Evidence from participatory research on community health systems for HIV treatment and support in East and Southern Africa

Synthesis of participatory research in Zimbabwe, Mozambique, Tanzania, Namibia, Malawi and Botswana

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Training and Research Support Centre (TARSC) in the Community-Based Systems in HIV Treatment (CoBaSys) programme

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Executive Summary

The Community Based Systems in HIV treatment (CoBaSys) programme aims to understand and support conditions for community empowerment in services providing treatment for people living with HIV in East and Southern Africa (ESA). A community system for health is understood to be the sum of the organisations, local government structures, civil society organisations, institutions and resources whose primary purpose is to improve health at community and primary care level. We implemented participatory research (PR) with community members, health workers and community leaders in twelve sites in Zimbabwe, Namibia, Mozambique, Malawi, Botswana and Tanzania to map the contexts and social differentials that affect HIV risk and vulnerability to AIDS, the resources, institutions and actors available at community and primary care level to respond to the epidemic, the factors affecting availability, access, acceptability, uptake, quality of care and the strategies and actions proposed to strengthen responses to HIV and AIDS at community and primary care level. We used thematic synthesis to synthesise the primary research given that the same PR methods were used in each site.

Within communities there were common factors leading to risk and vulnerability and affecting responses and uptake of services. Insecure employment, food insecurity and poverty generated difficult conditions for dealing with vulnerability and increased possibilities of non adherence to treatment due to lack of food or funds to use services. Some occupations such as brewing illicit alcohol and commercial sex or begging generated more intense risk environments for HIV. Food and income insecurity was reported to lead women to engage in high-risk commercial sex to earn a living and cross border trading was characterised by exploitation, separation from families and partners, and separation from the socio cultural norms that guide behaviours within communities. The risks were higher for women who were vulnerable to risky environments for commercial sex and child trafficking and who had little negotiating power in the face of social attitudes driving low condom use. Stigma, discrimination and fear persisted despite a decade since the epidemic onset, discouraging people from seeking treatment and care and leading to negative self perceptions that limit disclosure and uptake of services and that lead to psychosocial stress. Despite over a decade of social programmes on AIDS, gender norms in particular were found to affect women’s autonomy (economic, social and sexual), to feed stigma and to lead to low involvement of men in AIDS programmes.

Where services for AIDS were integrated with services for maternal and child health and treatment of common illnesses and were close to communities, as they were more accessible and supportive of responses for reducing both HIV risk and vulnerability to AIDS. However services were found to be crowded, stressed by rising demand, with poor facilities for privacy, shortfalls in supplies and frustrated and non communicative health workers undermining uptake. Of these factors the presence of trained health workers living in the community was found to be the most critical. With primary care services understaffed by skilled workers, they were also the biggest gap. Faced with poor pay, poor occupational protection, shortfalls in medicines and equipment in primary care services, limited space for services, poor supervision and mentoring, some health workers were reported to leave primary care services, to raise informal charges for rationed services like Antiretroviral Therapy (ART) or CD4 testing, or to have stressed and sometimes hostile communication with clients. Despite services being offered free of charge in public health institutions in Zimbabwe, Malawi, Mozambique, Botswana, the transport, food, lost work time and out-of-pocket costs for medicines and tests not always provided free, together with informal charges, mean that costs are a continuing barrier to uptake of services for the poorest in the community. There is limited social welfare support to buffer such costs for households, as these systems were themselves found to be underfunded or absent.

Within health care services, centralised service provision, and lack of services, staff and supplies for treatment at the primary care level close to communities were seen to be the biggest service constraint to building effective community systems for the response to HIV and AIDS. This lack of primary care focus in
the delivery of services has meant that workers at primary care and even district level received limited clinical mentoring to enable them to provide client-centred care and were poor entry points for referral services for treatment. Transport and communication barriers at primary care level further added to this. Adding to this major factor in the system, there were other issues raised that facilitate or impede community systems: the level of integration of AIDS programmes within wider services was seen as an important facilitator, as were measures to reduce the potential for stigma within services in the organisation of services and the communication from health workers.

While communities identified funding and other constraints to these barriers, they appeared to have limited power and role in decision making to change them. They perceived their participation in health systems to be symbolic, as objects of services, and without real power to actively participate in meaningful decision making. Policy interventions were thus seen to reflect international rather than people’s priorities. In contrast responses on the ground to prevent HIV and cope with AIDS were primarily seen to be driven by households and community based organisations, with support from primary level services. The underfunding of these community level resources, the continued disconnect between state and non state actors at local level, and the fragmentation between internationally supported activities in civil society with state services at local level were all raised as barriers to building a response to AIDS that is organised around communities.

These are not new findings. What is disconcerting is that over a decade after intervention on the epidemic has scaled up at both global and national level, these issues continue to be raised by communities and frontline health workers who see themselves as powerless recipients of other levels of decision making on how to respond to the epidemic.

Below, we suggest eight areas of action for strengthening community systems for HIV prevention and AIDS treatment, support and care.

### Within communities:
- Recognise and address the risk environments for AIDS within comprehensive primary health care approaches.
- Ensure that literacy campaigns include social dialogue and information sharing on community centred approaches to HIV prevention, AIDS treatment, support and care that raise rights and responsibilities, as well as challenge gender norms and strengthen collective responsibilities for support to vulnerable groups.

### In the interface between communities and health services:
- Recognise and ensure mechanisms for strategic partnerships, leadership, supported and mentored decentralisation and participatory decision making.
- Resource and align the role of community health workers for comprehensive client-centred care.
- Ensure that international and global health initiatives support within countries: is user-friendly for community and local health systems; strengthens local participatory decision making and mutual accountability between state and non-state actors; and supports comprehensive primary health care.

### Within the health system:
- Deploy, train and support health workers with incentives at community and primary care level, as well as mentor health workers and integrate clinical mentoring in national strategic plans.
- Ensure production, procurement and disbursement systems with sufficient capacity to prevent stock outs of medicines, diagnostics and other commodities at primary care level.
- Strengthen information systems and domestic public funding to meet entitlements for community systems on AIDS at primary care level.
1. Background

East and Southern Africa are at the centre of the global HIV and AIDS pandemic, yet research over the past few decades has consistently shown that these regions are failing to meet the growing demand for HIV and AIDS health services. UNAIDS statistics from 2009 indicate that over a third (34%) of people living with HIV worldwide are in southern Africa but only three countries of the region with generalised epidemics – Botswana, Namibia and Rwanda – have achieved universal access to ART, providing it to at least 80% of patients in need (WHO et al, 2011). Further, there are still serious coverage gaps in children receiving paediatric HIV treatment, with eastern and southern Africa serving only 26% of those estimated to be in need. Despite the shortfall in providing treatment, there has nevertheless been huge progress in scaling up provision more recently. In 2010 UNAIDS reported that 3.9 million people in sub-Saharan Africa were receiving Anti-retrovirals (ARVs), up from just 50,000 in 2002. The reasons why so many remain untreated are several: HIV and AIDS treatment is poorly decentralised to primary care level, with services that are fragmented and not well integrated with wider services, and countries in the region suffer from weak procurement and supply systems, frequent drug stock-outs, severe health worker shortages and low levels of community treatment literacy (UNAIDS, 2010).

The HIV and AIDS indicators for the countries covered by this report are summarised in Table 1. Of these countries, Mozambique has the biggest HIV burden with 1.4 million HIV-positive people, but Botswana has the highest HIV prevalence at 24.8%. Botswana had the highest adult ART coverage (83%) in 2010 compared to Tanzania and Mozambique with only 30% coverage.

