

A Review of HIV Counselling and Testing in Sports Development Programmes for Youth

– South Africa, Lesotho, Zambia and Malawi –



Researched and written by

Centre for AIDS Development, Research and Evaluation (CADRE)

www.cadre.org.za

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Disclaimer

This report does not necessarily represent the views of Comic Relief, UK Sport or any of the organisations that participated in the fieldwork.

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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
ART	Antiretroviral Therapy
CADRE	Centre for AIDS Development, Research and Evaluation
FGD	Focus Group Discussion
HIV	Human Immunodeficiency Virus
HCT	HIV Counselling and Testing (in some countries designated HTC)
HTC	HIV Testing and Counselling (in some countries designated HCT)
IDI	In-Depth Interview
NGO	Non-governmental organisation
PMTCT	Prevention of Mother-to-Child Transmission
SfD	Sport for Development
SRH	Sexual Reproductive Health
STI	Sexually Transmitted Infection
TB	Tuberculosis
VCT	Voluntary Counselling and Testing
YFHS	Youth Friendly Health Services

Executive summary

Background and aims of the study

Comic Relief's International Sport for Change programme and UK Sport International undertook to jointly review the range of approaches and methodologies being employed in child and youth-centred HIV counselling and testing (HCT) in Sport for Development programmes; including a focus on questions of ethics and good practice. Centre for AIDS Development, Research and Evaluation (CADRE) was contracted to conduct the review study on behalf of Comic Relief and UK Sport.

The broad aim of the study is to critically analyse and provide recommendations on the use of HCT in Sfd programmes, with an emphasis on the effective prevention and treatment of HIV/AIDS. This includes a review of the use of sport as an entry point to HIV-prevention behaviour change and health care, with a particular focus on promotion and use of HIV counselling and testing (HCT) by Sport for Development (Sfd) programmes.

Questions addressed

1. What are the different VCT/HCT models, methodologies and follow-up approaches used by youth-focused HIV organisations and Sport for Development organisations in particular?
2. Which approaches appear most effective and what are the circumstances associated with effectiveness?
3. In regard to the different stages of HIV counselling and testing (HCT) the following questions were asked.
 - What types of partnerships are required to ensure effective service delivery?
 - What process and actions need to be in place to ensure the realisation and protection of young people's rights to health, information, care and support, and participation?
 - What are the effective systems needed to refer people to long-term treatment and support?
 - What are the ethical considerations and how well are these addressed? Is the decision to get tested a voluntary decision in the hands of young people themselves?
 - What post-testing monitoring of stigma, discrimination, mental health and social concerns is in place?
 - How do these approaches link to the relevant legal frameworks at country level?

Research process

The research commenced with a comprehensive literature review and this was followed by fieldwork in four countries in Southern Africa, namely South Africa, Lesotho, Zambia and Malawi.

In each country two to three research sites were chosen, providing a balance between rural and urban settings and including 10 Sfd organisations. Participants included managers/directors, programme staff, coaches/programme implementers, HCT counsellors/medical staff, programme beneficiaries and community members.

Findings and recommendations

The findings are discussed under four headings.

1. The use of HCT in Sfd programmes
2. Ethics of HCT in SFD
3. Outcomes of HCT in Sfd programmes
4. Monitoring, evaluation and research in Sfd programmes

For each of these areas a review of the literature is presented, following by findings and recommendations.

1) The use of HCT in SfD programmes

The field research found three main models for providing HCT, treatment care and support to young people participating in SfD programmes:

- Tournament counselling and testing at mass sports events, offered through partnerships with external organisations that provide HCT using mobile HCT units, setting-up temporary facilities in locations convenient to community members
- Offering HCT and other SRH services through fixed Health Information Centres (HIC) which are either managed by the SfD organisation or partnered with
- Comprehensive Health Care (CHC) facilities, usually in the form of government or international NGO primary health facilities, to which are added sport and youth outreach programmes which facilitate youth access to HCT and SRH services, and sometimes ART treatment and management

Benefits of HCT at sports tournaments include: taking services to youth and communities otherwise not likely to attend health care facilities specifically to undergo HCT; encouraging the normalisation of testing; de-stigmatising HCT; and opportunity to implement a curriculum over time in preparation for young people to undergo HCT. The mobile unit approach allows HCT to be provided where there are no other facilities and to people who do not otherwise need health services; which significantly increases reach of services.

In many respects SfD programmes overcome barriers to youth HCT, and support youth-friendly practices for enhancing access to health and social services.

There are some concerns that mass testing may compromise the quality of counselling that is essential if HCT is to achieve its intended prevention and testing outcomes. There are also a number of risks associated with tournament testing, including risks issues related to standards of counselling, confidentiality, subtle coercion, social network curiosity and undue speculation about the HIV status of others. It is suggested that SfD organisations should strongly work to mitigate these risks, recognising the value offered by the innovative ways of delivering HCT services in terms of access and reach.

The facility-based approaches are not subject to the same risks, although their prospects for reaching large numbers of young people in diverse locations are limited.

Key to all HCT provision is the need to use HCT as an entry point for young people into health and social care service networks and the need to take measures to ensure the uptake of referrals by HCT clients. SfD organisations need to think carefully about the limits and extent of their responsibilities to those they expose to HCT. To improve prospects for optimal outcomes they should establish firm partnerships and referral follow-up protocols with health and social service providers. This is problematic in distant sites and may require scoping of service networks and joint preparation for tournaments.

While care and support are an element of some SfD, this is not common except where the organisations are associated with health information centres or clinics. The research found that a few organisations have developed innovations in how they offer care and support. Along with the referral to support groups for people living with HIV and AIDS, some organisations offer post-test clubs for young people who have undergone an HIV test, regardless of their test outcome.

Coaches play a pivotal role in promoting and modelling behaviour when it comes to HCT and HIV/AIDS attitudes and behaviour. Whereas the commitment and levels of concern apparent among coaches is as much as might be expected, they confess to not always being equipped to handle the

full responsibility for all aspects of their roles.

Recommendations made include the need to focus on building the capacity of coaches. The relationships that coaches have with participants must be considered the cornerstone of SfD programmes. Introducing a concern about HIV adds a significant burden to the more general youth development responsibility of coaches. The continuing development and support for coaches in guiding young people in difficult circumstances should be seen as indispensable in SfD programmes. There is also a need to consider the care needs of both coaches and peer-educators. They often feel burdened by the challenges they face in dealing with the many sensitive issues that arise in educating young people about HIV/AIDS and helping them face the realities of HIV in their lives.

Further recommendations made concern the need for strengthening partnerships between SfD programmes and other health and social support organisations in the communities they serve. Partnerships are tenuous in some circumstances, especially where SfD programmes are provided away from the home-base of the SfD organisation. Related to this is the need to strengthen functional integration between services in terms of referrals and strengthening the linkages between HCT services and treatment, care and support services.

