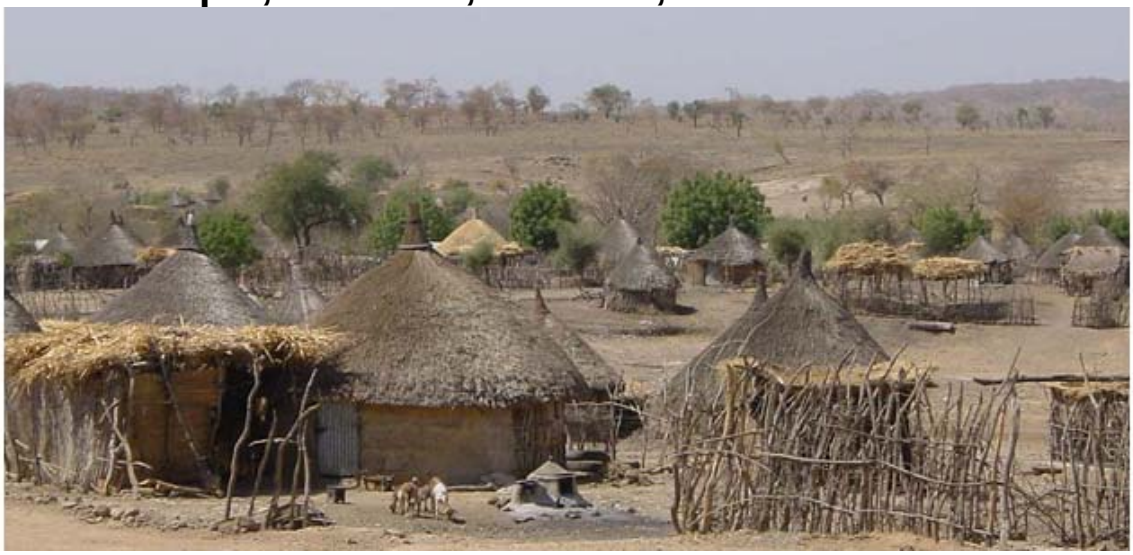
Evidence from Participatory Research on Community Health Systems for HIV treatment and support in East and southern Africa

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



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in the
Community Based Systems in HIV Treatment (CoBaSys) programme

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This report synthesises evidence from 21 country level reports in Work Package 2 of the CoBaSys consortium. The individual study reports are shown in the reference list and are available at www.cobasys.eu . We acknowledge the leads for the work in each country in producing the work

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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 organizations, local government structures, civil society organizations, 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 themselves 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 characterized 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 to have 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 womens' 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 top 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 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 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, 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.

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

Within Communities

1. To recognise and address the risk environments for AIDS within comprehensive primary health care approaches
2. 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 and strengthen collective responsibilities for support to vulnerable groups.

In the interface between Communities and health services

3. To recognize and ensure mechanisms for strategic partnerships, leadership, supported and mentored decentralisation and participatory decision making
4. To resource and align the role of Community Health workers for comprehensive client centred care.
5. To ensure international and global health initiative support *within* countries user-friendly for community and local health systems, strengthens local participatory decision making and mutual accountability between between state and non state actors and supports comprehensive PHC

Within the health system

6. To deploy, train and support with incentives and mentoring health workers at community and primary care level, and integrate clinical mentoring in national strategic plans
7. To ensure production, procurement, disbursement systems and capacities to prevent medicine, diagnostics and other commodity stock outs at primary care level
8. To 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 is heavily affected by HIV. In 2009, a third (34%) of people living with HIV (PLWHIV) worldwide lived in Southern Africa and only 37% of people needing treatment in sub-Saharan Africa were able to access antiretroviral (ARVs) (UNAIDS 2010). Nevertheless there has been huge progress: In 2010 UNAIDS reported that 3.9 million people in sub-Saharan Africa were receiving ARVs, from just 50 000 in 2002. The share of children is much lower, however, at 26% coverage. Many people in need of treatment do not access it, as treatment is poorly decentralized to primary care level, with services that are fragmented poorly integrated in wider services; weak procurement and supply systems; drug stock-outs; health worker shortages and weak community treatment literacy (UNAIDS 2010). The HIV and AIDS indicators for the countries covered by this report are summarized in Table 1.

Table 1: HIV AIDS in the countries in east and southern Africa covered by the report

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

Source: UNAIDS 2010; Country Progress Reports 2010 and UNAIDS estimates

As described in Table 2, the countries face challenges in:

- reducing new HIV infections by creating environments that support individual and social actions that reduce risk;
- providing health care, antiretroviral treatment, support and care to PLWHIV through services at community and primary care level provided in ways that ensure people are not impoverished by health care costs;
- providing support to those affected by AIDS mortality, including orphans and other children made vulnerable by HIV

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.

