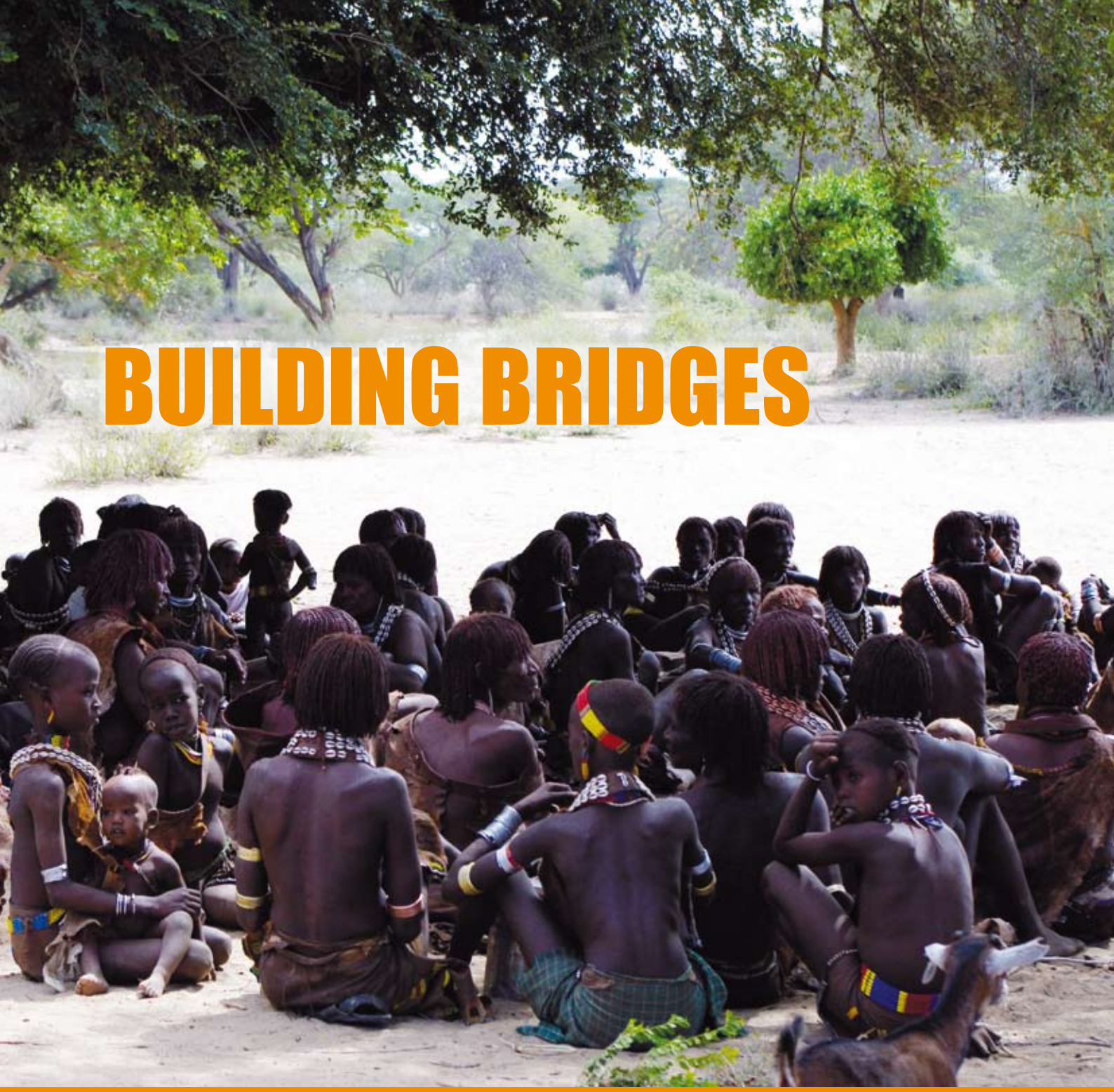

BUILDING BRIDGES

Lessons and best practices in empowering pastoralist communities to prevent HIV infection and reduce the impact of AIDS in Ethiopia

The first in a series of ad hoc briefing papers

COMIC RELIEF

HEALTH POVERTY ACTION

Building Bridges

Lessons and best practices in empowering pastoralist communities to prevent HIV infection and reduce the impact of AIDS in Ethiopia

See reverse for abstract

This paper was written by Elona Toska. Health Poverty Action also thanks Zoe Dibb, Sarah Edwards, Corinna Heineke, Tadesse Kassaye, and Nicole Tobin, Enhancing Pastoralist Research and Development Alternatives (EPaRDA), Local Associations of people living with HIV or AIDS, and Government officials from various departments in both woredas for their contributions. The compilation of this research would not have been possible without the financial support from Comic Relief.

For further information on the issues raised in this paper please e-mail **general@healthpovertyaction.org.**

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Contents

Acronyms & abbreviations

AIDS	Acquired Immuno-Deficiency Syndrome
ART	Anti-Retroviral Treatment
AMREF	African Medical and Research Foundation
ANC	Antenatal Care
CC	Community Conversations
CCE-CC	Community Capacity Enhancement – Community Conversations
EDHS	Ethiopian Demographic and Health Survey
EECMY	Ethiopian Evangelical Church Mekane Yesus
EMPC	Empowering Marginalised Pastoralist Communities
EPaRDA	Enhancing Pastoralist Research and Development Alternatives
FGC/M	Female Genital Cutting/Mutilation
GFATM	Global Fund to fight AIDS, Tuberculosis and Malaria
GOE	Government of Ethiopia
HAPCO	South Omo Zone HIV/AIDS Prevention and Control Office
HC	Health Centre
HEW	Health Extension Worker
HIS	Health Insurance Scheme
HIV	Human Immunodeficiency Virus
HPA	Health Poverty Action
HSDP	Health Sector Development Plan
HTP	Harmful Traditional Practices
IEC	Information, Education, Communication
IGA	Income Generating Activities
KAP	Knowledge, Attitude, Practice
MDG	Millennium Development Goal
MoH	Ministry of Health (Federal level)
MOUs	Memorandum of Understandings
M&E	Monitoring and Evaluation
NGOs	Non-Governmental Organisations
PA	Pastoralist Associations
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PLHIV	People living with HIV
PMTCT	Prevention of Mother To Child Transmission
SNNPR	Southern Nations, Nationalities and Peoples' Region
SOPDA	South Omo Peoples Pastoralist Development Association
STI	Sexually Transmitted Infection
TBA	Traditional Birth Attendant
VCT	Voluntary Counselling and Testing

Definitions

Pastoralist communities[i] Strictly defined as people who engage in pastoral production systems in which 50% of the gross household revenue comes from livestock or livestock-related activities. More broadly, the definition encompasses livestock and non-livestock dependent households within pastoralist ethnic groups and others with pastoralist perceptions and values on the importance of livestock.