2) Ethics of HCT in SFD

Guidelines for provision of HCT are reviewed and the practices of SfD organisations are examined, related specifically to provision of HCT and preparation of young people for HCT.

HCT is the culmination point of many SfD programmes. Programmes prepare young people to want to know their HIV statuses, creating pathways of thinking to living positively with HIV or ensuring that they don't become HIV infected as the case may be. It does this in ways which are engaging and accessible for young people. It provides information about HIV transmission and its effects, guides young people towards motivation for knowing their HIV statuses, prepares them for this, develops understanding of HIV and its treatment, and works against stigmatising attitudes towards HIV. Ideally anyone undergoing HCT would have been so prepared.

However, there is reason to be circumspect about the implications of some of the innovations that characterise HCT preparation and provision in SfD programmes.

There are some notable challenges associated with mobile HCT facilities and large-scale 'tournament testing'. These include uncertainties about follow-up and support prospects after an HIV- positive diagnosis, risks of compromised confidentiality in make-shift HCT facilities, and peer-pressure for disclosure of HIV status.

Although HCT is conducted in awareness of requirements of the need for confidentiality, informed consent and counselling, there are some instances where these are compromised by circumstances.

These do not generally involve flagrant disregard for accepted HCT principles. They are largely by-products of well-intentioned attempts to encourage young people. An example is a well-meaning coach disclosing his own test outcome and creating the impression that this is desirable. However, this was experienced as putting pressure on young people to do the same. A further example is the peer pressure that builds up as a testing tournament approaches. SfD organisations tend to see this as positive peer-pressure but some participants experience it as stressful and subtly coercive. Risks of breeches of confidentiality are also discussed.

These risks are generally recognised by SfD organisations, although not always mitigated. Some of these challenges are equally evident in government HCT campaigns, so this should not necessarily be construed as a particular consequence of SfD practice.

SfD organisations offering HCT need to have management capacity for quality control and ethical oversight.

For an HIV-positive person to live a happy and healthy life it is not necessary for them to be publicly

open about their HIV-status. They will likely need to disclose their status to some people and it may be counter-productive to disclose their HIV-status to others. It is suggested that this is a point of correction that needs to be adopted by many SfD organisations.

Recommendations are made about the need for development and adoption of ethics protocols by SfD organisations in keeping with country guidelines and international standards, need for caution about creating negative-peer pressure to undergo HCT, and introduction of steps to manage and mitigate ethics risks.

3) Outcomes of use HCT in SfD

The extensive literature review in this area finds that there has been relatively little published research on HCT outcomes, considering the prominence of HIV testing in national HIV prevention strategies in most countries with generalised epidemics. There is much evidence to show that HCT is an indispensable entry point to HIV prevention, treatment and care. However, the efficacy of HCT requires more than people simply knowing their HIV status.

The prevention value of HCT for both HIV-positive and HIV-negative diagnoses is strongly reliant on the quality of reflection, information provided, skills learned, and decision making that is part of the counselling process. The theory of change justifying the prominence of HCT in HIV prevention strategies requires linkages and successful referrals to other health and social support services. Regarding HIV prevention HCT on its own is a component of broader processes of change that require linkages to particular services, use of such services and support for people to make decisions, change attitudes and adopt different patterns of action.

The literature review indicates that mobile HCT services have been successfully used to deliver HCT to underserved populations, including youth, who have not previously used clinic-based services. However, there are some risks to providing HIV counselling and testing through mobile services or away from established health services and facilities. Such services create greater challenges of ensuring confidentiality in temporary testing centres, risks of hurried and poor quality counselling, and challenges in providing follow-up support and specific referrals.

HCT tends to have better prevention outcomes following an HIV positive diagnosis, as opposed to an HIV-negative diagnosis. Evidence shows that behavioural changes such as increased condom use and reduction of multiple partners following HCT are more likely in HIV positive people than those who test negative.

The overall prevention outcomes of HCT are optimised for both HIV-positive and HIV-negative test-results when HCT is offered in conjunction with other interventions and follow-up services and referrals. These include ongoing counselling, viral load tests, CD4 counts and referral for access to treatment and support. It is important that people who test negative - the large majority of people who undergo HCT processes - are properly counselled on how to remain HIV negative, as testing on its own is unlikely to have much impact on prevention behaviour. There is also some risk that without adequate prevention counselling, HIV-negative findings could lead to the false perception that there is no need to adopt HIV prevention measures.

The literature suggests that successful HCT models that increase HCT uptake among youth are those that: 1) involve youth as counsellors; 2) are innovative and creative, for example, those that include sports and games over traditional methods; 3) free of charge; 4) guarantee confidentiality and privacy, following ethical guidelines regarding confidentiality, volunteer participation, equality, informed consent, mandatory pre- and post-counselling with trained counsellors, and provision of follow up services; and 5) offer same-day

A number of recommendations are made about improving HCT practices. Most notably it is recommended that whereas organisations should aim at achieving widespread use of HCT services and actively promote 'knowing your HIV status', achieving targets for numbers of people tested

should not undermine the need for high standards of HCT practice. It is strongly suggested that programmes using tournament testing and those referring to outside HCT service providers, should closely monitor both the quality of testing and the consequences of testing social network and individual levels.

It is suggested that SfD organisations engage with the approach known as ‘combination prevention’. The value of HCT involves appropriate referrals, and SfD organisations should closely assess the quality of services and referrals, the forms of ongoing support and services offered, and the responses of young people to testing. This involves developing stronger linkages between organisations in the interest of comprehensive services through functional integration of services and development of referral networks.

It is recommended that organisations should do more to provide support for people receiving an HIV-positive result after HCT, following a range of initiatives on the part of some organisations aimed at supporting HIV-positive young people.

4) Monitoring, evaluation and research in SfD programmes

Recommendations for SfD organisations include improving the quality and provision of health information and services to young people, guidelines for ethical practice, protecting legal rights of young people with regard to HCT and SRH, the need for clear follow-up procedures following either test outcome, and greater integration of services.

Recommendations for funders include supporting the efforts of organisations to integrate services, developing and fostering long term relationships with partners, and supporting ethical practice by making ethical codes of practice part of funding agreements.

Although HCT often marks the end of a young person’s engagement with a SfD programme, its value is only realised if it moves young people on their path forward after testing; towards appropriate treatment and care services and HIV prevention behaviour. This is difficult to achieve when programmes are conducted in remote sites or where SfD programmes do not have an established base, as the management of outcomes, both positive and negative, is left in the hands of schools and community services. One way of addressing this problem is to build support networks in the process of running programmes.

However, it was found that the skills sets of those involved are not necessarily developed to meet these needs. It is unlikely that youth development organisations could expand to this extent and the only likely prospect for improving the situation is ensuring that partners are sufficiently prepared to provide support to youth post testing.