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). Treatment services encompass treatment of opportunistic and co-infections such as tuberculosis, the provision of antiretrovirals, . support interventions such as treatment literacy, psychosocial support, nutrition and other complementary interventions that may be provided through one or more providers. the CoBaSys programme is being implemented through a regional network in ESA and Europe with support from the European commission (EU) and African Caribbean and Pacific (ACP) countries. The project aims to understand what constitutes a community based system that supports equitable access to treatment for those with greatest need.

In this first phase of the programme we have implemented a participatory action research ({PAR} programme, discussed further below. In future phases the programme will generate learning on community based and patient centered approaches to HIV treatment; and share the knowledge generated for policy engagement at local and international level.

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Eleven institutions in Africa and Europe were involved in the PAR work, including Training and Research support Centre (TARSC) as co-ordinator of this specific area, working with, University of Zimbabwe; REACH Trust, University of Malawi,;University of Botswana; University of Namibia; University of Eduardo Mondhlane Mozambique; and University of Dar es salaam, Tanzania for the country work, in co-operation with University of Bologna, University of Modena Italy; University of Manchester United Kingdom; University of Helsinki, Finland and European AIDS Action Group Belgium. The PAR was conducted in Zimbabwe, Tanzania, Namibia, Mozambique, Malawi and Botswana to explore the factors that facilitate and block access to, use and effective coverage of services and responses to HIV. Drawing on community and local health worker inputs, we identified relevant and effective approaches to building community systems and supportive services for HIV and AIDS. A community system for health is understood to be the sum of the organizations, local government structures, civil society organizations, institutions and resources whose primary purpose is to improve health at community and primary care level. Specifically our work this sought to:

1. 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;
2. Map the resources, institutions and actors available at community and primary care level to respond to the epidemic.
3. 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;
4. 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, ie availability coverage, accessibility coverage (or the physical or financial barriers to access). acceptability of services to the population; contact coverage identifying uptake of services and effective coverage, or the extent to which use results in effective service coverage.

The work was conducted in between one and three sites in the six ESA countries, with a total of 12 sites included in this synthesis report (See Table 2).

Table 2: Participatory research sites on Community systems for HIV treatment

Country	**site**	**Timing of the PR**
Botswana	Old Naledi-Gaborone	April 2011
Malawi	Chiwamba-Lilongwe	November 2010
	Mchinji	July 2011
	Nkhata Bay	May 2011
Mozambique	Maluana Manhica	May 2010
	Marracuene	July 2011
Namibia	Chetto Caprivi	June 2011
	Ngweze Caprivi	July 2011
Tanzania	Bagamoyo	December 2010
Zimbabwe	Kariba	May 2010
	Goromonzi	January 2011
	Chitungwiza	May 2011

The PR in each site is separately reported, as listed in the reference list. In each site those included in the PR were People Living with HIV (PLWHIV), children made vulnerable by HIV (OVC), women; men; youth; health workers, HIV support group members, local authorities, traditional authorities, non governmental organizations (NGOs), community based organizations (CBOs), faith based organizations (FBOs) and religious groups.

In this report we present and discuss the findings from the PAR conducted in 12 sites in the six east and southern Africa countries between April 2010 and October 2011. We synthesize the findings up to the phase of setting actions, and do not include the actions taken or reflection on these actions, which will be the subject of later reporting. Hence this report covers only the participatory research (PR) work, which itself presents important information on community and local health worker views and knowledge on community systems and services for responding to HIV and AIDS and services .

2. Methods

In each of the countries the sites were purposively sampled from areas with high HIV prevalence where risk was high. The PR tools used were developed by TARSC and Ifakara Health Institute in a manual developed for the Regional Network for Equity in Health in East and Southern Africa (EQUINET) (Loewenson et al 2006). The protocol was developed and these tools adapted and piloted by TARSC working with country teams (Machingura et al 2010). Table 3 below summarises the protocol that was used in all the sites:

Table 3: Protocol used for the PAR work

Objective	Method
Prior to the PR field work	
Key informant interviews; review of literature, media; stakeholder discussions with NGOs, planners and community representatives	
PR field work and tools used	
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 AIDS	Social mapping, Map interview Discussion
Assessment of 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.	Stepwise diagram and Focus Group Discussion (use FGD guide
Identify for key social groups the priority factors that affect availability, access, acceptability, uptake, quality of care in and adherence to the Services for HIV prevention, treatment and care	Ranking and scoring Problem tree Discussion
Map the resources, institutions and actors available at community and primary care level to respond to the epidemic.	Stakeholder analysis Plenary community roundtable
Review the evidence to assess the opportunities and mechanisms to enhance facilitators and overcome priority blocks to access	Leaping blocks Market place, Discussion
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	Margolis wheel Spider web Group discussions, Market place

Sources: Loewenson et al 2006, 2007, 2008, 2009, Machingura et al 2010

The participatory approach used gathers experiences of social groups with common features and identifies common patterns within the groups included and between the different social groups in an area. The patterns identified are used to stimulate discussion and reflection on the causes of problems,. and on the actions that can be taken to respond to challenges and their causes. In this case the focus was on community based interventions for the treatment, support and care of AIDS; from the perspective and experience of those in community, particularly PLWHIV.