Vulnerability to HIV and AIDS Vulnerability refers to all factors that make a person more susceptible to HIV infection and to developing AIDS. The factors underlying vulnerability may reduce the ability of individuals and communities to avoid HIV risk and may be outside the control of individuals. These factors may include: lack of knowledge and skills required to protect oneself and others; accessibility, quality, and coverage of services and commodities; and societal factors such as human rights violations, or socio-cultural norms. These norms can include practices, beliefs, and laws that stigmatise and disempower certain populations, particularly women, limiting their ability to access or use HIV prevention, treatment, care, and support services and commodities.

Administrative Units Ethiopia is a Federal Democratic Republic composed of nine National Regional States and two city administrations, with 750 Woredas (districts). The Woredas represent the basic units of planning and political administration. Below the districts are Kebeles representing urban dwellers associations in towns and peasant associations in rural villages of approximately 15,000 people each.

Harmful Social Practices[ii] Social health practices and norms are highly prevalent in Ethiopia. These practices vary greatly from region to region and from one ethnic group to the other as they are influenced by factors such as culture, beliefs, and/or history of each of these social entities. In the six ethnic communities that participated in EMPC, a total of 15 beneficial and 30 harmful social practices were identified through qualitative research. Forced abortion, inheritance marriage (widow inheritance), unwanted 'Mingi' children, ceremonial whipping of women and female genital mutilation/cutting (FGM/C) were the most common harmful practices reported in the Hamer and Bena-Tsemay districts.

i. This definition has been adapted from a more detailed analysis by John Morton 'Conceptualising The Links Between HIV/AIDS And Pastoralist Livelihoods', The European Journal of Development Research, 2006. 18:2, 235-254.
ii. The author is aware that the conventionally used terminology is 'harmful traditional practices'. However, by using 'harmful social practices' Health Poverty Action recognises that it is the harmfulness of the practice that is to be opposed and not the fact that it is traditional. It questions the conventional association of the terminology with non-Western traditions. For more information see www.healthpovertyaction.org/news/harmful-labelling-practices.

1. Background

1.1 HIV and AIDS in Ethiopia

Ethiopia, the second most populous country in Africa, is one of the poorest nations in the world, with a per capita annual income of US$1,040, less than half the regional average and 10% of the global average per capita income.[1] Nearly 33% of the population lives below the absolute poverty line[2], while life expectancy at birth is 54 years (53 for men and 56 for women). Though lower in 2011 compared to 2005, the total fertility rate is high at 4.8 nationally, with women in rural areas having an average of 5.5 children compared to 2.6 children per urban woman.[3] Following the diagnosis of the first case in 1987, Ethiopia has been significantly affected by the HIV epidemic. According to ante-natal care surveillance estimates, HIV prevalence among pregnant women aged 15-24 declined from 5.6% in 2005, to 3.5% in 2007, and then to 2.6% in 2009 and 1.5% in 2011. Despite this lower HIV prevalence, given its large population, Ethiopia is home to nearly 800,000 people living with HIV (PLHIV) and about one million AIDS orphans. The lower national HIV prevalence rates hide substantial differences in urban and rural prevalence rates, respectively 5.2% and 0.8% among women and 2.9% and 0.5% among men.[4] Heterosexual transmission accounts for 87% of transmissions[5], with women of 30-34 years old having the highest prevalence rate.

Nationally, women are more vulnerable to HIV infection and make up 59% of the HIV positive population.[6] The main factors increasing their susceptibility include: earlier age of sexual debut, inequitable sexual relationships that render negotiation of safe sex difficult, exposure to various forms of violence and abuse, and prevalence of harmful practices, such as female genital mutilation/cutting (FGM/C). Furthermore, despite improvements in overall knowledge about HIV and its modes of transmission, only 19% of women and 32% of men have comprehensive knowledge of HIV transmission and prevention methods.[7]

1.2 Pastoralist communities and health services in Ethiopia

Pastoralist communities move cyclically or periodically to find pastures for their livestock. Prior to 2000 there were an estimated 30-40 million nomads in the world,[8] with pastoralist systems supporting an estimated 100-200 million people.[9] Though the pastoralist communities in Ethiopia constitute about 10% of the total population of the country, pastoralism contributed 12% of national GDP and 38% of agricultural GDP in 2005/6.[10]

The standard of living of pastoralist communities falls far short of the Ethiopian national average due to a lack of political representation and barriers to accessing basic public services or NGO support due to a long history of economic and socio-cultural marginalisation. Pastoralists are often excluded from basic services because of their geographical isolation, and even when services are provided they are frequently limited by a lack of staff and the absence of basic infrastructure.[11] Healthcare infrastructure in regions where pastoralist communities live is very weak, with ratios of nurses and physicians per 100,000 people below the minimum of 1:100,000 recommended by the WHO.[12] As a result, pastoralist communities have high maternal mortality figures, low rates of contraception use and low rates of births attended by trained birth attendants, key indicators of poor access to health services.[13] Starting in 2003, the Government of Ethiopia has rolled out a system of community-based Health Extension Workers. Nearly 33,000 of them have been trained and are expected to focus on prevention, promotion and rehabilitative services targeting the households, youth centres and schools in remote rural communities, including pastoralist ones.