Although there is much innovation in SfD programming, relatively little of it is accompanied by sound research or evaluation studies. It is however encouraging that a randomised control trial study is currently being planned, to test the impact of a SfD programme on HIV incidence. A sound foundation of evidence is needed to build the credibility of the SfD contribution to meeting the targets of national strategic plans for HIV/AIDS response. The opportunity provided by these organisations is promising, but to gain prominence and national support it will need more systematic development. This should be accompanied by monitoring and evaluation strategies to ensure that the theories of change which undergird HCT practice are optimally served and innovations in HCT practice do not undermine the necessary conditions for HCT effectiveness. There is also need to more closely monitor the functioning of referral networks and to ensure that the ethical propriety is not compromised by the drive to scale.

1 Background to the study

Many Sport for Development (SfD) programmes focus on or include elements of HIV prevention. For many years this did not extend much beyond basic HIV awareness building, prevention messaging and HIV stigma reduction; through games and sports drills.

However, increasingly SfD organisations have adopted more comprehensive approaches, extending to provision of HIV counselling and testing (HCT), and sometimes treatment within the remit of their programmes. They have done this in a variety of ways: sometimes working in partnership with local HCT specialists; training their peer-educators in HCT; and developing direct links to treatment partners. Some organisations have regular testing sessions in a fixed location, much like a health clinic; and others encourage testing at tournaments by awarding individual or team points to create incentives for testing.

This follows an increasing emphasis by public health specialists on the need for a more 'linked-up' or 'combination' approach to HIV prevention whereby testing, prevention and supportive counselling, referral for treatment and psychosocial support are all offered. However, in reality most sport-for-development organisations do not have the capacity or resources to offer all components of a comprehensive approach to HIV and AIDS. As a result there is a risk that the expanded investments in HIV prevention, support and care are less than adequate as a vehicle for HIV and AIDS responses.

In this context it is important to gain an understanding of how SfD organisations are adapting to the need to become more integrally involved in HIV and AIDS work. There is a need to take stock of the models that have been developed and to appreciate the strengths and weaknesses of different approaches. There has been much innovation in this area which needs to be reviewed in order to understand what has been learned and what is more or less effective in different contexts.

Should SfD programmes offer these services and, if so, how best should such services be shaped and managed? What methodologies are SfD organisations using to encourage youth to get tested and are they partnering with other credible organisations to offer easy access to treatment where it is required? Are they able to offer follow-up support in the longer-term?

Since 2007, Comic Relief's International Sport for Change programme and UK Sport International have worked in partnership, and have supported the increasing involvement of SfD organisations in addressing HIV and AIDS in the communities they serve. In the interest of building the evidence base for these interventions, they collaborated on a three-year (2007-2011) research project focussing on the impact of sport for development in Africa and India. The project highlighted a number of areas in which further investigation would be highly beneficial; one being the effectiveness of sports-based HIV and AIDS prevention programmes.

Comic Relief's International Sport for Change programme and UK Sport International undertook a joint research project to review the range of approaches and methodologies being employed in child and youth-centred HIV testing in Sport for Development programmes; including a focus on questions of ethics, confidentiality and good practice.

Towards this end they contracted the Centre for AIDS Research Development and Evaluation (CADRE) to conduct a study of Sport for Development organisations offering HIV counselling, testing and treatment as part of their programmes; focusing on Southern Africa. The research was conducted from November 2011 to January 2012.

The overall objective of the study is to gather knowledge that will inform Sport for Development practice and provide recommendations to Comic Relief, UK Sport and others on improving effectiveness and ensuring high ethical standards in this area.

More specifically the research aimed to address the following questions:

1. What are the different VCT/HCT models, methodologies and follow-up approaches used by

youth-focused HIV organisations and Sport for Development organisations in particular?

2. Which approaches appear most effective and what are the circumstances associated with effectiveness?

3. In regard to the different stages of HIV counselling and testing (HCT):

- What types of partnerships are required to ensure effective service delivery?
- What process and actions need to be in place at each stage to ensure the realisation and protection of young people's rights to health, information, care and support, and participation?
- What are the effective systems needed to refer people to long-term treatment and counselling?
- What are the ethical considerations and how well are these addressed? Is the decision to get tested a voluntary decision in the hands of young people themselves?
- What post-testing monitoring of stigma, discrimination, mental health and social concerns is in place?
- How do these approaches link to the relevant legal framework in any given country?

2 Methodology

2.1 Participating organisations

The research took place in four countries, namely South Africa, Lesotho, Zambia and Malawi. The principle of maximum variation was used in selecting organisations, aimed at covering the broad range of SfD programme-types as well as the kinds of HIV and AIDS services offered by such organisations.

Sport for Development non-governmental organisations (NGOs) were identified through online search engines, snowball-sampling from known SfD organisations, referrals from local contacts in the respective countries, and recommendations by Comic Relief and UK Sport.

Organisations sought for inclusion in the study use football (soccer) or other types of sport to promote health, social change, and youth empowerment; promote life-skills education (in school and or communities); communicate messages about HIV; and promote or offer HIV counselling and testing (HCT) to young people in their programmes. Appendix 1 provides further details of the ten organisations included in the research as well as a summary of the services they offer to young people.

Six of the participating organisations offer informal and semi-structured life-skills programmes, while four organisations offer formalised life-skills education ranging from five to eleven modules facilitated during 45-minute to one-hour long sessions.

2.2 Engagement of organisations and recruitment of participants

Selected NGOs were contacted via telephone and email (see letter of introduction – Appendix 2), requesting their participation in the study. Those that agreed to participate were asked to facilitate access to participants, volunteers, staff and programme partners.

The study participants were recruited by host organisations in consultation with a CADRE researcher. Selection of participants was guided by the need to include a variety of people involved in managing and participating in programmes.

This included:

- managers/directors
- programme staff
- coaches/programme implementers
- HCT counsellors/medical staff
- programme beneficiaries
- community members

Programme beneficiaries were required to be 18 years and older, to comply with country child protection legislation. In programmes where beneficiaries were younger than 18 years, those under 18 years old were not interviewed; although their coaches, other staff and older youth provided some insight into their experiences. Appendix 3 provides details of participants per organisation.

CADRE researchers travelled to each country and spent a day with each organisation interviewing participants and observing programmes in action.

2.3 Data collection methods

Question schedules were developed for use in interviewing: 1) programme managers and coordinators; 2) coaches and other programme implementers; 3) programme participants (see Appendix 4).

Participants were interviewed individually or in groups, depending on circumstances. The following formats for interviews were generally used:

- Individual interviews with programme managers and senior staff
- Individual interviews with HCT counsellors and medical staff
- Group discussions with programme implementers and coaches, as well as with some programme beneficiaries
- Individual interviews with programme beneficiaries.

Interview times varied between 30 and 90 minutes. With consent from participants, all interviews were recorded using a digital recorder and written notes were taken during interviews.