Table 1: HIV and AIDS indicators in selected countries in East and Southern Africa

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Botswana</th>
<th>Malawi</th>
<th>Mozambique</th>
<th>Namibia</th>
<th>Tanzania</th>
<th>Zimbabwe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of people living with HIV (PLWHIV) 2009</td>
<td>320,000</td>
<td>920,000</td>
<td>1,400,000</td>
<td>180,000</td>
<td>1,400,000</td>
<td>1,200,000</td>
</tr>
<tr>
<td>HIV prevalence in adults 15-49 yrs 2009</td>
<td>24.8%</td>
<td>11%</td>
<td>11.5%</td>
<td>13.1%</td>
<td>5.6%</td>
<td>14.3%</td>
</tr>
<tr>
<td>Adult ART coverage 2010 WHO recommended ART guidelines (CD4 350) 2009</td>
<td>83%</td>
<td>48%</td>
<td>32%</td>
<td>76%</td>
<td>32%</td>
<td>34%</td>
</tr>
<tr>
<td>Adult ART coverage 2006 Guidelines (CD4 200) 2009</td>
<td>&gt;95%</td>
<td>72%</td>
<td>51%</td>
<td>&gt;95%</td>
<td>49%</td>
<td>52%</td>
</tr>
<tr>
<td>PLWHIV 15 years + 2009</td>
<td>300,000</td>
<td>800,000</td>
<td>1,200,000</td>
<td>160,000</td>
<td>1,200,000</td>
<td>1,000,000</td>
</tr>
<tr>
<td>Women 15yrs+ living with HIV 2009</td>
<td>170,000</td>
<td>470,000</td>
<td>760,000</td>
<td>95,000</td>
<td>730,000</td>
<td>620,000</td>
</tr>
<tr>
<td>Children &lt;14 yrs living with HIV 2009</td>
<td>16,000</td>
<td>120,000</td>
<td>130,000</td>
<td>16,000</td>
<td>160,000</td>
<td>150,000</td>
</tr>
<tr>
<td>Deaths due to AIDS 2009</td>
<td>5,800</td>
<td>51,000</td>
<td>74,000</td>
<td>6,700</td>
<td>86,000</td>
<td>83,000</td>
</tr>
<tr>
<td>Orphans 0-17 yrs due to AIDS 2009</td>
<td>93,000</td>
<td>650,000</td>
<td>670,000</td>
<td>70,000</td>
<td>1,300,000</td>
<td>1,000,000</td>
</tr>
</tbody>
</table>

Source: UNAIDS 2010
As described above, countries continue to struggle to create environments that support individual and social actions that reduce risk and reduce new HIV infections. Most countries continue to face challenges in providing health care, antiretroviral treatment, support and care to PLWHIV through services at community and primary care level to reduce health care costs that impoverish people. Thus provision of care and support to those affected by HIV and AIDS including orphans and vulnerable children is often undermined.

1.1 Cobasys work on community systems for HIV treatment

In this paper, we will examine community systems for HIV treatment in East and Southern Africa. However, we first need to clarify what is meant by the term ‘community’. We understand ‘community’ to mean a group of people who have a shared relationship and interest. They could live in same geographical location or not, or link across areas based on common interests. We note that communities that live in the same geographical area may not be homogenous in terms of other characteristics or other interests beyond shared location. For the purposes of our research, we define ‘HIV services’ as encompassing the treatment of opportunistic and co-infections such as tuberculosis, the provision of anti-retrovirals, support interventions such as treatment literacy, psychosocial support, nutrition and other complementary interventions that may be provided through one or more providers.

The primary purpose of this paper is to report our findings from the first phase of the community systems in HIV treatment (CoBaSys) programme, which was conducted in Zimbabwe, Tanzania, Namibia, Mozambique, Malawi and Botswana between April 2010 and October 2011. The CoBaSys programme is ongoing, exploring the factors affecting peoples’ access to and use of HIV and AIDS services, as well as the factors determining effective coverage of these services. Drawing on community and local health worker inputs, we have identified relevant and effective approaches to building community systems and supportive services for HIV and AIDS. Ultimately, we hope to to define what constitutes an equitable, community-based HIV health-service system.

The CoBaSys programme is being implemented through a network of research institutions, academic institutions and professionals in East and Southern Africa and in Europe. It is being implemented with support from the European Commission (EU) to support science and technology in African, Caribbean and Pacific (ACP) countries. In this first phase of the programme we implemented a participatory action research (PR) programme. Eleven institutions in Africa and Europe were involved in the PR work, with the Training and Research Support Centre (TARSC) working as co-ordinator of this specific area with a range of partners. Country-level work was carried out by the University of Zimbabwe, REACH Trust, the University of Malawi, the University of Botswana, the University of Namibia, the University of Eduardo Mondlane in Mozambique and the University of Dar es Salaam in Tanzania. They worked in co-operation with the University of Bologna and the University of Modena in Italy, as well as the University of Manchester in the United Kingdom, the University of Helsinki in Finland and the European AIDS Action Group from Belgium.

1.2 Participatory research on community systems for HIV treatment

In our participatory research (PR) work in Zimbabwe, Tanzania, Namibia, Mozambique, Malawi and Botswana, we specifically sought to:

- Map the social differentials that affect HIV risk and vulnerability to AIDS, and the contexts environments for, distribution and burdens of the epidemic that raise the need for services.
- Map the resources, institutions and actors available at community and primary care level to respond to the epidemic.
- Identify the factors affecting availability, access, acceptability, uptake, quality of care in and adherence to HIV and AIDS services and how these factors can be addressed.
• Identify strategies and actions to strengthen responses to HIV and AIDS at community and primary care level, as recommended by communities, health authorities, opinion leaders and key stakeholders, and the progress markers for these actions.

We used the framework developed by Tanahashi (1978) to understand the level at which inequalities in peoples’ contact with health care may arise. Tanahashi provides five domains to understand levels of coverage:

• **Availability coverage:** Are the health care resources (infrastructure, medicines, personnel) available, and for whom?
• **Accessibility coverage:** Are these health care resources accessible, and for whom? There may be physical or financial barriers to access.
• **Acceptability coverage:** Are the health care resources and services acceptable to the population, and for whom? This includes social, cultural, financial and perceived barriers to using services.
• **Contact coverage:** Are people making contact with the services, and who are they? This domain looks at utilisation.
• **Effective coverage:** What share of the population in need of an intervention is effectively receiving that intervention?

Twelve sites were included in this CoBaSys synthesis report, with one to three sites in each of the six ESA countries (see Table 2).

**Table 2: Participatory research sites for CoBaSys**

<table>
<thead>
<tr>
<th>Countries</th>
<th>Sites</th>
<th>When the PR was conducted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Botswana</td>
<td>Old Naledi-Gaborone</td>
<td>April 2011</td>
</tr>
<tr>
<td>Malawi</td>
<td>Chiwamba-Lilongwe</td>
<td>November 2010</td>
</tr>
<tr>
<td></td>
<td>Mchinji</td>
<td>July 2011</td>
</tr>
<tr>
<td></td>
<td>Nkhata Bay</td>
<td>May 2011</td>
</tr>
<tr>
<td>Mozambique</td>
<td>Maluana Manhiça</td>
<td>May 2010</td>
</tr>
<tr>
<td></td>
<td>Marracuene</td>
<td>July 2011</td>
</tr>
<tr>
<td>Namibia</td>
<td>Chetto Caprivi</td>
<td>June 2011</td>
</tr>
<tr>
<td></td>
<td>Ngweze Caprivi</td>
<td>July 2011</td>
</tr>
<tr>
<td>Tanzania</td>
<td>Bagamoyo</td>
<td>December 2010</td>
</tr>
<tr>
<td>Zimbabwe</td>
<td>Kariba</td>
<td>May 2010</td>
</tr>
<tr>
<td></td>
<td>Goromonzi</td>
<td>January 2011</td>
</tr>
<tr>
<td></td>
<td>Chitungwiza</td>
<td>May 2011</td>
</tr>
</tbody>
</table>

The PR in each site is separately reported, and these reports are listed in the Reference list at the back of this paper. In terms of role players, we included in our research people living with HIV, children orphaned or made vulnerable by HIV, women, men, youth, affected by HIV, health workers, HIV support-group members, local authorities, traditional authorities, non-governmental organisations, community-based organisations, faith-based organisations and religious groups. In this paper, we synthesise our findings only up until the phase for setting actions, so we do not discuss the actions taken or reflection on these actions, which will be the subject of later reporting. Hence this report covers only the participatory research work, and we present the views and knowledge of community and local health workers regarding HIV and AIDS community systems and services. The CoBaSys programme is ongoing and the subsequent two years of the project aim to generate evidence on community-based and patient-centred approaches to HIV treatment.
1.3 Objectives