Traditional medicine is the main health care service to the pastoral communities due to its high acceptance among pastoralist communities. This acceptance is often forced by the lack of access to affordable formal health services.[14] The formal health services are accessed late, after traditional healers have attempted and failed to address the issue.[15] The effects of this delay are exacerbated by the long distances that pastoralists must travel to access medicine and trained healthcare workers. Most pastoralist women will give birth at home with the support of traditional birth attendants.[16]

1.3 HIV or AIDS risk and vulnerability among pastoralist communities

The combination of extreme poverty, lack of formal education, vulnerability to droughts and armed conflict, and extreme environmental, economic, socio-cultural and political marginalisation renders pastoralists highly vulnerable to the impact of AIDS and susceptible to HIV infection.[17] Though HIV incidence and prevalence data was, and still is, lacking, it was estimated that 2.9% people were living with HIV in 2007 in Ethiopia, rates much higher than the Ethiopia-wide rural prevalence at the time. This section briefly summarises the risk factors among pastoralist communities in Ethiopia:

Individual level risk factors

- Lower levels of HIV awareness and preventative methods: among all Ethiopian females, pastoralists ranked the lowest for knowledge of preventive methods (18.5%), while knowledge among pastoralist men was 39.3%. These levels were significantly lower than 43.8% in females and 64.8% in males among the general population.[18]
- Very limited exposure to condoms with extremely low rates of condom use.
- Pastoralist women lack the power to exercise their sexual and reproductive health (SRH) rights, with men being the main decision-makers with regards to contraception and access to healthcare services.[19]
- Misconceptions about HIV being a disease of urban people and highlanders.
- Low awareness and access to Voluntary Counselling and Testing (VCT) for HIV.
- Low awareness and access to antiretroviral treatment for individual and prevention of Mother to Child Transmission (PMTCT).

Community-level practices

- The practice of 'Evangadi' or traditional dancing events performed in the Hamer and Bena-Tsemay districts, where local boys and girls find sexual partners.
- Harmful practices such as female genital cutting, widow's inheritance and early marriage. In some pastoralist communities, the majority of girls and young women are subjected to female genital cutting (FGC).[20]
- Gender norms which not only reduce the ability of women and young girls to negotiate safe sex, but also result in women and girls bearing the greater burden of HIV infection.
- High levels of stigma against people living with HIV and AIDS.

Structural-level factors

- In addition to the limited access to formal health care services structural level factors that increase susceptibility to HIV infection and vulnerability to AIDS, include:
- Increased urban-rural mobility within Ethiopia due to infrastructure projects, tourism and reclamation of pastoralist land for large agricultural projects.[21]
- Severe levels of food insecurity due to droughts, wars and top-down infrastructure development projects.[22]
- Poverty at the household and community level. Poor people generally lack good nutritional status, access to health care and information and education. Access to education for all pastoralist communities is low, with dropout rates particularly high amongst girls. While national average primary Gross Enrolment Ratio (GER) for the country in 2005-06 grew to 91.3%, the average primary GER for Afar and Somali regions in the same year was merely 21.9% and 30.3% respectively.[23]

The combined effects of the above factors is a significant increase in the vulnerability of pastoralist communities to HIV infection and AIDS. Studies by the Ministry of Health show that harmful social practices and low awareness and knowledge of HIV and AIDS due to limited interventions are the main factors putting pastoralist communities at risk of infection.[24] The remaining sections of this paper present innovative and successful examples of building bridges between pastoralists and formal health services through community-based initiatives that address their unique lifestyles and challenges.

2. HIV and AIDS programming and health services for pastoralist communities

Over the last two decades, several initiatives have addressed the need for improved healthcare and HIV response among pastoralists in Ethiopia. This section highlights several examples of interventions which focused on addressing a combination of the risk factors identified above, starting with the *Empowering Marginalised Pastoralist Communities to Prevent HIV/AIDS and Promote the Rights of HIV-positive People* (EMPC), implemented by Health Poverty Action and local partners EPaRDA and AndiNet, as a case study.

2.1 Case study of EMPC project: Bringing HIV prevention to the communities

The project **Empowering Marginalised Pastoralist Communities to Prevent HIV/AIDS and Promote the Rights of HIV-positive People** (EMPC) was designed to address the vulnerabilities of pastoralist communities in Hamer and Bena-Tsemay woredas in South Omo region, in Southern Nations, Nationalities and Peoples' Region State. It was implemented by Health Poverty Action in partnership with the local organisation Enhancing Pastoralist Research and Development Alternatives (EPaRDA) and AndiNet, the association of people living with HIV based in Jinka, South Omo capital, in 2008-2011. The project was supported financially by Comic Relief's International grants programmes as part of their People Affected by HIV and AIDS Programme Strategy 2009-12.

EMPC's strategies for improving HIV Awareness and Access to Services included:

- **Youth sexual and reproductive health clubs (anti-AIDS clubs)** which conducted HIV awareness-raising among peers, distributed Information, Education and Communication (IEC) materials and condoms and supported PLHIV. Outreach activities were conducted through Club activities and during cultural events such as the 'Evangadi' dances.
- **Community conversations.** A transformational participatory methodology involving a process of engaging communities in interactive discussions where they can freely express their opinions and reach consensus on key community issues. EMPC focused on the original understanding of the sessions, which involves community leaders *and* members identifying issues and promoting dialogue on solutions. Volunteers from the community and healthcare workers were trained as CC facilitators.
- **Increased access to VCT through mobile facilities and outreach** complemented by a rigorous technical training component for staff providing HIV counselling and testing, and a mobile VCT initiative that reached pastoralist communities in appropriate locations and at appropriate times. VCT counsellors were trained following national guidelines and EMPC supplied HIV testing kits, to meet the demand generated through the strong outreach component.

Youth waiting for mobile VCT in South Omo region

- **Communities empowered through access to preventive information and condoms**. More than 33,000 condoms were distributed in bars, hotels and brothels, as well as in village communities prior to events such as an Evangadi traditional dance. IEC materials (leaflets, brochures, posters, t-shirts, and a 30-minute video in four local languages) were developed after a study identified IEC needs in the area, including content and most appropriate mode of delivery. Combined with outreach and CC sessions, this component was driven by individual learning and social change communication approaches.
- **Strengthening of two self-initiated associations of PLHIV through technical support, management training and a tailored income-generation scheme for their members.** One of the major components of this organisational empowerment was the support from Andinet.