Wherever possible, community members were also approached for informal conversations about their perspectives on programmes. This was, however, limited by time constraints.

Some telephonic interviews were held with particular South African organisations to learn about their models of HCT provision and ethical practice.

2.4 Fieldwork processes

Organisations agreed to recruit participants for interviews and group discussions in advance of each field visit. This allowed the researcher to spend an entire day speaking with project management, participants and partners. Despite some difficulties in scheduling and the availability of key people, in most cases the range of participants provided sufficient information for building an understanding of the key issues of concern.

Organisations were provided with a small monetary token of appreciation for devoting time and resources to planning the visit and accompanying the researcher during fieldwork.

The two fieldworkers are both formally trained social workers as well as social researchers.

2.5 Limitations of the study

Although the background review and fieldwork indicated that the range of organisations included in the study sample reflected a range of SfD programmes, it is possible that including other organisations with different implementation contexts may have provided further or richer insights into some of the issues discussed in the report.

It should also be noted that this study was conducted in a Southern and East Africa context, and so should not be generalised to other contexts and regions of the world. The countries included in the study are all experiencing mature generalised HIV epidemics; and introduction of HCT into SfD programmes is generally seen as a contribution to national AIDS control efforts. In countries with more localised epidemics the social and health service milieu may well regard the introduction of HCT into youth development programmes in a different light.

The study period of November to January proved problematic as some of the organisations did not operate their programmes at full strength during this period. The researchers were not able to witness the programmes in action in all cases, and in some visits there was limited opportunity to speak to programme partners and participants.

The researchers steered clear of exploring very sensitive issues with participants and did not include participants under the age of 18 years due to challenges of obtaining consent from parents or guardians.

3 The use of HCT in SfD programmes

3.1 History of HCT

Voluntary Counselling and Testing (VCT) was introduced as early as 1985 as both a prevention strategy to mitigate the spread of HIV and an entry point to HIV treatment and management.¹ The term 'voluntary' implies that counselling and testing is initiated by the user of the service. The term VCT is still used in some countries, but it is gradually being replaced by the term HIV Counselling and Testing (HCT). This makes room for provider-initiated counselling and testing (PICT), meaning that people seeking health services for reasons completely unrelated to HIV may be advised to undergo an HIV test even when they have not requested it. It also allows for more active involvement of health services in promoting and encouraging testing. The reality is that the terms are often used interchangeably, although 'HCT' is the more inclusive term. The term 'HTC' (HIV testing and counselling) and should be regarded as synonymous with HCT.

In Africa, the magnitude of the HIV and AIDS pandemic was realised in the early 1990s and governments, civil society organisations and international aid agencies have, at different rates and scales, developed policies and guidelines to mitigate its impacts and support prevention, treatment and care.² HCT has been one of the cornerstones of HIV and AIDS response, although only in the last six to eight years have there been country-wide drives for all to know their HIV status.

This development has resulted in much innovation in promoting and implementing HCT. However, although knowledge of HIV status is unquestionably important in relation to treatment and care, questions about the prevention and behaviour change effects of population-wide testing drives have been overlooked and remain partly unanswered.

3.2 General HCT strategies and innovations

The HCT policy environment

Most countries in East and Southern Africa have aligned their HCT policies with international policies on HCT, and HIV care and support. This has created an enabling environment for organisations in this sector, as there have been policy guidelines to follow. However, this is certainly not the case in relation to all forms of HCT; for example, HCT for couples and families, and support for self-testing. These areas have received little development of policy and clarity about standards of practice, although this is needed. In some cases there are training and implementation guidelines but national policies have not yet been adopted; for example, in relation to guidance on HCT for sero-discordant couples.

Multi-country data³ reported in 2008, shows that nearly 90% of countries had national counselling and testing policies. By 2008 there had been a significant shift towards provider-initiated counselling and testing (PICT), with health workers encouraged to propose counselling and testing to everyone regardless of presenting symptom and type of facility. This trend looks set to continue with policies giving greater attention to PICT.⁴

Where repeat population-based surveys have been conducted, the proportion of both women and

¹ Urbina & Galatowitsch (2008)

² UNAIDS (2009)

³ Source – 119 countries reporting.

⁴ WHO (2009)

men having an HIV test and receiving their results has increased dramatically in the period 2003 to 2008.⁵ However, according to a 2010 progress report released by the United Nations Children's Fund (UNICEF), UNAIDS and the WHO, the median percentage of people in sub-Saharan Africa living with HIV who are aware of their serostatus is below 40%.⁶

There appears to have been considerable expansion of the ways of providing HCT and the types of organisations that are providing services⁷; especially since the advent of rapid test technology which has simplified HCT implementation. Without the need for laboratory testing, there has been opportunity to extend the distribution of HCT. The introduction of mobile HCT has followed the use of rapid testing and this has attenuated the major structural barrier to testing⁸, which was the unavailability of local testing and failure to return for test results.

The WHO/UNAIDS guidance on provider-initiated HIV testing and counselling in health facilities issued in 2007, defined the conditions under which testing would be offered and conducted at health facilities, as well as the key elements designed to ensure that individuals' rights would be respected.

PICT has been widely rolled-out in the context of prenatal care, and increasingly through mobile testing units, including in workplaces and in people's homes. This progress has been especially evident in sub-Saharan Africa. In addition, there has been a move towards community-based modalities for testing and counselling, such as through mobile, home-based or door-to-door outreach; usually employing rapid HIV testing methods. SfD organisations have capitalised on this and it has provided the opportunity for them to include HCT in the context of their HIV awareness programmes, through a range of HCT mobile service providers.

Across southern Africa, women and adults access voluntary counselling and testing (VCT) at higher rates than men and youths respectively⁹ and the introduction of mobile and community-based HCT. This has meant reaching population groups often missed by health facility-based services, through providing more easily accessible and convenient locations. These groups include men, women who are not accessing reproductive health services, young people, rural populations with poor access to health care, ethnic minorities, and populations most at-risk.

Assessing the effectiveness of these services is critical, as they represent a substantial departure from the regular approach as exemplified in HCT guidelines. There has been little documentation of policies for mobile HCT services at country level, and it is evident that there has been much innovation at the level of motivating, incentivising and using available opportunities to reach populations. Innovation in an area as psychosocially sensitive as HCT should raise concern about fidelity to adequate ethical and practice standards. International guidance in these areas would create a more enabling environment with greater adherence to ethical and practice standards. Concern has been expressed at a high level about the availability of counselling and care services¹⁰ that need to be available to ensure that HCT achieves its desired outcomes. These concerns are of direct relevance to SfD organisations, especially those using tournament testing approaches.

This raises a number of questions which have not been satisfactorily addressed to date. There has been remarkably little work aimed at assessing the quality and outcomes produced by different models of HCT service provision and the management needs involved, even if only hosting HCT that

⁵ WHO (2009)

⁶ WHO (2010)

⁷ Menzies et al. (2009)

⁸ Morin et al. (2006)

⁹ Kaufman (2010)

¹⁰ WHO (2010)

is externally provided.