The main goal of our research was to identify barriers and facilitators of community systems for HIV treatment. The PR research aimed to:

- Map the social economic differentials within the communities that affect risk and vulnerability to HIV and AIDS, and that may have an impact on uptake of available services for prevention, treatment and care of HIV and AIDS.
- Identify the nature of the epidemic in the community in terms of risk groups and environments, the public health stage and burdens of the epidemic and discuss the nature of the responses needed for key social groups.
- Map the resources, institutions and actors available at community and primary care level to respond to the epidemic.
- Identify for key social groups the priority social and economic determinants at individual, household, community and system level that facilitate and block availability, access, acceptability, uptake, quality of care in and adherence to the resources above for prevention, treatment and care for HIV and AIDS (including community knowledge on social rights).
- Review the evidence to assess the opportunities and mechanisms to enhance facilitators and overcome priority blocks to availability, access, acceptability, uptake, quality of care in and adherence to services, for example, opinion leader and health worker attitudes and practices, communication processes and skills, mechanisms for social dialogue and communication, resource transfers, service organisation and so on.
- Identify strategies for strengthening these opportunities and mechanisms as recommended by communities, health authorities, opinion leaders and key stakeholders, including the actions that can be taken in the medium and long term for these strategies and the progress markers for these actions.
2. Methods

In each of the countries, we purposively sampled sites from areas with high HIV prevalence and where HIV risk was high. We used participatory reflection and action (PRA) tools that were developed by TARSC and Ifakara Health Institute in a manual published by the Regional Network for Equity in Health in East and Southern Africa (EQUINET) (Loewenson et al, 2006). In pursuance of the above objectives, a protocol was developed and TARSC adapted and piloted these tools while working with the country-level teams (Machingura et al, 2010). Table 3 summarises the protocol that we used in this study.

Table 3: Protocol used for the PR work in this study

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Methods used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prior to the PR field work</td>
<td></td>
</tr>
<tr>
<td>Key informant interviews; review of literature, media; stakeholder discussions with NGOs, planners and community representatives</td>
<td></td>
</tr>
<tr>
<td>PR field work and tools used</td>
<td></td>
</tr>
<tr>
<td>Map social differentials in communities that affect HIV risk and vulnerability to AIDS, and that may impact on uptake of available services for prevention, treatment and care of HIV and AIDS.</td>
<td>• Social mapping • Map interview • Discussion</td>
</tr>
<tr>
<td>Assess the nature of the epidemic in the community in terms of risk groups and risk environments, the distribution and burdens of the epidemic and the responses needed for key social groups.</td>
<td>• Stepwise diagram • Focus Group Discussion (use FGD guide)</td>
</tr>
<tr>
<td>Identify for key social groups the priority factors that affect availability, access, acceptability, uptake, quality of care and adherence to services for HIV prevention, treatment and care.</td>
<td>• Ranking and scoring • Problem tree • Discussion</td>
</tr>
<tr>
<td>Map the resources, institutions and actors available at community and primary care level to respond to the epidemic.</td>
<td>• Stakeholder analysis • Plenary community roundtable</td>
</tr>
<tr>
<td>Review the evidence to assess the opportunities and mechanisms to enhance facilitators and overcome priority blocks to access to services.</td>
<td>• Leaping blocks • Market place • Discussion</td>
</tr>
<tr>
<td>Identify strategies recommended by communities, health authorities, opinion leaders and key stakeholders, the actions that can be taken and the progress markers for these actions.</td>
<td>• Margolis wheel • Spider web • Group discussions • Market place</td>
</tr>
</tbody>
</table>


We decided to use a PR approach because it allowed us to gather and compare the experiences of social groups with common features living in a specific geographical area and to identify common patterns within the groups as well as between them. We were then able to use the patterns we identified to stimulate
discussion with participants and provoke them to reflect on the causes of problems and what actions can be
taken to mitigate them.

We encountered some challenges in the field work, particularly regarding a lack of time and language
barriers:

Participants at the site in Maraccuene, Mozambique, and the site in Old Naledi, Botswana, complained that
the protocol was too time consuming, and took time away from their other duties.

In Bagamoyo, Tanzania, health workers were unable to complete some activities owing to lack of time, so
some questions were left unanswered.

In Maraccuene, some participants perceived some of the tools we used, such as the spider diagram, as
childish and too much like ‘child’s play’, which made it difficult for them to take these activities seriously.

In Mozambique barriers in translation were faced, as some of the technical terms could not be adequately
translated into local languages, a problem most notable with the mapping exercise. Further, the research
depended on the capabilities of the facilitator to probe in discussions, and to collate and synthesise
the evidence for action. This could have undermined the data given that some facilitators did not have
much experience in facilitating PR research. The PR demanded clear facilitation to avoid diversion of the
discussion.

To search for a method that we could use to synthesise our findings, we conducted a literature review via the
search engines Pub Med and Google, using the keywords ‘synthesis’, ‘qualitative data’, ‘generalisation’ and
‘ethnography’. We chose fifty documents dated between 1962 and 2009 in grey literature and peer-reviewed
journals, and from those we compiled a list of potential methods for synthesising qualitative data.

We chose thematic synthesis as our preferred approach for synthesising our primary data, considering that
we used the same PR methods in each site. Thematic synthesis was appropriate as it is used to identify
major or recurrent themes and summarises findings under thematic headings. Information is tabulated
allowing identification of prominent themes and offering structured ways of dealing with the data in each
theme. It is a method for grouping evidence with common themes while noting possible differences in context
(Harden et al 2001, 2006; Shepherd et al 2001; Rees et al 2001; Thomas and Harden 2007, 2008; Thomas

Drawing on the conceptual framework that informed the work, we analysed the evidence across all the sites
according to these theme areas:

• the social conditions and determinants of HIV risk and vulnerability for AIDS;
• coverage of HIV prevention services and, treatment and care services for AIDS;
• factors within the community and health services affecting availability, access, acceptability, uptake,
  quality of care in and adherence to services; and
• potential strategies for improving community and health systems responses to AIDS.

Next we tabulated information from the various sites within each theme. We analysed the information within
each theme to identify recurring issues, words and concepts across sites and noted these. We also noted
specific outliers, identifying the relevant site and person (or social group) responsible for the outlier for follow
up.
There were some gaps in our data, where some sites could not supply the information we required for our analysis. These data gaps are shown in Table 4.

Table 4: Data gaps in our analysis according to theme areas

<table>
<thead>
<tr>
<th>Theme areas</th>
<th>Number of sites where evidence was found</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Social and economic factors</strong></td>
<td></td>
</tr>
<tr>
<td>Employment and poverty</td>
<td>7</td>
</tr>
<tr>
<td>Condom use</td>
<td>5</td>
</tr>
<tr>
<td>Treatment literacy</td>
<td>6</td>
</tr>
<tr>
<td>Health governance</td>
<td>5</td>
</tr>
<tr>
<td>Gender norms</td>
<td>9</td>
</tr>
<tr>
<td>Housing</td>
<td>1</td>
</tr>
<tr>
<td><strong>Access to services</strong></td>
<td></td>
</tr>
<tr>
<td>Distance and transport to services</td>
<td>8</td>
</tr>
<tr>
<td>Out of pocket spending and cost barriers</td>
<td>10</td>
</tr>
<tr>
<td><strong>Health service factors</strong></td>
<td></td>
</tr>
<tr>
<td>Social welfare services</td>
<td>4</td>
</tr>
<tr>
<td>Centralisation or verticalisation of programmes</td>
<td>7</td>
</tr>
<tr>
<td>Waiting times</td>
<td>6</td>
</tr>
</tbody>
</table>

We recognise a number of shortcomings in our analysis and have attempted to address them where possible. First, we acknowledge a loss of context in bringing the findings from individual studies together. We have attempted to address this shortcoming by providing a context analysis of each site to help in interpreting outliers. We have also identified the social group and/or person making the comment in cases of outliers. Second, our methodology focused on identifying the most frequently occurring comments as well as common patterns to the issues raised by participants, which may have led to some loss of important specific information necessary to understand vulnerability. We attempted to address this concern by noting outliers or differences, in addition to the common trends. Finally, we would like to emphasise that concepts used in one setting may not mean the same as when they are used in another. We have provided references for the individual reports for each site in the Reference list, as they can be consulted for the full findings in each setting.
3. Findings

3.1 Contexts

As mentioned earlier, the 12 sites for this study were selected on account of being high-risk areas with a high HIV prevalence. In these high-risk environments, people experience social and economic insecurity arising from limited secure employment, with low earnings from economic activities. In terms of health services, these are generally very limited, with extreme shortages of health workers, a lack of equipment and regular stockouts of medicines and other supplies. Table 5 supplies further details on the sites.