Sample IEC material

EMPC results and outcomes (I)

Mobile VCT and Outreach

- 28 health workers and local government staff trained as VCT counsellors.
- 6,711 people reached through mobile VCT services.

EMPC results and outcomes (II) [iii]

Impact of awareness raising activities:

- More than half of those having sex with a non-regular partner reported using condoms regularly (55.9%).
- Nearly 39% of those surveyed had used a condom before, a 77% increase compared to 22% reporting the same indicator at baseline.
- Compared to baseline, more people know that HIV could be transmitted from mother to child, while support for VCT remained stable at 84.2%.
- Nearly 56% said they would disclose their HIV status if they were found positive.
- Compared to baseline data, knowledge of modes of transmission of HIV increased to 85.3%, while 60.8% said that both condoms and faithfulness are modes of HIV prevention.
- 107 community members and Health Extension Workers (HEW) as CC facilitators who reached nearly 20,400 people through monthly Community Conversation sessions in 58 *Kebeles* (villages).

iii. ATEM Consultancy Service (2010). *Empowering Marginalised Pastoralist Communities to Prevent HIV/AIDS and Promote Rights of HIV Positive People in Hamer and Bena-Tsemay Woreda, South Omo Zone, SNNPR, Ethiopia – End-line Survey.* Addis Ababa, Ethiopia.

2.2 Improving the sexual and reproductive health of pastoralist communities

Improving the Sexual and Reproductive Health of Pastoralist Communities in Bale Lowlands, Ethiopia was a project implemented by Health Poverty Action with the local partner Ethiopian Evangelical Church Mekane Yesus (EECMY) in 2008-2012, funded by the European Commission. The project strives to improve the Sexual and Reproductive Health (SRH) status of remote marginalised pastoralist communities in Oromia Region, Bale Zone, Rayitu and Sawena districts. Its main components included:

- **Community Conversations (CC) processes** which successfully led to the complete abolition of FGC in some Muslim pastoralist communities in this project.
- Pilot HIV prevention education and **mobile VCT services offered to communities**, engaging PLHIV in outreach and education.
- Enhanced SRH Service Delivery Capacities by **improving clinical skills in Post-Abortion Care (PAC) services offered to communities, managing complicated labour, and STI diagnosis and treatment.**
- Improving quality and experiences of SRH services by pastoralist communities by **enhancing the capacity of local partner EECMY and MOH district level staff to manage SRH programmes.**
- Establishing a programme of community-based reproductive health agents (CBRHAs) trained to distribute contraception and support with referrals to SRH services.
- Development of **culturally appropriate IEC/BCC materials** on SRH priority topics including unsafe abortion, availability of safe abortion services, harmful traditional practices (including FGC), safe delivery, HIV/AIDS/STI, and FP, tailored to the needs of local communities.
- **Training of traditional birth attendants as 'wise women' and equipping them with clean birth kits** for cases when referral in time to a health facility is not possible.
- **Youth members of SRH clubs trained** as peer educators, using poems and drama.

Sawena District mobile VCT station

Musina Abdul
Orossa village, Bale Lowlands

"I have learnt a lot from the training that I received six months ago. Before the training, […] I used one blade on many many women to cut the umbilical cord and I did not use gloves. Now I know that using a clean blade will reduce the risk of HIV, and gloves can protect from HIV and infection. The project has made us aware to prevent harmful traditional practices, female circumcision, HIV, and diseases."

The 2010 evaluation of the Community Conversations project found that the communities that had turned most quickly against FGC where those in which i) religious leaders, ii) the village head, and iii) communities themselves (through Community Conversations) had all publicly verbalised their feeling that the practice should be abolished.

Other Programmes addressing structural HIV vulnerabilities

Several additional Health Poverty Action programmes have offered innovative approaches to addressing the HIV and health needs of pastoralist communities through accessible and acceptable approaches, described below.

2.3 Pastoralist Health Development Project I (PHDP I)

PHDP I, supported financially by the Big Lottery Fund, piloted innovative approaches to reaching pastoralists with Maternal and Child Health (MCH) services in Hamer and Bena-Tsemay districts. The project was delivered by Health Poverty Action in close partnerships with local NGOs, EPaRDA and Pastoralist Concern (PC) in close coordination with Ministry of Health and Ministry of Women and Children Affairs.

Innovative PHDP I components:

1. **Mobile Outreach Camps**
2. **Community Birthing Huts**
3. **Health Insurance Schemes**
4. **Culturally appropriate trainings**
5. **Engaging TBAs**

2.4 Realising maternal and child health rights (ReACH)

Realising maternal And Child Health rights in difficult environments (ReACH) is a four-year European Commission (EC)-funded MCH project, delivered by Health Poverty Action with partner Pastoralist Concern (PC). ReACH is applying an innovative cross-border approach to target Somali pastoralists living along the Ethiopia/Kenya border, recognising their mobile lifestyles that often do not match with state borders. The project is being implemented in Dollo Ado, Ethiopia and Mandera, Kenya and aims to improve the supply-side capacity of health service delivery by MoH in Dollo Ado and Mandera.

ReACH has several innovative components, compared to EMPC and PHDP I:

- **Community-Based Reproductive Health Agents (CBRHA)** from within the communities, trained and supported to distribute contraceptives.
- **Strong referral networks** for women facing complications by training former TBAs as 'wise women' by equipping them with mobile phones and phone credit.
- Women are supported to form women's **community-based health insurance groups** (CBHIS) so that they can save together and take loans when they need to pay for maternal health services that are not free.
- Women members of CBHIS were supported to set up **fast growing demonstration gardens** along the river's edge using riverbed irrigation/flood retreat farming, which only takes two months to grow.

While the above initiatives were lead by Health Poverty Action, the following programmes were developed and implemented by various organisations to address the health and HIV response needs of pastoralist communities in Ethiopia and neighbouring countries.

The ReACH programme directly complemented PDHP II in Ethiopia, by ensuring that higher levels of health-seeking behaviours were met with quality services within the pastoralist communities.