There were some challenges encountered in the field work. The protocol was reported to be long (Mozambique-Maraccuene), demanded time that wasn't always available for health workers (Botswana Old Naledi). When time did not allow activities to be completed some questions were left unanswered (Bagamoyo Tanzania). As the tools such as the spider diagram were simple some participants did not take the process seriously and likened it to 'child's play' (Maraccuene - Mozambique). It was also difficult to translate some terms used to local languages, such as in the mapping exercise in Mozambique. The research depended on the capabilities of the facilitator, to probe discussion to collate and synthesize the evidence for action. The PR demanded clear facilitation to avoid diversion of the discussion.

This report provides a synthesis of the findings. The method used for the synthesis was selected from review of fifty background documents between 1962 and 2009 in grey literature and peer reviewed journals. These were; found in pub med and Google search using the key words *synthesis; qualitative data, generalization; ethnography.* Table 4 shows the methods found in the review.

Table 4: Methods for synthesis of qualitative information

Synthesis Method	Basic assumptions and methods	References
Meta-narrative synthesis	A framework used to integrate multiple qualitative studies by summarizing key issues from individual sites. It seeks to interpet rather than aggregate information.	Greenhalgh et al 2005; Popay et al 2006;
Critical interpretive synthesis	Builds new concepts and theories from primary studies. It presents and interprets evidence presented by individual participants as a basis for grouped analysis. Depends on research team interpretation so not reproducible	Dixon-Woods et al 2006; Gough 2007
Meta-ethnography	Involves the selection, comparison and analysis of studies to create new interpretations or concepts. It is used to identify key concepts, compare and contrast findings to develop new concepts.	Britten et al 2002; Campbell et al 2003; Graham et al 2005; Harden et al 2004; Hammersley 1992; Noblit et al 1988; 2007; Pound et al 2005. Sandelowski et al, 2004, 2008; Schutz 1962; Strike and Posner 1983Turner 1980;;
Grounded formal theory/ Grounded theory	Uses a constant comparative element to define emergent concepts based on common issues from research sites. It involves an iterative process to move from evidence grounded in specific contexts towards a generic theory with a broader application..	Barroso and Powell-Cope 2000; Campbell et al 2003; Charmaz 1983; Chesler 1987; Finfgeld 1999; Finfgeld-Connett 2008Glaser and Strauss 1967; Kearney 2001; Miles and Huberman 1984; Pope et al 2007; Strauss and Corbin 1990; 1998; Thomas et al 2007;
Thematic synthesis	Identifies major or recurrent themes and summarizes findings under thematic headings. Information is tabulated allowing identification of prominent themes and offering structured ways of dealing with the data in each theme	Harden et al 2001, 2006; Shepherd et al 2001; Rees et al 2001; Thomas and Harden 2007, 2008; Thomas et al 2003, 2007, 2008;
Textual narrative synthesis	Describes findings across existing research reports using content analysis approaches with an frequency used to determine strength of evidence	Harden et al 2007; Lucas et al 2007;
Qualitative synthesis / meta-synthesis/ meta study	Combines findings from different studies using different qualitative approaches for practice drawing common categories. It can be misleading in comparing different types of information, due to variation (heterogeneity) in study characteristics	Paterson et al 2001; Ritzer 1991; Sandelowski and Barossa 2007; Thorne et al 2004;
Content analysis	An organized technique for categorizing data into themes and counting frequency of themes	Davies 1999; Evans and Fitzgerald 2002; Hodson 1991; Newman et al, 2006; Suikkala and Leino-Kilpi 2000;
Case survey	Translates recordings and information from qualitative research using common categories.	Yin 1994
Qualitative comparative analysis	summarizes and compares qualitative evidence from individual research studies	Ragin 1987

Across the described methods, difficulties are noted in comparing qualitative data, including in making assumptions about common determinants of outcomes (Dixon-Woods et al 2005); in making comparisons across different contexts and environments; and in determining common categories or themes across different settings. Acknowledging these challenges, we identified thematic synthesis as a useful approach for synthesis of this primary research given that the same PR methods were used in each site. It is a method for grouping evidence on common themes while noting possible differences in context. For this synthesis report we identified thematic headings drawing from the conceptual framework that informed the work, and analysed the evidence across the sites using these thematic categories. The recurrent themes across the 12 sites were organized within the key areas where we sought to build common knowledge, i.e. on

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

Information was tabulated from sites within each theme. The text within each theme was analysed to identify recurring issues, words and concepts across sites and these were noted. Specific outliers were also noted with the site and nature of the person making them to indicate differences that may need further interrogation and follow up. The findings were based on all twelve sites in each case except for those shown in Table 5 below. In these cases some sites did not have information on the issue:

Table 5: Thematic categories with evidence from less than the full twelve sites

Thematic category	Number of sites where evidence was found
Social and economic factors	
Employment and poverty	7
Condom use	5
Treatment literacy	6
Health governance	5
Gender norms	9
Housing	1
Access to Services	
Distance and transport to services	8
Out of pocket spending and cost barriers	10
Health service factors	
Social welfare services	4
Centralisation or verticalisation of programmes	7
Waiting times	6

We recognize that there could be some sources of bias and error in the methods used.