Table 5: Country contexts for the 12 CoBaSys sites

<table>
<thead>
<tr>
<th>Country and site(s)</th>
<th>Geography and population</th>
<th>Social and economic factors</th>
<th>Health system</th>
</tr>
</thead>
<tbody>
<tr>
<td>Botswana Old Naledi</td>
<td>Old Naledi is divided into three areas – South, North and Central – with a population of about 90,000.</td>
<td>It has high unemployment, with few socio-economic activities. The community depends on social safety nets provided by Gaborone City Council. Those in work are low-income earners.</td>
<td>It has one health centre that serves the entire community.</td>
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<tr>
<td>Namibia Caprivi Region</td>
<td>Caprivi borders four countries: Angola, Zambia, Botswana and Zimbabwe. It has a population of 79,826, comprising about 4% of Namibia’s population.</td>
<td>Most of the area is used as communal pasture and small-scale subsistence farming. Communities have limited access to schools, health centres and safe sources of drinking water. The socio-economic situation in the region is worse than in other parts of the country, with 39% of the population classified as poor and 31% as very poor.</td>
<td>It has one district referral hospital, three health centres and 25 clinics. Recurrent floods impede access to services. Few clinics provide CD4 count and ART services. Most facilities offer AIDS care and support services, but with weak information systems and diagnostic capacities. Only 16% of facilities offer PMTCT or ARV treatment. Only 7% of facilities provide ART.</td>
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<tr>
<td>Malawi Lilongwe Rural Nkhata Bay Mchinji</td>
<td>Lilongwe Rural has a population of 1.2 million people. Nkhata Bay is a rural district located along the shore of Lake Malawi, one of the main ports and the second-busiest holiday resort on the Lake, with 213,779 people. Mchinji Rural District has 456,558 people. It borders with Zambia and Mozambique.</td>
<td>Chiwamba is predominately a Moslem community. It has poor water, education and health facilities. Villagers draw drinking water from contaminated shallow wells. Tonga is the main language spoken in Nkhata Bay; people depend on fishing, cassava farming, rubber plantations and tourism for their income. Mchinji District relies on tobacco and groundnut farming, and has rich soils and favourable climate.</td>
<td>Chiwamba has only one health centre, which does not provide ART so people travel long distances to the Lilongwe city to access ART. Understaffing, negative staff attitudes, shortages of medicines and equipment contribute to poor service coverage. In Nkhata Bay District only 35% of households have access to improved latrines. Poor waste management during the rains leads to waterborne diseases. Open wells are a breeding ground for mosquitoes, leading to malaria.</td>
</tr>
<tr>
<td>Country and site(s)</td>
<td>Geography and population</td>
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<td>Health system</td>
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<tr>
<td>Mozambique</td>
<td>Maputo province has 1.2 million people and an HIV prevalence of 19.8%. Marracuene is rural and bordered by Manhiça District and by Maputo City.</td>
<td>Poverty, gender inequality, cultural conditions and high levels of labour mobility create high-risk environments for HIV infection in Marracuene and Maputo – Mozambique. Peasants are the main social group in rural Marracuene, together with state officials working in the district.</td>
<td>Lack of transport and poor roads undermine access to health centres. There are shortfalls in essential medicines and staff, as well as lack of equipment and other supplies, undermining coverage. Lack of safe water and inadequate sanitation facilities increase the risk of preventable diseases.</td>
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<tr>
<td>Tanzania</td>
<td>Bagamoyo is 65 km from the capital, Dar es Salaam. It is bordered by the Kibaha District, the Tanga and Morogoro regions, and the Indian Ocean. The population is 230,164.</td>
<td>Bagamoyo was once a fishing village, but has grown considerably, with a fish market on the sea front. Most residents earn income from petty trading and temporary employment in tourism, including housekeeping and restaurant work.</td>
<td>There is one hospital in a far corner of the district, with access limited by poor quality of roads. There are four health centres and 50 dispensaries, which offer basic care. There is a shortage of health workers, medicines and equipment.</td>
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<tr>
<td>Zimbabwe</td>
<td>Goromonzi, a rural district, is 30 km southeast of Harare, with a population of 178,000. Kariba is on the north eastern border with Zambia with about 25,000 people. Chitungwiza, a high-density town, has three main suburbs with mainly high-density units and 321,782 people.</td>
<td>Economic and social instability characterises most households, with high levels of unemployment, few social and economic activities and low industrial productivity. Those in work are low-income earners with limited coverage by social security.</td>
<td>In Kariba District, HIV prevalence was last estimated at 19.1% in 2008, above the national average of 14.1%. Neither the district hospital nor the health centres and clinics in the area provide ART. Shortage of medicines, equipment, health workers and low health worker pay undermine service delivery. Safe water is lacking.</td>
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Sources: MOHSS 2011; Office of the Prime Minister, 2009; MOHCW, 2009; Kula, 2009; GTM, 2008; GoM, NAC, 2008; CSO, 2009; Kambewa et al, 2009

3.2 How do poverty and inadequate health services increase HIV risk?

Our fieldwork revealed some interesting trends and links between the living conditions of communities, their risk and vulnerability to HIV and the inadequacy of the HIV services being provided in their area (or not provided, as the case may be). We found that people in the communities we studied experienced high levels of unemployment, poverty and food insecurity, which together helped to create high-risk HIV environments, particularly for women. This situation was exacerbated by poor HIV and AIDS services – undermined by severe underfunding – leaving communities feeling powerless to initiate any positive changes in the services they received.

Insecure employment, food insecurity and poverty were common. Insecure employment was prevalent in Zimbabwe, Tanzania, Malawi, Botswana and Namibia, leading to income insecurity. Work in the civil service, in the NGO sector, in local government, hotels and supermarkets in these countries was reported to generate more regular income, but these were not common jobs, and people more often worked in cross-border trading, carpentry, brick moulding, phone credit vending, money changing/black market, hair salon...
work, urban farming, farm labouring, building and informal trading like selling vegetables, cigarettes and sweets. There were also illegal occupations mentioned, like ‘stealing’. Some occupations created high-risk environments for HIV, such as brewing illicit alcohol in Zimbabwe, as well as commuter bus driving, commercial sex or begging. Insecure incomes were reported to be associated with food insecurity at household level in Manhiça (Mozambique), Goromonzi (Zimbabwe) and Mchinji (Malawi). This combination of food and income insecurity was reported to lead women to engage in high-risk commercial sex to earn a living in the absence of other means of survival, notably in Bagamoyo, Tanzania. In Zimbabwe, Malawi and Namibia, cross-border trading was characterised by exploitation, separation from families and partners, and separation from the socio-cultural norms that traditionally guide behaviour within communities.

Poverty seemed to be a proxy for lack of income in Zimbabwe, Malawi, Mozambique, Namibia, and Botswana. In Zimbabwe and Mozambique, women participants noted that lack of income created stress for them and meant they could not pay their children’s school fees or provide adequate, nutritious food for themselves and their children. In Kariba, Zimbabwe, they reported that some women forgot to take their treatment or deliberately skipped it when they did not have food. In four countries, namely Tanzania, Namibia, Zimbabwe, Malawi, participants observed that there were few programmes promoting economic opportunities for women, such as microfinance, micro-credit, vocational and skills training or income-generating activities.