2.5 Project Accept

Project Accept (HTPN043)[25] was the first international multi-site community randomised, controlled study to compare a multi-component community-based VCT intervention with clinic-based VCT. The intervention was delivered in 48 communities in Tanzania, Zimbabwe, South Africa and Thailand with the aim of increasing knowledge of HIV status, changing community norms, and enhancing social support for people living with HIV.

Project Accept (HTPN043) components:

- **Community-based HIV mobile voluntary counselling and testing (CBVCT)**
- **Community mobilisation (CM)**
- **Post-test support services (PTSS)**

A four-fold increase in testing was observed in the communities accessing mobile VCT compared to clinic-based VCT. The provision of mobile services, combined with appropriate support activities, may have significant effects on utilisation of VCT. This trial also provided support for community mobilisation as a strategy for increasing testing rates.

2.6 Community Capacity Enhancement through Community Conversations (CCE-CC) to prevent FGM/C[26]

A holistic project implemented by Womankind Worldwide and Kembatta Mentti Gezzima (KMG) in Kembatta/Tembaro zone in Ethiopia. **Community Capacity Enhancement through Community Conversations (CCE-CC)** was used as a tool to promote community discussion, which provided a space for active interaction and dialogue without fear or discrimination, using participatory tools to assist community members in understanding the harmful impact of FGM/C and deciding what action to take to abandon it.

Drivers of change and effective incentives for decision-makers to address violence against women and girls:

- **Combination of normative frameworks and community action** – Decisions to abandon FGM/C were first made in CC gathering points, then *idir*,[iv] then more formal gatherings.
- **The reinforcing circle of law and community action** – engaging uncircumcised girls in discussions supported a bottom-up approach to enforcing the decision to abandon the practice mandated by the revised laws.
- **Human rights work is absolutely necessary** – simply changing laws relating to physical harm is not enough. In other areas (Amhara and Wolyata) FGM/C was forced underground without a human rights framework.
- **Monitoring framework** – a combination of linear/log frame approach and Theory of Change. Questions on assumptions of theory of change and mapping of stakeholders improved measurements of impact and change.

Elements of success

Working with men and boys, though some discussions took place in women's only spaces, some in CC groups.

Multi-sectoral approach: health services, legal services, financial support and income generation activities for TBAs.

2.7 Berhane Hewan by Population Council and ARBOYS

Berhane Hewan was a two-year pilot project conducted in 2004–2006 that aimed to reduce the prevalence of child marriage among Amharic agriculturalists in rural Ethiopia. The Berhane Hewan pilot project was a joint project between the Population Council and the former Amhara Regional Bureau of Youth and Sports (ARBOYS), now the Amhara Regional Bureau of Women, Children, and Youth Affairs. The overall goal was to address the cultural and economic drivers of early marriage by establishing appropriate and

iv. *Idir* – a voluntary community-based organisation that supports its members with funerary needs and arrangements. Membership in an idir is family-based. The size of each idir varies from about 500 to 3,000 members. (FHI 2010)

effective mechanisms to protect girls at risk of forced early marriage and support adolescent girls who are already married, and increase the use of reproductive health services among sexually experienced girls. Specifically, Berhane Hewan components included:

- Group formation by adult female mentors **to create safe social spaces for the most vulnerable and isolated girls** to meet same-sex friends and interact with caring adults.
- **Support for girls to remain in school** (including an economic incentive) and participation in non-formal education (e.g. basic literacy and numeracy) and livelihood training for out-of-school girls.
- **Community Conversations** to engage the community in discussion of key issues, such as early marriage, and in collective problem solving.

A quasi-experimental design demonstrated the effect of the programme on girls exposed to Berhane Hewan activities.[27] The intervention was associated with considerable improvements in girls' school enrolment, age at marriage, reproductive health knowledge and contraceptive use. Particularly among girls aged 10–14, those exposed to the programme were more likely than those in the control area to be in school at the endline survey and were less likely to have ever been married. Sexually experienced girls exposed to the intervention had elevated odds of having ever used contraceptives.

Following the success of this initial pilot, USAID is supporting a continuation of Berhane Hewan in the Amhara region. To determine the most effective strategy to delay early marriage, various interventions are being implemented in different districts, focusing on girls aged 12–17.

2.8 Community conversations for reducing stigma & discrimination by Care International

Community Conversations (CC) were introduced by UNDP around the world and in Ethiopia in 2002 in cooperation with the National HIV/AIDS Prevention and Control Office (NHAPCO). Care International in Ethiopia integrated CC into the Health Improvement and Women Owned Transformation (HIWOT) programme, in which 105 CC groups in 14 districts in 4 zones (5-7 districts), one per selected PA, were formed to engage on issues related to HIV and sexual and reproductive health (SRH) between 2006 and 2007.[28] HIWOT was the first programme adopting CC on integrated HIV/SRH issues including harmful traditional practices and family planning. Participants of a CC discussion group were representative of different segments of the community: farmers, civil servants, shopkeepers, craftsmen, religious and informal leaders, PA administrators, men, women, adolescents, and so on.

Care International's HIWOT project

After 12 months of implementation, the CARE team witnessed changes in risky behaviours and stigmatisation in remote rural areas where HIWOT was working:

- CC helped reduce stigma and discrimination towards people living with HIV. Though in the first sessions participants shared negative attitudes regarding PLHIV, through discussion participants concluded that *"all of us are at risk of acquiring HIV for one reason or another."*
- Some groups condemned early marriage to avoid the related negative outcomes.
- Others decided to stop FGM/C and related harmful practices.
- Others reached a consensus to avoid practicing behaviours that increase risk of HIV infection, such as going to night clubs and drinking alcohol, and widow inheritance.

Unexpected results of Care International's HIWOT Project:

- Demand for VCT services increased due to the discussions and the flexible HIWOT programme facilitating VCT outreach services provided by health-centre staff.
- An intrinsic outcome of CC is empowerment of communities and individuals to identify and address issues that are important to them.

3. Best Practices in addressing HIV or AIDS vulnerability in pastoralist communities

3.1 Leveraging community knowledge and experience for change

Approaches such as the Community Conversations, the Project Steering Committee and stakeholder meetings before, during and at the end of the project enabled successful programmes to leverage existing community knowledge and experiences to address complex problems such as HIV risk and AIDS vulnerability.