There has been little research on standards of practice, or analysis of the forms and adequacy of networks and community engagement processes in support of community level HCT. There is a need for ongoing empirical research as HCT services expand and diversify, in order to understand the achievements of the expansion and diversification of services and service providers; but also the risks.

SfD organisations offering HCT need to have management capacity for quality control and ethical oversight. They need to know how to work in partnership with other health and social service providers in efficient ways, and think carefully about the limits and extent of their responsibilities to those they expose to HCT.

Approaches to HCT

Diverse client- and provider-initiated strategies have been used to scale up HCT.

Variations include HCT for couples, client- and provider-initiated models, mobile services, HCT integrated into marriage preparation, group HCT, and HCT as part of comprehensive support for HIV-positive expectant mothers. Appendix 6 outlines a number of models of HCT, their current status and considerations that must be made before each model is adopted.

The diversity of HCT models is appropriate given the need to reach to different populations and circumstances. Whereas there are recognised challenges in applying universal standards across different implementation settings, the need to adapt HCT practices in different settings is widely accepted. There is need to tailor HCT models to ensure: a) accessibility - e.g. language, geography and transport; b) effectiveness, defined variously as behaviour change for HIV prevention, take up of treatment for HIV-positive outcomes; c) scale – high proportion of those that need services receiving them; and d) cost efficiency – value along with affordability and sustainability.

For example, the success of provider-initiated HCT in Botswana, Lesotho and South Africa is based on the premise that it cuts transport costs for clients who are offered services in primary health care facilities rather than at dedicated HCT facilities, resolving an issue which has been identified as a major barrier to HCT in these regions. Similarly, mobile HCT in Uganda facilitates the reach of remote rural areas that would not otherwise be reached with services. There are various models and innovations besides this for targeting specific populations with the premise of maximum coverage and minimum disadvantages.

Evidence indicates that the uptake of client-initiated approaches is limited largely due to fear, stigma, underestimation of personal risk, negative reactions to disclosure, limited access to treatment and care services, and gender inequality.¹¹ This has led to increasing emphasis on provider-initiated, incentivised and targeted HCT campaigns; and much adaptation of HCT models to suit circumstances in keeping with social, cultural, economic and religious contexts.

Such adaptation has in part led to wider uptake of HCT. For example, it was found in Uganda that 70% of the population expressed a desire for HCT, but only 15% accessed it. The reasons for not seeking HCT were associated with the distance and travelling costs to HCT clinics, having to return for the results in instances where rapid testing was not used or where fully-equipped mobile HCT sites were not used.¹² Interventions to deliver door to door HCT increased HCT uptake from 10% to 37% in rural Uganda because it overcame problems of transport, stigma and breach of confidentiality at health centres. Similarly, Lesotho adopted a door-to-door HCT campaign which

¹¹ WHO (2008)

¹² Morin et al. (2006); Menzies et al. (2010); Nglazi et al. (2012)

failed as it was not equipped with adequate infrastructure and enough qualified counsellors. However, routine HIV testing did increase HCT uptake in the country.¹³ These studies represent a limited reflection of a large number of interventions in different countries and types of context, that have been undertaken to increase reach, efficiency and interest in HIV testing and counselling services.

Research has pointed to the need for a range of models of HCT to suit different populations and settings.¹⁴ However, there is an important challenge beyond improving reach, convenience and efficiencies in terms of cost and reach of services. Services must be shaped for the ultimate purposes they are intended to serve, rather than the narrower purposes of maximising numbers of people tested and containing costs.

It has been found that adding mobile HCT to existing stand-alone HCT is a cost-effective approach for expanding HCT coverage to reach different target populations, including young people, and for identifying persons with newly diagnosed HIV infection for referrals to treatment and care.¹⁵ This research shows that mobile HCT reports a higher proportion of clients than are found in stand-alone facilities who have: no prior HIV test, higher levels of HIV-exposure risk, lower household expenditure for women, more instability of income sources for men, and who cite distance to testing as a reason for not previously testing.¹⁶

There may be some risk of watering down the counselling aspects of HCT in favour of reaching large numbers of people. Rapid test kits have become widely available, allowing on-the-spot diagnosis of HIV infection. This has done away with the most important barrier to HCT; people not returning for their test results before they could be communicated in on-the-spot. Also, mobile testing units have enabled taking HCT to people in community settings, workplaces, education institutions, mass gatherings and other contexts. This has greatly increased access.¹⁷

However, there has been some loss of emphasis on, and possibly appreciation of, the theory of change that qualifies HCT as a component of HIV prevention. Pre- and post-test counselling are both important in determining the HCT prevention outcomes discussed above. There has been almost no research on whether mass roll-out of HCT has compromised the intended theory of change. Anecdotal evidence of very brief counselling times suggests that HCT may be implemented in some contexts in ways that undermine the opportunity to properly understand HIV prevention prospects and challenges. In South Africa in 2002, even before the advent of rapid testing, average length of post-test counselling was 20 minutes¹⁸; suggesting that what was considered as counselling could not have been much more than an information session.

Questions need to be asked about what the adaptations of HCT mean at the level of prevention outcomes; themes which will be picked up on later in the study.

Incentives and event-based HIV testing

Empirical evidence¹⁹ suggests that incentives improve HCT uptake.

Incentives have been shown to increase likelihood of people returning to receive their HIV test results where rapid testing is not available. A Malawian field experiment showed a marked increase

¹³ Menzies et al. (2010); Ministry of Health and Social Welfare, Lesotho (2009)

¹⁴ Menzies et al. (2009)

¹⁵ Grabbe et al. (2010); Ostermann et al. (2011)

¹⁶ Ostermann et al. (2011)

¹⁷ WHO (2009)

¹⁸ Magongo et al. (2002)

¹⁹ Thornton (2005); Kranzer et al. (2012)

in the likelihood of people returning for results even with a very small monetary incentive.²⁰

It has been shown that incentives tend to draw in people who tend to otherwise not use HCT services. A South African study among unemployed men found a higher HIV-prevalence among men accessing incentivized mobile testing, compared to men attending non-incentivized mobile and clinic-based services. Another study found that incentivized mobile testing services may reach more previously untested men and significantly increase detection of HIV infection in men.²¹

Incentivisation led to higher proportions of newly diagnosed HIV infection than was the case in non-incentivised settings. This suggests that incentivisation improves the likelihood of people with HIV undergoing testing. It was also found that incentivisation draws higher proportions of first-time testers. Compared with routine voluntary HCT available at clinics, selection and invitation, in combination with incentives, doubled the yield of newly-diagnosed HIV infections and increased the yield almost fourfold of individuals needing antiretroviral therapy. This may be an important strategy to increase community-based HIV diagnosis and access to care.