There was limited reporting on lack of decent housing as a risk environment for HIV (re)infection. Participants from Old Naledi, Botswana, raised the issue of poor housing. Theirs is an urban area characterised by dilapidated structures, poor sewerage disposal, inadequate safe water and sanitation and high population density.

**Economic insecurity is associated with risk environments for HIV, especially for women, especially where social norms further increase risk.** Participants noted that economic insecurity in women led them to engage in commercial sex activities in Chitungwiza and Kariba in Zimbabwe, Old Naledi in Botswana and Caprivi in Namibia. Sexual transactions were reported to be carried out in bars and night clubs in
Evidence from participatory research on community health systems for HIV treatment and support in East and Southern Africa

Chitungwiza, in Nkhata Bay and Lilongwe in Malawi and in residences in Old Naledi. In Bagamoyo, Tanzania, sites where commercial sex work took place were also reputedly sites for drug dealing. Sex workers in Manhiça in Mozambique and in Caprivi reported low levels of condom use and there were also reports of child trafficking, with bars and rest houses (lodges) in Mchinji, Malawi, allegedly acting as hiding places for traffickers. A main trend emerging from our findings is therefore that the 12 sites exhibit the co-existence of economic insecurity with high-risk environments for HIV.

We found that low condom use was not only associated with commercial sex, but also with patriarchal attitudes, religious dogma and social stigma against HIV-positive people. Community members, particularly men, appeared to believe that condoms reduced their sexual pleasure, resulting in low reported levels of safe sex in Zimbabwe, Botswana and Mozambique. In Zimbabwe and Malawi, men also considered condoms to be unreliable as they were easily damaged and many married women associated condoms with infidelity because they felt the only reason their husbands would need to use a condom to prevent HIV transmission was if they were guilty of engaging in extramarital sex. Participants further reported that some men living with HIV apparently refuse to use condoms with their sexual partners. In Lilongwe and Nkhata Bay in Malawi, and Kariba in Zimbabwe, certain religious faiths were reportedly discouraging members from using condoms and ARVs. Cultural beliefs also played a role in stigmatising HIV-positive people in Mozambique, Zimbabwe and Malawi, where they were perceived as having been ‘bewitched’, or cursed, by jealous people or by partners as punishment for cheating on them. In Malawi, Namibia and Zimbabwe, lack of knowledge about HIV was reported to fuel such views, leading to stigma, discrimination and shame, and discouraging people from seeking treatment.

The socio-economic conditions highlighted above are mitigated or worsened by features of the health system. This was particularly evident with vertical approaches to HIV services, where the services are separately funded and run parallel to other health services. Vertical approaches were reported to create inefficiencies in service delivery in Zimbabwe and perpetuate stigma against HIV-positive people in Botswana and Zimbabwe, while in Malawi and Zimbabwe they raised the cost of health care for communities and reduced quality of care, adherence to treatment and treatment follow-up. Participants in general – particularly service users in Malawi – complained that HIV and AIDS treatment facilities were overcrowded with rising levels of common medical conditions, some of which were associated with HIV, such as tuberculosis. Health workers in Malawi, Botswana and Zimbabwe were working under increasing pressure caused by a rise in demand for voluntary counselling and testing (VCT), prevention of mother-to-child HIV transmission services and ART. At the same time, community members who went to get tested for sexually transmitted infections reported that they faced prejudice and moral judgement from health workers. Most of the sites in our study lacked private offices in which to conduct VCT, so counselling was often done outside, with no privacy. In Chitungwiza in Zimbabwe, counselling was allegedly conducted outdoors, close to the mortuary.

Two factors appeared to be important to improving access to HIV and AIDS services: the level of integration of health services and the proximity of health care facilities to those who need them. In this regard, participants from Chitungwiza, as well as in Caprivi in Namibia, Mchinji in Malawi and Manhiça in Mozambique, reported that their HIV and AIDS services were integrated with services for maternal and child health and treatment of common illnesses and were close to the communities they served.

Human resources is another important component of equitable health services. The effective delivery of and access to services by communities depends on whether there are trained health workers living in the community. However, most health facilities did not have adequately trained health workers. Participants raised problems of understaffing and migration of health workers out of the public health system. In Botswana, Namibia, Malawi, and Zimbabwe, they reported that health workers at lower levels of the health system had worse conditions and pay, leading to them to migrate to higher level services where pay was better. In Mozambique, Malawi, and Zimbabwe health workers administering treatment programmes were
only found at district hospital or higher levels of care. Understaffing in primary care services led health workers to be stressed and frustrated. They were reported to take their stress out on their patients through negative attitudes and poor communication, leading to poor relations being reported between health workers and communities in Malawi, Namibia and Zimbabwe.

**Services lack the funds and communities the power to change these conditions.** Poor health funding in Zimbabwe, Malawi, Botswana, Namibia and Tanzania was identified by participants as undermining HIV service quality and provision. Participants in Chitungwiza in Zimbabwe, Mchinji in Malawi and in both sites in Mozambique believed that funds from central levels of government were not reaching rural health centres or community level services.

It appears that communities have little influence on the HIV services they receive. In Zimbabwe, Malawi, Mozambique and Namibia, opportunities or mechanisms for community participation in health services planning were extremely limited, while management structures and procedures did not include community input. In Goromonzi, Zimbabwe, community participation was seen as merely symbolic, as communities lacked real power to participate meaningfully in decision making processes. In Chitungwiza in Zimbabwe and in Mchinji in Malawi, participants even argued that participatory mechanisms like country committees for the Global Fund to Fight AIDS, TB and Malaria were not genuinely participatory, as they perceived communities as target groups and beneficiaries of services rather than as partners and decision makers.

Policy interventions were thus seen to reflect the priorities of international funders rather than the priorities of the people the services are intended for.

> “These CBOs think they know everything simply because they get donor funds...they don’t even do anything apart from boasting with riches when they buy cars or build houses at the expense of the poor. In fact all they know is to buy expensive clothes and move from one workshop to the other...they can’t even point at what impact they have brought with their so called projects” - Male participant living with HIV, Chiwamba, Lilongwe, Malawi.

### 3.3 Limited contact between communities and services

**Shortage of health workers undermine service interactions with communities.** In five countries – Zimbabwe, Malawi, Mozambique, Namibia and Botswana – health worker shortages were raised one of the primary obstacles to service delivery, leading to unrealistic workloads for remaining health workers and consequently undermining service quality. Work-related stress and lack of time to attend to patients were compounded in Zimbabwe, Malawi and Tanzania by poor pay and lack of career opportunities, demotivating their health workers. Occupational health for health workers was poor or non-existent, as workers reported hazardous working conditions, with some of them having no access to post HIV-exposure prophylaxis in case of accidental exposure to HIV in the workplace. Post HIV-exposure prophylaxis for health workers was noted in Malawi to be in short supply and in Zimbabwe participants were unclear as to whether it was available or not. As noted earlier, frustration amongst health workers reported in Zimbabwe, Malawi, Botswana and Namibia, led to poor interaction between health workers and clients and loss of trust in health workers by communities. This was reported in Malawi, Tanzania, Mozambique, Botswana and Zimbabwe. The poor communication stemmed from the frustrations in workload, poor remuneration and career opportunities. In Caprivi in Namibia and Kariba in Zimbabwe, participants reported incidences of favouritism and corruption, while in Zimbabwe, and Lilongwe and Mchinji in Malawi, some health workers were alleged to be charging informal payments for people to have their CD4 counts taken. In all countries there were allegations of health workers charging for ARVs that should not have been charged.
Primary care service links with communities limited by inadequate infrastructure, medicines and equipment. Participants argued that the primary health care level of the health system was critical in supporting community systems for HIV. However in all countries except Namibia primary care clinics were not able to initiate, administer or follow up ART, due to shortages of medicines and trained health workers, particularly in rural areas where services were less available, for example the Gutu and Mwanza wards in Goromonzi district in Zimbabwe. Rural communities tended to perceive themselves as significantly marginalised when compared to urban areas, receiving inferior services for HIV literacy, and voluntary counselling and testing (VCT). While most health facilities in all countries provided VCT, ante-natal care and PMTCT services, these services target women, and not men, due to their link with maternal health care. Patients on ART in Zimbabwe reported that health workers could not conduct their repeat CD4 counts due to equipment failure, and in Zimbabwe, Botswana and Malawi, patients were deterred from going for appointments due to the excessively long queues, reportedly a major problem since HIV services were centralised in these countries. In Mozambique, Malawi and Zimbabwe, some patients felt that the process for ART initiation was long, cumbersome and expensive in terms of transport costs and user fees, which they believed caused some patients to opt for indigenous medicines and religious faith healers, whom they consider to be easier and cheaper to access.