1. There is loss of context in bringing the findings from individual studies together. We addressed this by providing a context analysis of each site to help in interpreting outliers. We also indicate the nature of the social group and or person making the comment in cases of outliers,.
2. The focus on the most frequent evidence and common patterns can lead to some loss of important specific information necessary to understand vulnerability. We addressed this by noting also outliers or differences, as well as common trends.
3. Concepts used in one setting may not mean the same as when they are used in another. We provide individual reports for each site in the reference list in which there was rigorous presentation of the full findings, and these were used to better understand the terms used in the synthesis.

3. Findings

3.1 Contexts

The contexts for the six countries, summarised in Table 6 below, describe contexts of high risk environments, with social and economic insecurity arising from limited secure employment, low earnings from economic activities, limited health services, health workers, medicines, equipment and supplies.

Table 6: Contexts for community systems and HIV and AIDS

Country and site(s)	The area and population	Social and economic factors	Health system
Botswana Old Naledi	Old Naledi is divided into three areas South, North and Central with a population of about 90 000.	It has high unemployment, few social and economic activities. The community is dependent on social safety nets provided by Gaborone City Council. Those in work are low income earners	It also has one health centre that serves the entire community.
Namibia Caprivi Region	Caprivi borders four countries - Angola, Zambia, Botswana and Zimbabwe. It has a population of 79,826, comprising about four percent of Namibia's population	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 socioeconomic situation in the region is worse than in other parts of the country with 31% of the population classified as very poor and 39% poor. (office of the Prime Minister 2009)	It has one district referral hospital, three health centers and 25 clinics. Recurrent floods impede access to services. A clinic provides CD4 count and ART. Most facilities offer AIDS care and support services, but with weak information systems and weak diagnostic capacities. Only 16% of facilities offer PMTCT or ARV treatment for HIV infected women. Only 7% of facilities provide ART.(MOHSS 2011)
Malawi Lilongwe, Nkhata Bay, Mchinji	Lilongwe Rural has a population of 1,2million people. Nkhata Bay is a rural district located along the shore of Lake Malawi, one of the main ports and the second "busiest resort" on the Lake, with .213,779 people. Mchinji rural district has 456, 558 people. it borders with Zambia and Mozambique.	Chiwamba has a 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 (Kambewa et al 2009). Mchinji district relies on tobacco and groundnut farming, and has rich soils and favorable climate.	Chiwamba has one health centre not providing ART - people travel long distances to the Lilongwe city to access ART services. Inadequate health workers, negative attitudes, shortages of medicines and equipment contribute to poor service coverage. In Nkhata Bay District only 35% of households access improved latrines, and poor waste management during the rains leads to waterborne diseases (GoM, NAC 2008). Open wells are a breeding ground for mosquitoes; leading to malaria.
Mozambique Manhica - (Maputo) Marracuene	Maputo province has 1,2 million people and an HIV prevalence of 19.8%. Marracuene with a population of 41817 is rural and bordered by Manhiça district and by Maputo city.	Poverty, gender inequality, cultural conditions and high levels of labour mobility, are risk environments for HIV infection within Marracuene and Maputo – Mozambique. Peasants' are the main social group in rural Marracuene, together with .state officials working in the district	Lack of transport, and poor roads in Marracuene undermine access to health centers. There are shortfalls in essential medicines, staffing; equipment and other supplies (KULA 2009), undermining coverage. Lack of safe water and adequate sanitation facilities lead to risk of preventable disease (GTM 2008)
Tanzania Bagamoyo	Bagamoyo is 65 kilometers from the capital, Dar es Salaam it is bordered by the Kibaha District, Tanga, Morogoro regions, and the Indian ocean. The population is 230 164	Bagamoyo is a "fishing village" with a fishing market place on the sea front. Most residents earn a living from petty trading and temporary employment in the tourist businesses, including housekeeping and restaurant work. .	There is one hospital in a far corner of the district, with access limited by poor quality of roads. There are four health centers, the next lower level of facility, and 50 dispensaries, which offer basic care. There is a shortage of health workers, medicines and equipment.
Zimbabwe Kariba Goromonzi	Goromonzi, a rural district, is 30km southeast of Harare with178,000 people.	Overall high unemployment, few social and economic activities, low industrial productivity implies	In Kariba District, HIV prevalence was estimated at 19.1% (CSO 2009), above the 2008 national average of

Chitungwiza	Kariba district 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 a population of 321 782.	economic and social instability in most households. Those in work are low income earners with limited coverage by to social security.	14.1% . Neither the one district hospital nor the health centers and clinics in the area provide ART. Shortage of medicines, equipment, health workers and low health worker pay undermines service delivery. There is poor cover of safe water (MOHCW 2009)