In particular, **Community Capacity Enhancement through Community Conversation (CCE-CC)** has been increasingly recognised as a highly effective tool in engaging communities, leveraging their knowledge and experience to mobilise for changing risk factors for HIV infection and increased vulnerability to AIDS. **Since 2002, Community Conversations has been applied widely to address both HIV-specific issues, such as prevention methods, uptake of VCT, and HIV-related issues, for example, FGM/C, mother and child health, delaying marriage among pastoralist girls, and tackling stigma and discrimination towards PLHIV.**

Phases of the CCE-CC process

Dialogue & planning phases:

1. Relationship building
2. Concern identification
3. Concern exploration
4. Local capacity & resource identification
5. Planning and decision-making

Action and review phases:

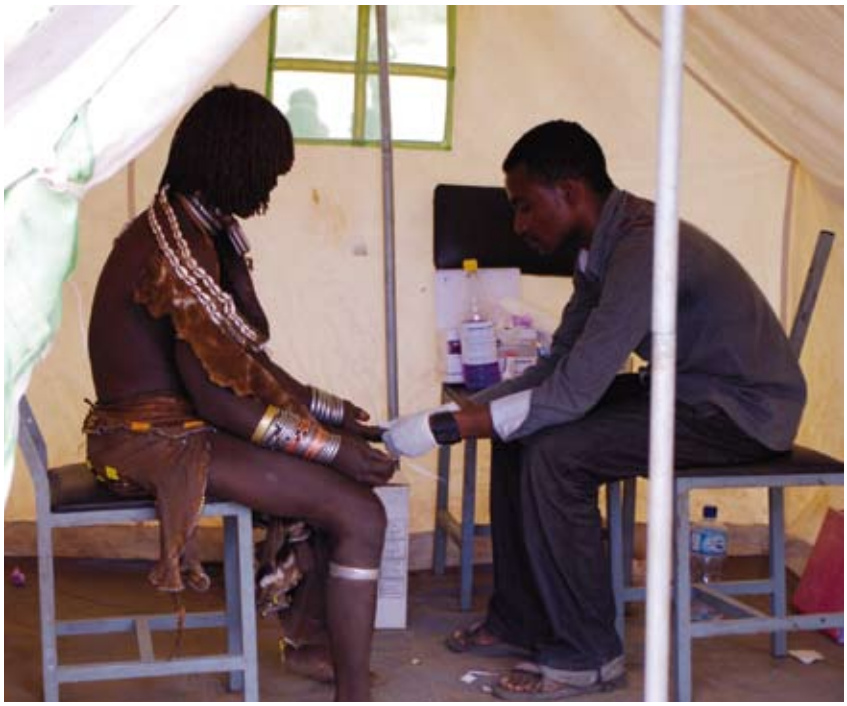
6. Action (implementation)
7. Review and reflection

Community Conversation is a systematic cycle of discussion and debate among community members on sensitive issues by which participants examine issues from various angles and reach a communal understanding and decision on what should be the norm. Each phase identified above involves a set of tools and activities used by a trained facilitator(s), with each phase taking up to two to three months to complete, with some phases (e.g., those that concern exploration and action) usually taking the greatest amount of time to complete.[29] CCs have achieved success in raising awareness and empowering the marginalised to speak out,[30] with several projects successfully using this approach to engage marginalised pastoralist communities in Ethiopia through HIV-focused or HIV-related programmes.

3.2 Continuum of HIV prevention, testing, treatment, care & support

The components of EMPC comprehensively covered the full continuum of care for addressing vulnerability to HIV and AIDS and their incidence among pastoralist communities.

- Outreach activities through youth clubs and community conversations increased HIV and AIDS knowledge, which in turn raised awareness of counselling and testing, increasing demand for VCT.
- Mobile VCT services met this increased need by reaching pastoralist communities at times and places when and where they could access services.
- Those who tested positive were then referred to anti-retroviral treatment (ART) and prevention of mother to child transmission (PMTCT) services as needed.
- The two associations of PLHIV established with EMPC support provided continuous care and support to the newly diagnosed community members.
- Finally, the focus on promotion of rights of PLHIV complemented the above HIV services by addressing issues of stigma and discrimination.



Mobile VCT station

85% of people found to be HIV-positive during the mobile VCT were successfully referred to the Health Centres for treatment

3.3 Community-based mobile VCT

The severe economic, political and physical marginalisation faced by pastoralist communities results in limited or no access to government-provided HIV services. Community-based mobile VCT services in conjunction with community-based support services have been shown to increase utilisation of VCT in several sub-Saharan countries four-fold compared to clinic-based VCT,[31] leading to an uptake among people who have never tested before.[32] However its uptake has been limited among youth.[33] EMPC and ReACH projects successfully demonstrated that community-based mobile VCT is successful in reaching out to pastoralist communities and bridging the structural divide between these communities and formal healthcare services. In the case of EMPC, more than 6,000 people, nearly three times as many members of the pastoralist communities as initially planned, accessed VCT. The community-based mobile VCT provided a crucial momentum to the demand for VCT uptake among pastoralist communities, acting as a catalyst for demand-creation for voluntary testing and care (VCT) through the formal health services.

Additional elements of success included:

- Strong referrals and linkages to ART, PMTCT services and PLHIV associations.
- Involving PLHIV and youth in outreach for awareness raising and mobilisations.
- Engaging traditional healers and training them as counsellors to refer cases to VCT and other HIV services was a crucial element of this referral system.

3.4 Extending the current health care systems: formal and informal

Though not initially included in the design of EMPC, the Health Extension Workers were engaged in project activities to improve their skills in providing health services that met the needs of pastoralist communities in South Omo. **Several projects that engaged the informal networks of traditional birth attendants (TBAs), traditional healers, and voluntary community-based reproductive health agents (CBRHA) succeeded in reducing harmful practices and improving health promotion and referral systems.** This important component extends the reach of current health care systems in meeting the needs of marginalised pastoralist communities. Initiatives of the African Medical Research Foundation (AMREF) in three pastoralist communities in Ethiopia, Kenya and Tanzania, Womankind/KMG in Ethiopia, and EMPC exemplify this best practice.[34] Lessons learned included: (i) engaging traditional healers (who are often those performing FGM/C) in exchange for economic benefits and offering them skills training for alternative livelihoods is key to ensuring that legal reforms and bans do not drive such practices underground, and (ii) establishing the infrastructure and human resources for bringing pastoralist communities into the health system through mobile services, such as mobile birthing huts, was also successful in Health Poverty Action's ReACH project for Mother and Child Health services.