"Many people are dying with HIV and some people are developing a problem of drug resistance to ARVs because they are unable to access the ARV medicines easily. Transportation costs from here to the central hospital, or Area 25 Health Centre and other centres where the ARVs are provided are very high." - Woman participant living with HIV, Lilongwe, Malawi.

In all countries except Tanzania community members and health workers reported that HIV and AIDS services were offered in existing facilities in spaces that were not adequate for their purpose. A lack of funding has meant facilities have been unable to purchase and maintain diagnostics equipment for CD4 counts or liver function tests. Community members perceive health workers as partly responsible for the inadequate space and supplies, which erodes the trust between health workers and their patients that is central to effective HIV services. The inadequacy of facilities is highlighted below:

"There is no CD4 Counting machine at Makumbe Mission Hospital, there is no space for adherence counselling, and often we are forced to receive the counselling in groups outside. You can imagine how embarrassing it is if you see someone you know while you are seated in the counselling session. Further you need specialised sessions that are individualised so that one can self prepare. Sometimes we get in very small spaces for counselling. These services are being forced in never planned for spaces. We need to really plan strategically on how this will be done, otherwise it compromises the quality of care." - Community member, Goromonzi, Zimbabwe.

Cost and transport barriers limit community use of services. HIV services (ARVs, PMTCT, ANC, VCT) are offered free in public health institutions in all the countries we surveyed. All country sites, except in Namibia, acknowledged that access to ARV treatment at no charge has greatly reduced the financial burden for people living with HIV and AIDS, as well as improved their access to HIV services. However the poorest patients and those living in rural areas identified barriers to accessing HIV services in the form of prohibitive transport and other out-of-pocket costs. Community members from Chitungwiza gave an indication of the hidden costs they experience: direct costs included US$2 for a return journey to the hospital and US$35 at the hospital for the CD4 count, while indirect costs included loss of income, estimated at between US$10 and US$30 per visit, due to the long waiting times at facilities. They also had to buy food to eat while waiting and travelling, amounting to a further US$3-5. This amounts to a direct cost of US$40, which is beyond the reach of most rural Zimbabweans, who have limited or no income. Rural communities in Namibia and Mozambique also lacked reliable, affordable and safe transport, a significant barrier to their access to services. Poor
transport, particularly in rural areas, was noted to lead to missed doses or interruption of treatment in Malawi and in Marracuene in Mozambique. User fees or other out-of-pocket costs were seen to discourage return visits in all countries except Namibia.

**Gender norms, stigma and discrimination are strong determinants of treatment uptake.**

Despite the longstanding nature of the HIV and AIDS epidemic in all the countries in our participatory research, stigma seems to be persistent. In Malawi, Tanzania and Zimbabwe, discrimination appeared to affect girls and women more than boys and men, affecting their uptake of education and health services, access to treatment and autonomy to make decisions on safer sex or on treatment. Women suffer high levels of social vulnerability compared to their male counterparts. In Zimbabwe, Malawi and Mozambique, participants acknowledged that women had little control over their male partners’ unsafe sexual behaviours. If known or suspected to be HIV positive, women in Zimbabwe and Botswana may face violence or they may be abused or abandoned, as reported in Tanzania. Participants in Tanzania, Malawi and Zimbabwe argued that women who were HIV-positive may hide their status from their partners because they feared blame, violence, divorce or loss of economic support if their partner left.

Gender norms and roles also affect men negatively, albeit to a lesser degree. In Zimbabwe, Malawi, Tanzania and Namibia, participants pointed out that men tended to rely on their spouses for HIV and AIDS information, as HIV and AIDS services in those countries have so far mainly targeted women. In Mozambique and Zimbabwe, participants reported that men usually do not test for HIV and only ascertain their HIV status after their partners have tested, often during ANC. In Lilongwe in Malawi, as well as in Zimbabwe, there were reports that men generally found it difficult to talk openly about sex and to reveal their HIV status. We found that social and cultural stereotypes about masculinity affected men’s sexual behaviour and health-
seeking behaviour. Men generally adhered to stereotypes that expected them to always be in control, to have know-how, be strong, disease free, highly sexual and economically productive. The assumption that a man must be disease free and strong may lead them to stop going for regular hospital checkups, as reported in Mozambique and Botswana, and their desire to prove sexual prowess may fuel alcohol consumption and unprotected extra-marital sex, as reported in Old Naledi in Botswana. Cultural taboos about discussing sex in Zimbabwe made it difficult for men to talk about sex with their partners and they were afraid to reveal their HIV status, as this would expose their infidelities. We found that advocating abstinence, faithfulness or condom use was problematic for couples in Namibia, and openly discussing STIs was not generally accepted in Malawi due to local taboos about discussing sex.

Stigma against HIV-positive women is illustrated in this quote, where these women are excluded from productive social life:

“Oftentimes in big family gatherings such as back home in the rural areas at funerals or during Christmas gatherings you are often told, rest a bit, take it easy-don’t bother yourself, wait we will do this, don’t cut the veggies you may cut yourself, aah can you cook for all these people? Will you be able? They will need us or those ones with strong bones (physical strength).” - HIV-positive female participant, Chitungwiza, Zimbabwe.

Stigma against HIV was reported to have powerful psychological influence over how people with HIV see themselves and adjust to their status, making them vulnerable to blame, depression and self-imposed isolation, in all countries except Tanzania. In Zimbabwe, HIV-positive people reported feeling distress at exaggerated kindness towards them from neighbours, fellow church members and work colleagues. Fear of stigma thus continues to be a strong determinant of non-disclosure, or poor uptake of services. Non-disclosure of HIV-infection within families was reported by women to leave orphans and other bereaved dependents economically deprived and marginalised after the bread winner had died, particularly if community members found out the person had died of AIDS, as reported in Zimbabwe and Malawi. In some cases this can lead to social isolation, according to participants in Botswana.

In the countries in our study, we found limited provision of wider social welfare benefits to people living with HIV (PLWHIV). In Zimbabwe, Botswana, Malawi and Mozambique participants reported that there was limited social welfare support, and some argued that social welfare programmes were under resourced. However, we did find evidence of some social welfare initiatives in the countries we surveyed. The government in Botswana runs the Ipelegeng Scheme, which provides support to PLWHIV in the form of food packs. In Malawi the US$35 cash grant civil service workplace programme helps to support nutrition among PLWHIV, most of whom live on an income of less than US$100 per month. In Zimbabwe, we identified the Basic Education Assistance Programme (BEAM) programme, which targets vulnerable children by helping finance their school fees, and the national AIDS levy, which provides finance for purchasing ARVs.

We suggest that the reason why participants reported limited support is due to poor coverage and underfunding of these schemes. Although there were no reports of social welfare services being denied to PLWHIV, in Caprivi in Namibia, we were informed that children with foreign parents are not entitled to the child welfare grant offered to other vulnerable children in Namibia, despite their legal residency in the country. Our findings indicate that this lack of wider social welfare support isolates responses to health services, makes communities dependent on their own resources to support vulnerable groups and undermines nutrition and health in HIV- and AIDS-affected households.

Our findings show that poverty played a multi-faceted role in disrupting continuity of treatment. HIV-positive individuals who lacked a regular address could not be contacted by the clinic or hospital when necessary and
it was most often these same vulnerable people who had their care unintentionally disrupted, or terminated, due to communication breakdowns with health service providers or caseworkers. Yet we argue that it is these very people who need more support than others, as they live in insecure settings with poor diets that make the side effects of treatment more difficult to manage. A high frequency of late or inappropriate referrals was reported, making care more difficult for patients, their families, the health workers who help them and the health system itself.