3.2 Conditions within communities affecting risk and vulnerability

insecure employment, food insecurity and poverty were common

Insecure employment was found 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 commonly worked in cross border trading, carpentry, brick moulding, 'stealing', phone credit vending, money changing /black market, hair salon work, urban farming; farm labouring; building and vending (vegetable, cigarette, sweets). Some occupations were themselves risk environments for HIV, such as brewing illicit alcohol (Zimbabwe); commuter bus driving, commercial sex or begging. Insecure incomes were reported to be associated with food insecurity at household level (Mozambique, Manhica; Zimbabwe Goromonzi, Malawi Mchinji). 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 (Tanzania Bagamoyo). Cross border trading was characterized by exploitation, separation from families and partners, and separation from the socio cultural norms that guide behaviours within communities (Zimbabwe, Malawi, and Namibia).

Poverty seemed to be a proxy for lack of income (Zimbabwe, Malawi, Mozambique, Namibia, and Botswana). Women participants noted that lack of income affected their ability to pay school fees or to provide adequate nutritious food for themselves and their children and to lead to stress (Zimbabwe, Mozambique). They reported that women forgot to take their treatment or deliberately skipped it when they do not have food (Zimbabwe, Kariba). In four countries (Tanzania, Namibia, Zimbabwe, Malawi) participants observed that there were few programmes promoting economic opportunities for women, such as through microfinance, micro-credit, vocational and skills training or income generation activities.

There was limited reporting on lack of decent housing as a risk environment for HIV (re)infection. This was raised in Old Naledi, Botswana, an urban area characterised by dilapidated structures, poor sewerage disposal, inadequate safe water and sanitation and high room densities.

Economic insecurity is associated with risk environments for HIV, especially for women, especially where social norms further increase risk

Economic insecurity in women was reported to lead to commercial sex in , Chitungwiza, Kariba; Old Naledi and Caprivi. Sexual transactions were reported to be carried out in bars and night clubs in Chitungwiza, Nkhata Bay and Lilongwe and in residential areas in Old Naledi. Low condom use was reported in women (Mozambique, Manhiça; Namibia Caprivi). There was also report of child trafficking, and of bars and rest houses acting as hiding places for traffickers in Mchinji in Malawi. Sites of commercial sex were reported to be places of drug dealing in Bagamoyo Tanzania. The PR sites thus indicate a clustering of economic insecurity and high risk environments for HIV.

Low condom use was not only associated with commercial sex. Community members, and particularly men, perceived condom use to lead to low sexual satisfaction and unfaithfulness, depressing their use of condoms in Zimbabwe, Botswana and Mozambique. Men considered

condoms to be unreliable and immoral for married partners in Zimbabwe and Malawi, leading to *unfaithfulness* (Zimbabwe, Malawi). Men living with HIV were reported to refuse condom use with their sexual partners in Malawi and Zimbabwe (Chitungwiza), while some religious faiths were also reported to discourage use of condoms and treatment with ART (in Lilongwe Nkhata Bay, Zimbabwe Kariba). Community members in some sites perceived that PLWHIV had been "bewitched" by jealous people or by partners as punishment for 'cheating' (in Mozambique, Zimbabwe, and Malawi). Lack of knowledge was reported to fuel such views, leading to stigma, discrimination and embarrassment, discouraging people from seeking or getting timely treatment and care for AIDS (as reported in Malawi, Namibia, and Zimbabwe).

These socio-economic conditions are mitigated or worsened by features of the health system

Where services for AIDS were integrated with services for maternal and child health and treatment of common illnesses and were close to communities,as found in Zimbabwe-Chitungwiza, Namibia Caprivi, Malawi-Mchinji and Mozambique Manhiça, there was report that they were more accessible and supportive of responses for reducing both HIV risk and vulnerability top AIDS.

In contrast to the positive gains of integrated services, vertical approaches were reported to create inefficiencies in service delivery in Zimbabwe, to perpetuate stigma in Botswana and Zimbabwe, to raise costs of care for communities and to and reduce quality of care and adherence and follow-up in Malawi and Zimbabwe. Health services were found to be crowded with rising levels of other common conditions, some o0f which such as tuberculosis were associated with HIV. Services were also reported to be stressed by the rising demand for voluntary counselling and testing (VCT), prevention of vertical transmission of HIV, and for ART (Malawi, Botswana, Zimbabwe). This led to crowding of services, making service environments unfavourable for clients (Malawi). Community members reported that they face stigma from health workers when visiting services for any form of Sexually Transmitted Infection (STI). With limited infrastructure for counselling, these sessions become group sessions that lack privacy. For example in Chitungwiza Zimbabwe counselling was being done in '*outside open space close to the mortuary'* (Zimbabwe-Chitungwiza).