3.5 Focus on socio-economic empowerment

Increasingly, research on the structural drivers of the HIV epidemic recommends that complex multi-component programmes are needed to address them.[35] EMPC used the PLHIV associations as vehicles for socio-economic empowerment. Support for the two associations included training in advocacy, community mobilisation and HIV and AIDS education. Some of the PLHIV who obtained business start-up grants also experienced positive social effects of the grants: greater acceptance and lesser stigma and discrimination. In cooperation with Andinet, both associations became active in the SNNPR regional networks of PLHIV to advocate for their rights in regional meetings alongside representatives of the regional and zonal MOH and HAPCO offices.

28 of the 30 start-up grants received by PLHIV resulted in successful businesses that enabled their owners to put aside savings.

3.6 Appropriate, relevant and effective individual and social change communication

Given the low literacy rates amongst the pastoralist communities, culturally appropriate social change communication materials were designed following an assessment of IEC needs by several projects, including EMPC. This included posters, songs and taped messages to spread information about HIV, AIDS and other health issues discussed by the communities. Non-written materials that adhered to the oral traditions of the communities and featured images of the relevant pastoralist groups ensured that the IEC materials were appropriate, relevant and effective in addressing some of the barriers to accessing HIV services among pastoralist communities.

For most communities this was the first time they had seen 'themselves' reflected in communication messages and they responded enthusiastically to their content and presentation. Outreach and awareness-raising was founded on this principle and timed for maximum impact, for example during the mentioned 'Evangadi' celebrations, market places, areas where vaccination programmes were taking place and home-to-home education through a programmed called *Buna Tetu* (let's drink coffee).

3.7 Sustainability

All of the programmes described in section 2 were successful in reaching pastoralist communities because of partnerships with local institutions, social and political, which allowed them to have a sustainable effect. The partnerships included:

- Implementation cooperation in the case of EMPC where Health Poverty Action partnered with EPaRDA.
- Community Capacity Enhancement through Community Conversations which engaged tribal and religious leaders in Womankind/KMG's initiative aiming to reduce FGM/C.
- Engaging local government by training department of health staff, counsellors, HEWs and mobile VCT providers.
- Including the informal healthcare system to ensure that TBAs and traditional healers were also engaged in building bridges through improved primary response to health needs and stronger referral systems.
- Liaison with other major partners in the field of HIV services and pastoralist health among implementers such as Health Poverty Action and the Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM), the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) and AMREF to continue the provision of condoms, IEC materials, VCT and ART to the communities at the end of projects.

A second element of sustainability was the focus on the quality and long-term effect of all programs implemented. The training and service-delivery of EMPC and other projects had a strong focus on community systems strengthening and training of individuals as a means to improve the quality of care interventions, particularly of MoH staff in charge of service delivery at different levels. An additional core element of the capacity enhancement and skill building activities of EMPC was investing in local organisations, such as EPaRDA in EMPC and Pastoralist Concern in PHDP I.

3.8 Addressing HIV or AIDS-related stigma and discrimination

The stigma experienced by PLHIV can be external (community, healthcare providers) and internalised, while their families can also experience secondary stigma, or stigma-by-association. When enacted, stigma becomes discrimination, as a result of which, many PLHIV fail to access VCT, ART, PMTCT, care, and support services in pastoralist communities and more widely in Ethiopia.[36] Furthermore, experiences of stigma and discrimination affect disclosure to family, partners and communities, which in turn affects adherence to treatment.

The above interventions highlight several practices that reduce stigma and the ensuing discrimination experienced by PLHIV:

- **Engagement of PLHIV in prevention activities and home-based care and support for newly diagnosed HIV-positive pastoralists** led to a reduction of stigma and discrimination during EMPC. Another big stride made by EMPC affirmed by members of the PLHIV associations was the reduction in the level of self-stigmatisation among the PLHIV. Standing together and helping each other as association members and engaging in useful self-help economic activities and opportunities brought about by the project helped PLHIV to regain their self-esteem and to feel honoured and accepted.
- **The engagement of communities to question their misconceptions and (mis) understanding of HIV through Community Conversations resulted in reduced stigma in Care International's HIWOT project.**

4. Conclusion

The response to the HIV epidemic in Ethiopia over the last decade has had positive results, with Ethiopia being one of the few countries in the world to reduce HIV prevalence by over 25%. However, a recent systematic review found that few single-focus interventions reduce HIV risk and prevalence.[37] This paper highlights how the gap between pastoralist communities and the formal health/HIV services was bridged through participatory approaches, appropriate use of community conversations and social change communications, and engagement of youth, PLHIV, traditional healers, and other members of the community. Many of the best practices and lessons learned could be generalised to addressing the HIV and AIDS vulnerability of pastoralist communities in Ethiopia and the wider region.

The *health systems approach* to health development recognises that a principle barrier to good health among marginalised communities is the gap between communities and formal health systems.[38] Several of the highlighted projects worked well because **multiple programmatic components reinforced each other in the same pastoralist communities.** The following sections summarise the best practices and lessons learned from programmes among pastoralists in Ethiopia and elsewhere grouped by: (i) strategic approaches, (ii) mobile solutions for pastoralist lifestyles, (iii) other programmatic components, and (iv) structural solutions.