3.4 Challenges within health services

Some of the countries in our survey have decentralised their health services, namely Zimbabwe, Malawi, Tanzania, Namibia and Botswana. However, centralisation of ART locates treatment resources far from communities. In Malawi and Zimbabwe, the centralisation of ART initiation was considered to be responsible for increasing congestion in waiting rooms, staff workloads and patient out-of-pocket costs in a health system that is already stretched beyond its capacity. Communities in Mozambique, Malawi and Zimbabwe called for ART and other services for HIV and AIDS to be decentralised to primary level, arguing that this will help overcome barriers in access to services and provide some measure of financial protection to patients.

Mentoring and support for community and frontline health workers is missing. As mentioned earlier, health workers face a number of challenges in the workplace, and one of these is lack of support from management. According to the World Health Organisation (2006), since HIV is a chronic condition, health workers need ongoing clinical mentoring to foster their professional development in managing ART and treating opportunistic infections. They also need support in building their case study review and require feedback on case management so they can provide a reasonable level of client-centred care (ibid). In all the countries we surveyed health workers reported a lack of clinical mentoring. This, they argued, increased the frequency of late or inappropriate referrals, thereby inconveniencing PLWHIV and their families. Funding for clinical mentoring was problematic in Zimbabwe and Namibia, where health systems do not have a budget for the resources required to conduct clinical mentoring such as phones, radios and internet access.

Health workers in Zimbabwe, Malawi, Tanzania, Botswana and Namibia highlighted the fact that members of the workforce had significant expertise in managing ART and opportunistic infections, yet the dissemination of this crucial knowledge by district management teams was limited by severe staff shortages and heavy workloads, both of which were consuming time that could be spent on training and development. Some doctors expressed a desire to mentor other staff but lack of time was a barrier:

“As health workers we know we have to conduct clinical mentoring as well as monitoring the progress amongst those we are mentoring who presumably we believe could also become mentors to others. However, this is not possible because we don’t have the time to do this.” - Health worker participant, Lilongwe, Malawi.

Doctors at district hospitals were perceived by respondents to have limited experience in managing difficult cases and were not always able to provide sufficient clinical mentoring to lower-level cadres of health workers. In Chitungwiza in Zimbabwe, clinical staff reported that visiting doctors, senior nurses and midwives at the central hospital had no time to mentor them, while in other sites, other lower-level health workers noted that existing training programmes were inadequate:

“We do get mentoring or task shifting, whatever they call it, but the problem is the training is short and often not adequate to instil and equip us clinicians with knowledge of how this should be done.
That’s why some people here complain that the quality of care in ART and HIV management is poor.” - Health worker participant, Goromonzi, Zimbabwe.

“They just orient us and off they go. This leaves us wondering if at all they really want this to bear fruit or not… if they were paying us such visits it would invigorate us to working hard and i don’t think we could be talking of such a gap here. Even the issue you have asked of mentoring they could be the ones encouraging us to teach others as well, but they don’t say anything… perhaps they also do not know how it’s done.” - Health worker participant, Nkhata Bay, Malawi.

Vertical programmes raise transaction costs for communities. HIV programmes were seen to be using vertical approaches in Zimbabwe, Malawi, Botswana, and Tanzania. These approaches were seen to create problems for PLWHIV who need not only HIV related care, but also care for other infections and chronic illnesses, including tuberculosis, diabetes, cancers and mental stress. These all need to be managed as part of the overall response to AIDS and to improve health. Segmentation of services was reported to mean that some conditions are not adequately addressed, or that people have to move between different providers in both public and private sectors to access a comprehensive range of services. There was progress reported in Zimbabwe, Malawi, Botswana, Mozambique Tanzania in integration of services, particularly for VCT, PMTCT and Antenatal are services, and for male circumcision in Zimbabwe, although this mainly happens at district than primary care facilities. Fragmentation happens when non-state organisations provide AIDS programmes such as PMTCT, HIV follow up, as communication with other services may be ad hoc and based on funder rather than community priorities or needs, as reported in Malawi, Zimbabwe and Mozambique. Participants in Namibia, Zimbabwe and Malawi argued that links across providers were important to ensure follow up of referrals to determine if the client’s need has been satisfied.

Primary health care facilities lack effective referral services. We identified the shortage of ambulances reported in Namibia, Malawi, Botswana and Zimbabwe as an important gap in the referral system. Participants in Kariba in Zimbabwe reported that ambulances were simply unavailable in their area, and those from the sites in Malawi and Mozambique reported they had ambulances, but they were few and always late. In Botswana and Namibia, participants evaluated their ambulance services as inefficient. For example in Caprivi in Namibia, although ambulances were provided to drop patients at the local hospital, no provision was made to return them by ambulance to their villages upon being discharged.

Lack of effective referral systems also overburdened staff, who keep getting patient referrals without proper notice:

“Our service delivery is compromised because of these referral problems… we normally experience shortages of medicines, lack of time to rest due to tiredness, there should be coordinated institutions including NGOs, FBOs and other community groups all working with us as institutions that we can refer a patient to. That way we do less work but we do more for the patient.”
- Health worker participant, Nkhata Bay, Malawi.

Stigma against HIV-positive people in the workplace negatively affects workers and patients. We found that discrimination against HIV-positive people in HIV and AIDS services operated in both directions: not only did health workers discriminate against people seeking HIV and HIV-related services but health workers in Botswana and Zimbabwe said that some patients preferred not to be treated by HIV-positive health workers if they knew their status. In Kariba in Zimbabwe patients were alleged to discriminate against health workers based on their political affiliation, particularly if patient and health worker knew each other socially.
Discrimination against patients attending opportunistic infection (OI) clinics was reported in Zimbabwe. Participants called this form of stigma ‘door labelling’, as it was derived from the fact that anyone who walks into the door of the clinic is automatically assumed to be HIV positive:

“Once you get to the hospital and you go straight to the OI clinic people give you an eye that talks! It says there is an HIV positive person; she probably has genital warts or TB. The next thing is they do not even want to be near you because they think that you will give them TB, It sucks! We do not want the OI clinic separate from OPD, in fact, if this is too difficult please remove the door label ‘OI Clinic’. The nurses should be the ones responsible for showing us where to go. Have you ever gone to a hospital and you see a label on the door written ‘Headache Clinic’ or ‘Abdominal Pain Clinic’? Why ‘OI Clinic’? This is why some refer to the OI Clinic as ‘Obviously Infected Clinic’ instead of ‘Opportunistic Infections Clinic’. It just reinforces stigma.” - Community member participant, Chitungwiza, Zimbabwe.

Civil society organisations are unrecognised and underfunded. In the countries we surveyed, we found a range of non-state actors providing HIV and AIDS services, including non-governmental organisations, community-based organisations and faith-based organisations. These civil society organisations (CSOs) appeared to be on the forefront of community level responses to HIV, but were reported to receive limited and inconsistent funding support, with little formal interface with public sector health services. While CSO roles are generally recognised in national HIV and AIDS strategies, participants in Zimbabwe, Botswana and Malawi were not clear on the formal measures to operationalise the role of CSOs in the health system. They noted that the role of civil society is not acknowledged by government, despite committed (and often volunteer) cadreship that is well embedded in communities in Botswana, Malawi and Zimbabwe. Participants called for greater investment in and use of these valuable social resources and more formal links to connect them to state services.

International funders and civil society need stronger links with public health services. In Zimbabwe there was some discussion of the need for external funders and civil society to make stronger links to public sector services, as part of the strategy for community systems. Participants reported that some funders bypass country plans and processes, leading to uncoordinated multiple processes. They proposed that institutions like the GFATM work with in-country technical agencies with capacities to support assessment and strategic planning at country level and to align external funds with each country’s National Health Strategy.
4. Conclusion and recommendations

4.1 Conclusion

In Phase 1 of the CoBaSys programme, we began with an analysis of the socio-economic trends of those communities in which our study was conducted. In all 12 sites, insecure employment, food insecurity and poverty were common. We found that economic insecurity was associated with risk environments for HIV, especially for women living in communities where social norms undermine women’s rights. The socio-economic conditions highlighted above were mitigated or worsened by features of the health system, in which a critical shortage of health workers seriously undermined service interactions with communities, and primary care service links with communities were limited by inadequate infrastructure and a lack of medicines and equipment.