Key to delivery of and access to such services was the presence of trained health workers who live in the community. However health workers at lower levels of the health system were reported to have worse conditions and pay, leading to outmigration to higher level services where pay was better (reported in Botswana, Namibia, Malawi, and Zimbabwe). Health workers were reported to be frustrated and to relay their stress to their patients, leading to sour relations (Malawi, Namibia, and Zimbabwe). In Mozambique, Malawi, and Zimbabwe health workers administering treatment programmes were only found at district hospital or higher levels of care.

Services lack the funds and communities the power to change these conditions

In Zimbabwe, Malawi, Botswana, Namibia, and Tanzania the problems with service quality and limited provision of treatment services close to communities was seen to be undermined by poor health funding.

Communities appeared from their reports to have little influence on their services. In Zimbabwe, Malawi, Mozambique, and Namibia it was observed that there were limited opportunities or mechanisms for communities to input to health service plans. There was a perception in Zimbabwe Chitungwiza, Malawi Mchinji, and in Mozambique that funds from central level were not reaching rural health centres or community level services. Community participation was thus reported to be symbolic, without real power to actively participate in meaningful decision making processes (Zimbabwe Goromonzi). Management structures and procedures did not include community input. Even participatory mechanisms like country committees for the Global Fund for AIDS, TB and Malaria (GFATM) were perceived in Chitungwiza Zimbabwe and Mchinji Malawi to

include people more as target groups and beneficiaries than as decision makers. Policy interventions were thus seen to reflect international rather than people's priorities.

"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 Contact between communities and services

Shortage of health workers undermine service interactions with communities
In five countries (Zimbabwe, Malawi, Mozambique, Namibia, Botswana), health worker shortages were raised as critical bottlenecks to service delivery. They were seen to lead to unrealistic workloads for the few available health workers undermining the quality of services. Poor pay and lack of career opportunities was seen to add to this stress (Zimbabwe, Malawi, and Tanzania) further demotivating the health workers. Health worker participants reported that they face difficult and often dangerous working conditions, particularly in the absence of occupational post exposure prophylaxis which was noted in Malawi to be in short supply or in Zimbabwe to not be available at all. Health workers were thus frustrated (Zimbabwe, Malawi, Botswana, Namibia) leading to poor interaction with clients and loss of trust in health workers by communities (Malawi, Tanzania, Mozambique, Botswana, and Zimbabwe). As one response, in Namibia Caprivi Chetto and Zimbabwe Kariba there was report of favouritism and corruption with informal payments charged for people to access ARVs in all countries or to have their CD4 count (in Zimbabwe, Malawi Lilongwe and Mchinji).

Primary care service links with communities limited by inadequate infrastructure, medicines and equipment
The primary care level of the health system was noted to be critical to support community systems for HIV. However in all countries except Namibia this level was 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, such as in Gutu and Mwanza ward in Goromonzi district in Zimbabwe. There was a strong perception of marginalisation by rural communities compared to those in urban areas, including in relation to services for HIV literacy, testing and counselling, comparing Lilongwe with Mchinji in Malawi, or Goromonzi compared with Chitungwiza in Zimbabwe. While most health facilities in all countries provided VCT, ANC and PMTCT services, these services mainly covered women due to their link with maternal health care. Clients reported failing to do repeat CD4 counts in Zimbabwe due to equipment failure or long queues due to centralisation of this service in Zimbabwe, Botswana and Malawi. The process for ART initiation was noted as long, cumbersome, expensive and unnecessary (Mozambique, Malawi, Zimbabwe) leading to some clients opting for indigenous medicines and religious faith healers (Mozambique, Malawi, Zimbabwe), from whom they perceive they can receive sympathy if not "cures".

"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 services for AIDS were offered in existing facilities in spaces not planned for with inadequate funds to purchase and maintain diagnostics equipment for CD4 counts or liver function tests. Community

members perceive that health workers are partly responsible for the inadequate space and supplies eroding the trust and health worker-client interaction that is central to HIV services. `

"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 specialized sessions that are individualized 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 **- Zimbabwe**

Cost and transport barriers limit community use of services

While these services (ARVs, PMTCT, ANC, VCT) are offered free of charge in public health institutions in Zimbabwe, Malawi, Mozambique, Botswana, there are transport and other out of pocket costs that raise costs to clients. Community members from Chitungwiza raised that they needed to pay $2 for a return journey to the hospital, $35 at the hospital for the CD4 count, and losses of income from vending or other activities due to long waiting times of about home $10-$30. They also had to buy food ($3-5). A direct cost of $40 was significant compared to their earnings, even if services do not charge a consultation fee.. The lack of reliable, affordable and safe transport, particularly for people living in poor, rural communities (Namibia, Mozambique) creates barriers in the links between communities and services, even when the latter are available. Poor transport, particularly in rural areas, was noted to lead to missed doses or interruption of treatment in Malawi and Marracuene - Mozambique. User fees or other out of pocket costs were seen to discourage return visits in all countries except Namibia. All country sites, except in Namibia, acknowledged that access to ARV treatment at no charge has greatly reduced the financial burden for PLWHA households and expanded access to health for PLWHIV . However the poorest and rural clients indicated they were still facing barriers to access, in all countries, given the payments for transport, food and in some cases accommodation to get to the ART centre (in Goromonzi - Zimbabwe).