Many countries have introduced HIV testing weeks and specific campaigns which are advertised through mass media and locally. Such campaigns have worked to increase the number of new people testing as well as to encourage retesting. However, many questions remain unanswered about the quality and circumstances of testing, about people's preparedness for testing, about the quality of support and referral following mass testing events, and about the outcomes of this testing where the key emphasis from the service providers' point of view is high numbers of participants.

Other experimental studies²² show that incentives mask the stigma that is associated with HIV and testing. Incentives may give people 'legitimate' reasons to test, especially if the community perceives testing or the desire to test as suspect behaviour.²³

There have been a number of programmes that use incentives to encourage people to know their HIV status; for example, a popular newspaper in South Africa ran a competition to encourage HIV testing and a health insurance company²⁴ provides incentives to its members to get tested. In another instance in South Africa, members of the public were given free access to a music concert if they underwent an HIV test.

As is the case with adaptations in modes of HCT service provision, there may be risks in incentivisation; and ultimately the value proposition in HCT involves an opportunity to develop more effective HIV prevention skills and behaviours, and to seek treatment. Effective prevention outcomes require development of active agency for HIV prevention. There is some chance that over-incentivising HCT, or not creating a sufficiently serious and reflective environment for HCT, may run counter to the underlying theory of change.

These concerns are of direct relevance to SfD organisations, especially under tournament testing conditions, where the atmosphere is pervaded by a generally festive mood; and where there is strong encouragement to test. It must be said, however, that those who have undergone thorough preparation for testing in preparation for the tournament, would not be subject to the same risks. The problem is that service providers tend to use the opportunity of large numbers of people gathered for the event to opportunistically engage people. The key issue in SfD tournaments is the appropriateness of the contexts

Discovering one's HIV status without adequate preparation and in a social setting may be unsettling

²⁰ One-tenth of a day's wage

²¹ Nglazi et al. (2012)

²² Muthoni (2011)

²³ Downing et al. (2001)

²⁴ Geffen (2011)

and traumatising. There has been little to no research on these issues to this point, but it is known that discovering one's HIV status even in health service settings can be traumatising and lead to lasting negative outcomes²⁵, with both personal and epidemiological significance.²⁶ For these reasons, even though incentivisation increases HCT uptake it should be used cautiously so as not to undermine adequate preparation and mitigation of trauma required after discovery of one's HIV-positive status.

Supply-side factors known to facilitate HCT demand in young people

Literature on health-seeking behaviour²⁷ points to the following as some of the reasons why young people do not attend HCT at health facilities:

- Fear of being judged or reprimanded for engaging in sex
- Being seen by community members at these facilities induces HIV-related stigma
- Suspicion that health workers are not likely to maintain confidentiality
- Lack of youth-friendly services aimed specifically at the needs of young people.

For these, and possibly other reasons, young people often seek sexual and reproductive health (SRH) services or information through a variety of alternative sources to government health clinics, such as private clinics; pharmacist; peers; and in some countries, through traditional healers.

Community-based HCT has proved to significantly enhance community uptake of HIV testing for the first time, and it also proved much more likely to detect HIV cases than standard clinic-based services. Community-based services also proved to improve repeat testing. Community-based services involved mobile HCT, community mobilisation and community-level post-testing services.²⁸

There is no ideal HCT model for reaching youth;²⁹ nevertheless, there is a body of literature that identifies desirable features of Youth-Friendly Health Services (YFHS):³⁰

- There should be participation of young people in decision making, planning and delivery of services.
- Services should be free of charge.
- Service should be able to provide same-day appointments to drop-in visitors, and must accommodate the needs of male and female users.
- Services should be accessible to young people in terms of location and time of opening; including dedicated service sites at general facilities such as 'youth-friendly corners' at clinics and freestanding HCT sites.
- Service providers should guarantee privacy, maintain strict confidentiality, emphasise informed consent and voluntary participation, and provide mandatory pre- and post-counselling; in keeping with country guidelines and child-protection laws.
- Service sites should accommodate needs for discretion and confidentiality and avoid situations where accessing HCT or other HIV and AIDS services involves separate queues or waiting rooms.
- Service providers should be 'in touch' with youth cultures, trained in youth-friendly

²⁵ Obi & Ifebunandu (2006)

²⁶ Kelly et al. (2008); Young (2011)

²⁷ Horizon (2001); Klepp et al. (2008)

²⁸ Sweat et al. (2011)

²⁹ Boswell & Bargaley (2002)

³⁰ YouthNet, (2002); HIV Prevention Now (2002); UNICEF (2001)

approaches to communication and counselling, non-judgemental about youth sexual activities, and should be selected for having personal characteristics and interpersonal skills which make youth feel comfortable discussing personal issues and concerns related to sexual and reproductive health.

- Education should be innovative, creative and participatory, and enjoyed by young people; incorporating activities that youth engage in (e.g. drama, sports, music or competitions).
- Services should be accompanied by community mobilisation to increase understanding of young people's health needs.
- Recruitment for services should incorporate peer-education through community outreach, clinic-based educators, and possibly incentives to ensure participation and motivation.
- Services should incorporate post-test support and information services for anyone having undergone a test, and should be geared for referral to treatment, care and support programmes. Referral services that should be available include: capacities to provide CD4 count measurement, ART provision and support, and management of sexually transmitted infections. Facilities should be part of functionally integrated networks of service providers to provide access to sexual and reproductive health commodities such as condoms and contraception; as well as psychosocial support services such as on-going counselling, support groups and education.
- The youth-friendly services approach is frequently coupled with, or embedded in, programmes for youth development and empowerment, and life-skills education. Some of the desirable features mentioned above are challenging for small organisations without adequate facilities and experience in providing SRH services. There is inevitably some risk that provision of HCT is not done in optimal ways, potentially eroding its efficacy.
- There is especially cause for concern in programmes where HCT is externally provided and there are limited possibilities for follow-up, treatment and support for young people who have been encouraged to test. Mobile services are less likely than permanent local services to understand local service networks and to assist in seeing referrals through when there is uncertainty and perhaps resistance. Further, while testing has benefits for HIV prevention and treatment, consideration needs to be paid to the on-going responsibility that organisations have to young people, as well as how these services intersect with country child protections laws.

These concerns have a strong bearing in regard to the increased tendency over the past few years for sports for development (SfD) programmes to engage in promoting and providing HCT and other SRH services. The general logic of intervention of their engagement is sound. Young people respond better to services offered in places they frequent, it cuts the cost and 'hassle' of young people searching for HCT and SRH services, and it promotes early detection and treatment of HIV and sexually transmitted infections (STIs) among youth.

3.3 HCT models and innovations in SfD programmes

With the increasing need to address HIV and other social and economic challenges facing youth, SfD organisations have evolved over time to include HIV prevention programmes; life-skills programmes; and more recently, HCT services targeting youth.