In our analysis of HIV and AIDS services, we found that costs and transport barriers prevented many community members from using HIV and AIDS services, especially since centralisation of ART in some countries has meant that rural treatment centres may now be far away from the communities they serve. At the same time, gender norms, stigma and discrimination continue to be strong determinants in reducing treatment uptake. We received reports that stigma against HIV-positive patients and HIV-positive health workers in health facilities negatively affected both workers and patients. The success of ART programmes was also undermined by the limited provision of wider social welfare benefits to people living with HIV. In the workplace, health workers faced many challenges, including accidental exposure to HIV and unrealistic work loads. Junior staff receive little support or mentoring by senior staff, while senior senior staff argue that they are too overworked to find time to mentor staff.

Effective service delivery was further hampered by the fact that primary health care facilities often lack effective referral services, such as ambulances. Unfortunately, these services lack the funds and communities lack the power to change the situation. Despite official government commitment to ensuring community participation in providing health services, we found that civil society organisations go largely unrecognised by government and are seriously underfunded, revealing a breakdown between international funders, civil society and public health services.

These are not new findings. What is disconcerting is that over a decade after intervention on the epidemic has scaled up at both global and national level, they continue to be raised by communities and frontline health workers who see themselves as recipients of other levels of decision making on how to respond to the epidemic.

4.2 Recommendations

Arising from the PR findings and from the proposals of the communities and frontline health workers themselves, we suggest eight areas of action for strengthening community systems for HIV prevention and AIDS treatment, support and care.

Within communities

1. There is need to recognise and address the risk environments for AIDS within comprehensive primary health care approaches that provide for treatment of communicable and non communicable diseases, ensure intersectoral actions to support safe water, sanitation, food security and strengthen opportunities for incomes and social security coverage in vulnerable groups. These programmes need to be facilitated by health workers that have a PHC orientation and are resourced and rewarded for their outreach to
Evidence from participatory research on community health systems for HIV treatment and support in East and Southern Africa

communities and, together with community leaders, for leveraging broader action to address vulnerability and tackle risk environments for HIV within communities.

2. To support this, communities and frontline health workers can play a lead role working with PLWHIV, local leaders across all sectors, local government, local civil society and state services to ensure that literacy campaigns include social dialogue and information sharing on community centred approaches to HIV prevention, AIDS treatment support and care that raise rights and responsibilities, that challenge gender norms that undermine women’s autonomy and men’s involvement, and that strengthen collective responsibilities and mobilisation of resources within communities to support vulnerable groups and children.

3. It is important to provide technical support to community groups on how to improve their lobbying and advocacy abilities for adoption of measures to prevent and combat HIV.

In the interface between communities and health services

4. The role of strategic partnerships, leadership, supported and mentored decentralisation and participatory decision making needs to be given more recognition and support. With regard to governance, communities should have the right to co-decision making with services over resources for responses to AIDS and health systems generally, and mechanisms should be in place for this, along with training and support for participation. Community partnerships and involvement are central to treatment preparedness and to the effective design, uptake of and adherence to HIV-related services and to building a comprehensive, client centred approach. Community roles are needed to ensure accountable performance of health systems, to support primary care workers and to control informal charges and other practices that undermine uptake. At the same time health workers and authorities themselves need a channel to challenge social norms and practices that weaken the response to HIV and AIDS, or poorly use the available resources. Much greater attention thus needs to be given to sustaining, strengthening and, in some cases, revitalising the capacities, processes and mechanisms for dialogue and co-decision making between communities and state services.

5. Community health workers are important actors in strengthening comprehensive client-centred care. They are a contribution from the health system to local employment and social status of often vulnerable groups, including women or PLWHIV, and a contributor to the community orientation, uptake and adherence of services. Their role as comprehensive cadres that integrate client-centred approaches to AIDS and other chronic conditions needs to be strengthened.

6. International and global health initiatives working on and resourcing HIV and AIDS programmes should not only meet the commitment to alignment with national level policies but should go further and ensure that the processes they support within countries are also coherent and user-friendly for community and local health systems in terms of how resources are managed and disbursed, how they align to and strengthen local participatory decision making and mutual accountability between state and non-state actors and support comprehensive health systems and foster wider involvement across different sectors in the responses to HIV and AIDS.

Within the health system

7. Health workers are perhaps the most critical determinant of community-oriented systems. Without adequate workers deployed and trained at primary care level, supported by incentives and mentoring for more client-centred approaches, community systems for HIV and AIDS will be weak, if non-existent. This demands much greater focus on addressing the health worker shortage at community and primary care levels, on ensuring that clinical mentoring is integrated in national strategic plans and that health workers
themselves are protected from occupational risk and see visible commitment and progress in addressing the push factors that cause them to leave service in facilities close to communities.

8. To address access and coverage gaps, health workers need to be trained and resourced to ensure cost-effective procurement systems to prevent supply and medicine stock outs and a supply of diagnostics and other commodities at primary care level. This raises wider issues of how countries improve domestic funding for these services, improve domestic procurement and prequalification and production capacities to meet essential medicines needs, and develop push and disbursement systems to ensure that supplies reach primary care levels and are not blocked at higher levels of the health system.

It also calls for wider systems support in terms of the information systems that track and report on demand and performance, and importantly the domestic public funding to meet the entitlements that people should have for community systems on AIDS at primary care level, that can act as leverage of wider community, private and international resources, but not be substituted by these resources. AIDS must be recognised as a chronic condition calls for longer-term funding commitments at both national and international level to sustain community systems and responses, backed by wider social security coverage for protection against the combined burdens of economic insecurity, food insecurity and ill health.
5. References

5.1 Participatory research publications in CoBaSys


5.2 References in the paper


### 6. Acronyms

<table>
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<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACP</td>
<td>Africa Caribbean Pacific</td>
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<tr>
<td>AIDS</td>
<td>Acquired Immune-Deficiency Syndrome</td>
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<tr>
<td>ART</td>
<td>Anti-Retroviral Therapy</td>
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<tr>
<td>ARV</td>
<td>Anti-Retroviral</td>
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<tr>
<td>ANC</td>
<td>Ante-Natal Care</td>
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<tr>
<td>CBOs</td>
<td>Community Based Organisations</td>
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<tr>
<td>CD4</td>
<td>Cluster of differentiation 4: a glycoprotein on the surface of T cells</td>
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<tr>
<td>CoBaSys</td>
<td>Community Based Systems in HIV treatment</td>
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<tr>
<td>CLWA</td>
<td>Children Living with HIV AIDS</td>
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<tr>
<td>CSO</td>
<td>Civil Society Organisation</td>
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<tr>
<td>ESA</td>
<td>East and Southern Africa</td>
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<tr>
<td>FBO</td>
<td>Faith Based Organisations</td>
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<tr>
<td>HIV</td>
<td>Human Immune-deficiency Virus</td>
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<td>MOHCW</td>
<td>Ministry of Health and Child Welfare</td>
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<td>NAC</td>
<td>National AIDS Council</td>
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<tr>
<td>NGO</td>
<td>Non Governmental Organisation</td>
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<tr>
<td>OVC</td>
<td>Orphans and other Vulnerable Children</td>
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<tr>
<td>PR</td>
<td>Participatory Action Research</td>
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<tr>
<td>PHC</td>
<td>Primary Health Care</td>
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<tr>
<td>PLWHIV</td>
<td>People Living with HIV</td>
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<tr>
<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission</td>
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<tr>
<td>PRA</td>
<td>Participatory Reflection and Action</td>
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<tr>
<td>REACH</td>
<td>Research for Equity and Community Health</td>
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<tr>
<td>STI</td>
<td>Sexually Transmitted Infections</td>
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<tr>
<td>TARSC</td>
<td>Training and Research Support Centre</td>
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<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on AIDS</td>
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<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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