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

Despite the longstanding nature of the epidemic in all the countries, stigma seems to be persistent. Womens burden from household chores, child care responsibilities (Botswana, Zimbabwe) weak control over their male partners' unsafe sexual behaviours (Zimbabwe, Malawi, Mozambique) perpetuate their vulnerability. If known or suspected to be HIV positive, women face violence (Zimbabwe, Botswana) or may be abused or abandoned (Tanzania). Discrimination appears 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 (Malawi, Tanzania; Zimbabwe).

Gender norms and roles do also affect men, In Zimbabwe, Malawi, Tanzania, and Namibia men rely on their spouses for information on AIDS as HIV responses have mainly targeted women. In Mozambique and Zimbabwe, participants reported that men do not test for HIV and only ascertain their HIV status after their partners have tested, often during ANC. Men were reported to find it difficult to talk openly about sex and to reveal their status (Malawi-Lilongwe, Zimbabwe) and women withhold their status from their partners out of fear of blame, domestic violence, divorce and loss of economic support (Tanzania, Malawi, Zimbabwe). Men were reported to be required to act in control, to have know-how, be strong, disease free, highly sexual and economically productive (Zimbabwe Chitungwiza). They fail to attend regular hospital visits (Mozambique and Botswana) and to engage in alcohol consumption and unprotected extra-marital sex, in part due to traditional perceptions of their role (Botswana-Old Naledi). Men were said to find it difficult to talk about sex and to fear revealing their HIV status (Zimbabwe). Advocating abstinence, faithfulness or condom use was found to be difficult for couples (Namibia) as was openly discussing STIs, not accepted due to local taboos (Malawi).

" often times 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)" .Woman Participant - 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 (Zimbabwe, Malawi, Mozambique, Botswana, Namibia). Exaggerated kindness seen in the community from neighbours, church colleagues, and work colleagues and from other social groups was also seen to trigger psychological distress (Zimbabwe). 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 marginalized once the bread winner dies particularly if the link to AIDS becomes known (Zimbabwe, Malawi). This can lead to social isolation (Botswana).

3.4 Factors within health services affecting coverage

There is limited provision of wider social welfare benefits

In Zimbabwe, Botswana, Malawi and Mozambique people were found to have limited social welfare support, and social welfare programmes to be under resourced. In Botswana, the *'Ipelegeng Scheme'* and in Malawi the $35 cash grant civil service workplace programme both provide support to PLWHIV, in the latter case with support to nutrition among PLWIV, most of whom are on incomes of less than US$100. In Zimbabwe the Basic Education Assistance Program (BEAM) programme targets vulnerable children with school fee support and the AIDS levy provides support for medicines purchase. There are thus some initiatives, and there was no report of social welfare services being denied to PLWHIV. The main problem thus appears to be the poor coverage and underfunding of these schemes. In Caprivi Namibia, a further barrier was reported, where 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. 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 affected households.

Centralisation of ART locates treatment resources far from communities

ART initiation is reported to be more central facilities, increasing congestion, workloads and out of pocket costs in already resource stretched areas (Malawi, Zimbabwe). Communities in Mozambique, Malawi and Zimbabwe felt that it was necessary to decentralise ART and other services for HIV and AIDS to primary level to overcome barriers in access to services and provide financial protection.

Mentoring and support for community and frontline health workers is missing

As a chronic condition HIV demands that health workers need clinical mentoring to foster their ongoing professional development in managing ART and the treatment of opportunistic infections and build the case study review, feedback on case management to provide a reasonable level of client centred care (WHO 2006). All countries reported a lack of clinical mentoring which was reported to increase the frequency of late or inappropriate referrals, inconveniencing PLWHIV and their families. Doctors at district hospitals were seen to have limited experience in managing difficult cases and to not be providing the clinical mentoring needed at lower levels.

In Zimbabwe, Malawi, Tanzania, Botswana and Namibia health workers reported that expertise in managing antiretroviral therapy and opportunistic infections is available, but limited and not

adequate in the district management team due to already limited health workers. In Chitungwiza, for example, health workers reported that visiting doctors and senior nurses and midwives at the central hospital had expertise in managing ART and opportunistic infections, but did not have time to mentor clinical staff at the district hospital, and even less at clinic level. In Malawi mentoring was seen to be undermined by heavy workloads and shortages of staff for this.

"We do get mentoring or task shifting, whatever they call it, but the problem is the training is short and often not adequate to instill 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 - Goromonzi Zimbabwe

"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". Malawi –Lilongwe Health worker Participant

Health systems do not have budgets to support phones, radios and email for clinical mentoring (Zimbabwe and Namibia).