All of the SfD programmes visited by the research team offered HCT; using sports as a medium to engage young people in HIV prevention. SfD programmes are conducted in schools, community centres and recreational clubs, and use local coaches and volunteers to implement programme activities.

Whilst HCT services have been available in many communities through mobile services or health service facilities, they have not traditionally been targeted specifically at youth, nor connected

specifically to HIV and SRH education programmes. In keeping with national and international strategies, which have positioned HCT as one of the cornerstones of HIV response, SfD programmes focused on life-skills and HIV education among youth have been extended to include HCT in a range of ways. They have generally adopted HCT as a part of the services they offer to you, on the understanding that HCT is an entry point to prevention, treatment and care.

Members of SfD programmes provided the following responses to questions about why it is important for their organisations to offer HCT.

- 1) Young people respond better to services offered in places they frequent.
- 2) SfD programmes have contacts with large numbers of young people that are otherwise difficult for HCT providers to target.
- 3) There is a natural flow and ease of introduction of HCT since SfDs already engage young people in HIV awareness coaching.
- 4) SfD organisations cut cost and ‘hassle’ to young people searching for HCT services.
- 5) HCT personalises HIV education; and promotes care, treatment, support and prevention.
- 6) HCT promotes detection and treatment of HIV and sexually transmitted infections (STIs) among youth.
- 7) HCT connects people to health service sites and creates pathways to utilisation of existing services.
- 8) The counselling component of HCT helps to identify psychosocial support needs in the lives of young people as well as of friends and family members they express concern about, and the HCT process provides a context for referral to relevant support agencies and opportunities.

A general challenge that HIV education programmes face is ‘HIV fatigue’ or a dampened interest in engaging with information on the disease brought about by the current generation of youth’s prolonged exposure to HIV prevention messaging. In order to break through the resignation youth have towards engaging with issues around HIV, SfD programmes have had to find novel and innovative ways of communicating prevention messages.

A common notion expressed during our fieldwork interviews was that it is helpful to use activities that youth enjoy to attract young people to HIV education programmes. In the case of SfD programmes, sport activities and other forms of play are used as vehicles for delivering healthcare information to youth in a way that is more appealing than other types of messaging they may have previously been exposed to.

This may under-represent the real value of SfD innovations. Certainly SfD organisations do educate about HIV/AIDS and related issues in ways which steer well-clear of the ‘lessons’ and ‘warnings’ that have characterised some classroom-type HIV education. But their contribution represents a different approach altogether, beyond representing information in new ways; and much can be learned from the social learning approaches that have evolved in SfD programmes. Some organisations have engaged experts to assist in developing, testing and refining their approaches whilst others have evolved their methods through learned experience.

The concern here is to focus on HCT in particular, aiming to understand how SfD programmes have used HCT as a component of their broader efforts aimed at youth development and HIV/AIDS education.

In some respects, and this was the case in all organisations visited in the course of this research, the culmination of the learning process which young people go through when they participate in SfD HIV/AIDS programmes involves participants knowing their HIV statuses. It is a significant achievement that SfD organisations have proved to be effective channels for facilitating HCT in the

population category least likely to undergo testing; youth aged 16-24.

However, following the discussion of HCT prevention efficacy above, the provision of HCT in SfD programmes raises many questions about whether the specific context and different ways of providing HCT services are in fact contributing to the greater purpose of HCT. It is also important to ask whether the ways of presenting HCT as a service have been ethical.

Reach of HCT services facilitated by SfD programmes

Whilst a few SfD programmes do record the number of people tested in their programmes, most programmes don't systematically collect testing figures because their HCT is conducted by external service providers that don't specifically report back to the SfD programmes on HCT delivery statistics and test outcomes (see Chapter 6 – Monitoring, evaluation and research).

It is not possible to estimate the overall contribution of SfD programmes to HCT service provision nationally or regionally, or to appreciate what contribution SfD programmes are making to young people knowing their status and enrolling in treatment and support programmes.

In terms of numbers tested, one large multi-country organisation³¹ accounted for over 16,000 tests in four years, and tournament testing may cover a few hundred people in one day. The opportunity for scale is clearly offered by the model of tournament testing and SfD programmes are proving successful in the challenge of engaging young people in testing.

There is both a data need and a need for onward service provision planning.

Data is needed about the scale of HCT being provided by SfD organisations, the unit costs of providing HCT services, the effectiveness of the preparatory methods leading to HCT in achieving prevention outcomes, and the effectiveness of referral systems.

HCT practices in SfD programmes

While pre- and post-test counselling is a constant component in all approaches to HCT, the setting and context of care and support varies across programmes.

Rapid diagnostic tests are used at all events, and immediate referrals are made for individuals testing positive

SfD organisations have incorporated or associated with HCT services in a range of ways. They typically do not provide HCT themselves, but facilitate access to HCT through relationships with external service providers, while conducting youth development activities and HIV education as their main business. The overall model fits most closely with the 'youth centres' model presented in Appendix 6. However, a closer look at how organisations actually provide HCT in practice reveals that SfD programmes generally provide HCT in one of three main ways: 1) tournament testing; 2) health information centres; and 3) comprehensive health centres. These are discussed below with a view to understanding their relative value and what each means for the prospects of HCT as an aspect of HIV-prevention behaviour change, as well as access to HIV treatment, care, support and impact-mitigation services.

1. Tournament testing

SfD organisations tend to promote HCT as a key component of programmes rather than an end-point; although HCT often takes place during the sports tournament that is staged at the end of the programme.

³¹ Kaufman et al. (2010)

The actual HCT service is offered by partner organisations in the form of mobile testing services or walk-in centres. In many cases the HCT service providers are invited to mass sporting tournaments where HCT is then promoted and carried-out. The onus of referral for further counselling, treatment and care lies with the organisations offering HCT at these events. Often referrals are made to partner organisations and government health institutions.

All of the organisations covered in the field visits facilitated mobile HCT services at sports events or tournaments, often utilising several different service providers that conduct HCT and provide other health information. Sports tournaments are seen by SfD organisations as an effective way to disseminate information about HIV and AIDS to large numbers of people. In addition to the mobile services, some SfD programmes also offered more permanent HCT services on their own premises, often partnering with service providers to do so.

Truncated HCT procedures

The quality of pre- and post- test counselling in tournament contexts is lower than in other testing environments. It is often too brief to accommodate in-depth exploration of the underlying motivation for young people to test and the behaviours that have placed them at risk.

The accessibility of HCT in the open environment of a sports tournament was said to contribute to what some discussants saw as the normalisation of HIV testing, making it *'less of a big deal'*. Several described a sense that it is becoming more customary and that people feel *'proud'* after testing. Another informant explained that *'it's easy for people who come to sports events to test'*.

On a more negative note a high demand for testing at tournaments and limited available staff results in the number of people tested being prioritised over the quality of pre- and post-test counselling.