Strategic approaches

- Given the poor maternal and child health and overall primary health among pastoralist communities, **HIV services should be integrated with other healthcare services for pastoralists**. Some of the projects noted above integrate HIV services in MCH services, while HEW can act as a single point of contact for all health issues and referrals.
- Pastoralist communities in Ethiopia and elsewhere are diverse communities. **Leveraging knowledge and experiences of communities** to reduce harmful practices and increase knowledge and prevention practices should be done **through a combination of Community Conversations and other participatory approaches** from the conception of the project throughout the full implementation cycle, including monitoring & evaluation.
- **Involving influential members of the community such as tribal and religious leaders,** has been shown to have positive outcomes in addressing harmful practices in the communities, such as FGM/C, early marriage and widow inheritance.
- Furthermore, including those who may be assumed not to be supportive of project aims – for example traditional healers who make their living by performing FGM/C – is essential. **Extending the reach of the informal health services and enhancing their role as connectors to the formal health services through referrals** results in improved access to HIV and general health services by pastoralists, given the trust and faith they have in the informal healers. Providing alternative livelihoods for these traditional healers is crucial to ensuring that the change in social norms and practices is sustainable.
- Last, but not least, **engaging people living with HIV** in outreach activities, Community Conversation sessions, IEC and condom dissemination and awareness raising is crucial in reducing misconceptions about HIV and its transmission and AIDS.

Mobile solutions for pastoralist lifestyles

- In addition to improving the health-seeking behaviours of pastoralist communities, interventions such as **mobile community-based VCT, mobile birthing huts, and skill-building of community-based healers** will ensure that the immediate needs of pastoralists can be met until they can reach formal health service centres and providers. These solutions must always be coupled with comprehensive outreach and awareness-raising activities.
- Specifically, the rigorous evidence from trials (Project Accept HPTN043) and practical results from EMPC in showing that the model of **mobile community-based VCT** worked among the pastoralist communities in Southern Omo, indicates that this model should be included in the HIV services offered to pastoralist communities. Donors and organisations involved in HIV preventions should promote its inclusion in health services for pastoralists.
- In light of a dearth of prevalence and incidence data on HIV, STIs and several other health-related issues among pastoralists, it is crucial to establish systems that monitor health indicators of these communities so that evidence-based programmes are developed. Data collected through current processes must be disaggregated by gender and ethnicity. Innovative models in this area have been promoted by AMREF in Kenyan pastoralist communities (functional community-based health information management system).

Programmatic components

- As FHI concludes, **CCE-CC by itself primes communities for behaviour change to occur**. **Behaviour change must be fostered through additional components of projects**, such as appropriate IEC materials and increased availability of prevention methods such as condoms, VCT and PMTCT.
- **Developed IEC materials should build on locally recognised social change communication such as oral traditions, songs, and story-telling, to increase their acceptability, relevance and effectiveness.**
- **Innovative evaluation methodologies that address complex initiatives are needed.** For example, evaluations must assess the relative effectiveness of various components: e.g. peer education vs. mobile VCT outreach. Furthermore, the progressive roll-out of universal programmes over time, for example integrating HIV prevention in the work of Health Extension Workers, should be evaluated through impact and process evaluations.

Berhane Hewan Project

A shortcoming of the evaluation was that it was unable to determine which component of the intervention – community conversations, school supplies, sheep/goats, or the mentoring groups – was most successful.

Structural interventions

Programmes that address the structural causes of HIV, also known as HIV-sensitive programmes, should be rolled out and piloted among pastoralist communities.

- The **benefits of providing socio-economic empowerment for marginalised communities** are attested to by many PLHIV. Improved understanding of which interventions (microfinance, health insurance schemes or income generation activities) are the most appropriate to pastoralist communities need to be explored through further projects and matched research. At the same time, nationally pooled resources are needed to ensure that everyone has access to treatment, care and support without risk of financial hardship.
- Potential **prevention programs that address increased migration and the side-effects of infrastructure development** could include partnerships with companies to incorporate HIV awareness-raising and VCT services in the workplace. Coordination with the Ministry of Health and the Health Extension Workers Program could be a vehicle for providing these services.
- Limited research on stigma by health care providers in southwestern Ethiopia indicates complex interacting factors.[39] **Stigma by others, self-stigma, and secondary stigma (of families of people living with HIV) need to be researched further so that appropriate interventions can be introduced**. Some tools to measure stigma have recently been validated in Ethiopia and could potentially be used to inform future programme baseline research.[40]
- There are limited interventions that successfully and terminally **address the stigma and discrimination experienced by people living with HIV or AIDS**. Previous programmes in Ethiopia used CC as a catalyst for stigma reduction and social change.[41] A study of health care workers in south-western Ethiopia found that those whose training included topics of stigma and discrimination were less likely to have stigmatising attitudes towards PLHIV.[42] Therefore, a potential approach to tackle these issues among marginalised pastoralist communities is to **integrate topics of stigma and discrimination into training provided** to HEW, CC facilitators, VCT counsellors, traditional healers, youth peer educators, and teachers.
- **Awareness of the protective effect of education in reducing early sexual debut, FGM/C, and sexual risk-taking** among young girls in Kenya, Malawi and Ethiopia[43] should drive the development or application of solutions for increasing access to education among pastoralist communities. Some of these solutions, such as mobile schools and open and distance learning combined with short periods of residential schooling have been shown to work in small-scale studies in increasing uptake in education, though further research is needed.[44]

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Building Bridges

Lessons and best practices in empowering pastoralist communities to prevent HIV infection and reduce the impact of AIDS in Ethiopia

This paper reviews examples of health programming for mobile and pastoralist populations focused on addressing risk and vulnerability to HIV and AIDS, in particular the *Empowering Pastoralist Communities to Prevent HIV Infection and Reduce the Impact of AIDS* (EMPC) programme implemented by Health Poverty Action and EPaRDA (Enhancing Pastoralist Research and Development Alternatives) in Southern Omo region, Ethiopia.

It presents innovative and successful examples of building bridges between pastoralist communities and formal health services through community-based initiatives that address the unique lifestyle of pastoralist communities. Furthermore, it highlights successful interventions such as community-based mobile voluntary counselling and testing (VCT), Community Conversations, engaging the informal/voluntary health systems of traditional healers, traditional birth attendants, and increased access to appropriate information, education, communication (IEC), condoms and other health services as tools for reaching out to pastoralist communities.

Finally, the paper makes a set of recommendations on how HIV and AIDS issues can be addressed through health services targeted to the complex needs, risks and vulnerabilities of pastoralist communities.

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