neglected themes, outside of this framework.
- Capacity building for community groups, organisations, networks in strategic investment of resources, financial planning, financial management and resource mobilisation, planning for sustainability.
- Development and management, and where possible standardisation of schemes for remunerating community outreach workers and volunteers or providing other incentives and income-generation support.
- Procurement of infrastructure and equipment as well as other materials and resources required by community groups, organisations and networks and appropriate to their needs and roles within the response.
- Support to ongoing organisational running costs in line with roles in the national response.
- Development and dissemination of good practice standards for community sector service delivery and implementation including protocols, supervision and management.
- Development of accountability and governance plans for leaders of groups, organisations and networks.
- Development of systems for M&E and other data collection of community led action, sharing of information, and integrating this information with national monitoring systems.
- Adaptation of health sector assessment tools to ensure they capture community systems and CSS.

ANNEX 4: Community-based activities to find missing TB patients

To achieve the End TB Strategy, WHO and partners promote an ENGAGE-TB approach²⁰ that emphasises the role of community-based activities in preventing, finding and treating 'missing' TB patients. The approach calls for the integration of a wide range of possible TB activities [see below] into existing community-based health and development interventions [see right], alongside stronger collaboration between National TB Programmes, communities and civil society.



Theme	TB activities to integrate into community-based interventions
Prevention	Awareness-raising, IEC, BCC, infection control, stigma reduction, training providers
Detection	Screening, contact tracing, sputum collection, sputum transport, training providers
Referral	Linking with clinics, transport support and facilitation, accompaniment, referral forms, training providers
Treatment adherence support	Home-based DOT support, patient education, adherence counselling, stigma reduction, pill counting, training providers, home-based care and support
Social and livelihood support	Cash transfers, insurance schemes, nutrition support and supplementation, voluntary savings and loans, inclusive markets, training providers, income generation
Advocacy	Ensuring the availability of supplies, equipment and services, training providers, governance and policy issues, working with community leaders
Stigma reduction	Community theatre or drama groups, testimonials, patient and peer support groups, community champions, sensitising and training facility and CHWs and leaders

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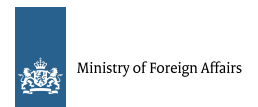
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FREE SPACE PROCESS



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.

Over the past 10 years, the FSP has brought together the leadership of the (now 11) global HIV civil society and KVP communities' networks to facilitate linking and learning, shared strategizing and (increasingly) enhanced collaboration and division of labour.



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.

**FREE
SPACE
PROCESS**



PITCH Partnership to Inspire, Transform
and Connect the HIV response