"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". ' Malawi-Nkhata Bay Health worker participant

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 communities when they access and use services. There was progress reported in Zimbabwe, Malawi, Botswana, Mozambique Tanzania in service integration, particularly for VCT, PMTCT and Antenatal care (ANC) services, and for male circumcision in Zimbabwe, although this mainly happens at district than primary care facilities. Fragmentation happens when non stateorganizations 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 (Malawi, Zimbabwe, Mozambique).. Links across providers was seen to be important to ensure follow up of referrals to determine if the client's need has been satisfied (Namibia, Zimbabwe, Malawi)

Primary care services need more effective referral services

The shortage of ambulances reported in Namibia, Malawi, Botswana and Zimbabwe was reported as an important gap in the referral system. The participants highlighted that either the ambulances are not available (Kariba, Zimbabwe), very few and always late (Malawi, Mozambique,) or present but not efficient (Botswana, Namibia). In Caprivi for instance participants reported that ambulances drop patients at the Hospital, but that the hospital does not provide mechanisms to bring them back to their villages.

"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

Clear public health signals discouraging stigma in services are needed to support uptake
Discrimination was two sided, with health workers in Botswana and Zimbabwe indicating that those health workers known to be HIV positive are discriminated by clients, who prefer service from health workers who are not infected. Related to this was '*door labelling'*, reported in Zimbabwe, a label for Opportunistic Infection (OI) clinics based on a perception that anyone who goes into these rooms is 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". Zimbabwe- community member)

In Kariba Zimbabwe the political affiliation of a health worker was noted to influence acceptability of services, particularly if the patient and the health worker know each other from the community.

3.5 Strategies for improving community and health systems responses

Investing in community resources, institutions and actors to respond to AIDS
In all the countries civil society organisations (including NGOs, CBOs and FBOs) 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 recognized in national HIV and AIDS strategies, there participants were not clear on the formal measures to operationalise the role of CSOs in the health system (Zimbabwe, Botswana, and Malawi). Participants reported that civil society do not perceive that their role is taken seriously (Zimbabwe), despite committed and often volunteer cadreship, well embedded in communities (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.

"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

International funders and civil society to make 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 the National Health Strategy.

4. Discussion

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 themselves 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 characterized 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 to have 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 womens' autonomy (economic, social and sexual), to feed stigma and to lead to low involvement of men in AIDS programmes. Young people are at greater risk of getting infected by STI and HIV due to their sexual inexperience, multiple and concurrent partners and inconsistent condom use.

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 top 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 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 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. The centralization of ART at district and central level facilities undermines the continuity of services and client centred approach that is important for chronic HIV care and adherence. HIV-positive individuals who lack a regular address at which to be contacted for treatment and other service needs may have their care unintentionally disrupted, or terminated, due to interrupted communications with health service providers or caseworkers. Yet these are the very people who need more support, as living in insecure settings with poor diets makes the side effects of treatment more difficult to manage. A high frequency of late or inappropriate referrals was reported, making care difficult for the client, their family and the health system. 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.

This is compounded by vertical systems that support selective rather than comprehensive approaches to care. For example PLWHIV experience other infections and chronic illnesses, including tuberculosis, diabetes, cancers and mental stress, all of which also need to be managed as part of the overall response to AIDS and to improve their health. Segmentation of services means that some of these conditions are not adequately addressed, the resources are not provided for this or people have to move between different providers in both public and private sectors to access these services.

While communities identified funding and other constraints to these barriers, they appeared to have limited power and role in decision making to change them. Health centre managers also had limited autonomy or incentives to manage health resources and to improve outcomes. Communities 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, 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.

5. Conclusions and 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 based systems for HIV prevention and AIDS treatment, support and care.

Within Communities

9. 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 communities and, together with community leaders, for levering broader action to address vulnerability and tackle risk environments for HIV within communities.
10. 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 womens' autonomy and mens' involvement, and that strengthen collective responsibilities and mobilization of resources within communities to support vulnerable groups and children.
11. 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 and AIDS

In the interface between Communities and health services

12. The role of strategic partnerships, leadership, supported and mentored decentralisation and participatory decision making needs to be given more recognition and support. Governance. Communities should have the right to co-decision making with services over resources for responses to AIDS and health systems generally, mechanisms should be in place for this and training and support for participation. Community partnerships and involvement is central to treatment preparedness and to the effective design, uptake of and adherence to AIDS 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 revitalizing the capacities, processes and mechanisms for dialogue and co-decision making between communities and state services.
13. 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.
14. International and global health initiatives working on and resourcing HIV and AIDS programmes need to meet the commitment to alignment with national level policies but to go further and ensure that the processes they support *within* countries are 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 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

15. 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 the community and primary care level, 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 lead them out of service in facilities close to communities.
16. 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 if access and coverage gaps are to be addressed. 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.
17. This 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. It also calls for recognition that AIDS 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.

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7. Acronyms

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