Another concern relates to testing outcomes and responsibility. While a hosting sport organisation may convene an event that promotes HCT, it appears that their responsibility towards anyone who may discover that they are HIV positive ends there. Most organisations explained that when someone tests positive, they will receive a referral slip to a government clinic and then it is up to the individual to access government services. If the testing organisation provides any HIV support services, they will provide such information.

Follow-up problems

There is generally no further follow-up by the SfD organisation following the tournament and it is up to the individual whether they follow referrals suggested or return to the HCT service provider; although the latter is often not from the same locality. Hosting NGOs tend not to assume responsibility when it comes to ongoing care and support for the young people and community members who test HIV positive at their events. This poses questions regarding the duty of care and allegiance to the idea of *'continuity of care'* from the point of a young person discovering their HIV status.

An additional concern arose that all organisations providing HIV service at a tournament should ideally give uniform information and messages about HIV. One NGO described how typically a variety of SRH and HCT provider organisations will assist at a tournament, but may not partner closely with other organisations or follow the same procedures.

Competition among NGOs was also identified as a concern. When multiple service providers are present at a tournament, it was reported that some individuals will test with several organisations in order to receive each available incentive. Two organisations have concluded that when incentives are not available, HCT uptake is much lower, indicating that incentives played a large part in HCT uptake at these events.

There is also competition among NGOs to reach the greatest number of clients, which exacerbates incentivising. This also adds to pressures to prioritise the number of people tested over the quality of pre- and post-test counselling, onward referrals and continuity of care in the absence of staff and a supportive policy framework. One SfD staff member saw a need for greater collaboration among SRH and HCT service providers in order to avoid duplication of services in communities and tournaments.

Community mobilisation around tournaments can also be a challenge. Organisations sometimes fail to attract the appropriate audiences; for example, attracting young children rather than adolescents and young adults to events. This all means that tournament testing is not without detractors in SfD organisations and certainly the mass-scale of it creates by-products that need to be mitigated and worked around.

2. Health information centres

In addition to tournament testing, some SfD organisations offer regular HCT and family planning onsite through dedicated, static health information centres; as opposed to mobile services. Such centres typically offer limited services focusing on problem analysis and appropriate referral to other, more specialised services. They will offer HCT and SRH services, but not full clinic services. Such facilities usually have strong linkages to primary health institutions and organisations that provide HIV support for young people who test HIV-positive, and also make referrals to other agencies for family problems or welfare services.

The HCT services in such centres are sometimes manned by SfD coaches trained as HCT practitioners, but they are also often attended by external organisations that provide SRH services on site. In these cases, professional nurses and/or lay counsellors are employed to render the HCT service. Organisations may at times assign a volunteer, with the consent of the client, to follow up or support the realisation of the referral, but usually responsibility lies with the client to utilise the service they have been referred to.

These organisations offer HCT services on an ongoing basis and help to normalise testing among young people while also trying to make the HCT service more youth-friendly and accessible to those who want it. Such services are more integrated with SRH services, but they are more intensive and have much more limited reach.

3. Comprehensive health centres

In some cases, SfD programmes are based at primary health facilities, with the sport for development component having been added as part of their 'adolescent corner'/youth programmes. These programmes offer a range of health-related services using professional medical, as well as auxiliary youth development practitioners, employed to run the SfD components of the programme. Young people who access this type of service often have access to HCT, treatment for STIs, tuberculosis and antiretroviral medication. The sport aspect is often the outreach component of the programme, aimed at attracting youth to the health centre services and sometimes taking mobile services to other locations.

As above, the most significant problem identified is the limited consideration given to follow-up, treatment and support for young people who have been encouraged to test.

The onus of client follow-up is usually left to the individual, although in some instances clear attempts are made to connect the client and the referred to agency by communicating with both parties that a referral has been made. This is, however, a weak link in the process leading to HIV prevention and treatment. Much more consideration needs to be paid to the ongoing responsibility that organisations have to young people they bring to the point of testing, as well as how these services intersect with country child protections laws.

The benefits of tournament HCT are clear: it provides the opportunity for large-scale HCT, it engages

youth and communities otherwise not inclined or able to access HCT, it encourages the normalisation and de-stigmatisation of HCT, and it connects systematic HIV awareness and prevention to the value of HCT.

Challenges of mobile HCT facilities include the risks of no follow up after an HIV-positive diagnosis, confidentiality being breached and peer pressure for disclosure of one's status. However, sports incorporated into mobile HCT partly discounts these disadvantages as it can create a platform for peer support and stigma reduction which are less likely to be evident at standard health care facilities.³²

Overlaps often exist where organisations use sport as a vehicle to reach young people who would not otherwise readily use their services. For example in the Comprehensive Health Facility model, the primary focus is on medical treatment and support, but in an attempt to include young people in healthcare delivery, government and civil society partnerships offer decentralised youth programmes in communities with the aim of promoting the health services at the hospitals. Sport is then used as a container for popularising health, education and welfare among young people and the communities from which they come. In contrast, the Tournament Testers and Health Information Centres are primary youth SfD organisations that have evolved to include HCT and basic health initiatives to address the needs of the target population (See Appendix 3 for a detailed SWOT analysis of these models).

Creating mutually beneficial organisational linkages for youth SRH and HIV services

Interviews with SRH and HCT service providers to young people involved with SfD organisations revealed that they valued the opportunity to work together. They welcomed the facilitation of access to young people which was otherwise a challenging population to reach.

A health practitioner from one such organisation further explained that since young people often delay accessing SRH services, utilising sport as an entry point increases the accessibility of clinic services to this population before problems develop. Also, when a young person who participates in recreational programming encounters an SRH issue, they know that help is available and are more likely to access it.

The inclusion of HCT services in Sport for Development programmes has generally been part of a broader initiative to establish youth-friendly SRH services, increase accessibility of SRH services to young people, promote a culture of HIV testing, support national government campaigns promoting testing as both prevention and entry point into treatment, compete for aid, and meet donor expectations for new programme directions.

Advocacy by stakeholders and role players, has led to the initiation of youth-friendly HCT services in state-owned clinics and hospitals, 'adolescent corners' in SRH facilities and other innovations which increase the reach and appeal of services. However, development processes have been slow and have often faced challenges. While there have been many successes in the introduction of youth-friendly health care services, codes of ethical conduct for services to youth and child protection rights have been haphazardly implemented, often to the detriment of young people seeking health services³³.

Before the insertion of HCT into SfD programmes, some SfD organisations had little interaction with government health agencies. The introduction of HCT, which is largely driven by national policies, has provided an opportunity for SfD programmes to build stronger links with government agencies

³² Kaufman et al. (2010)

³³ More is said about this later.

that support HCT programmes. The preparedness of Sfd organisations to engage in partnerships around SRH and HCT has resulted in a greater recognition and formalisation of the role of Sfd organisations as well as an improvement in the general support given to Sfd organisations by government.

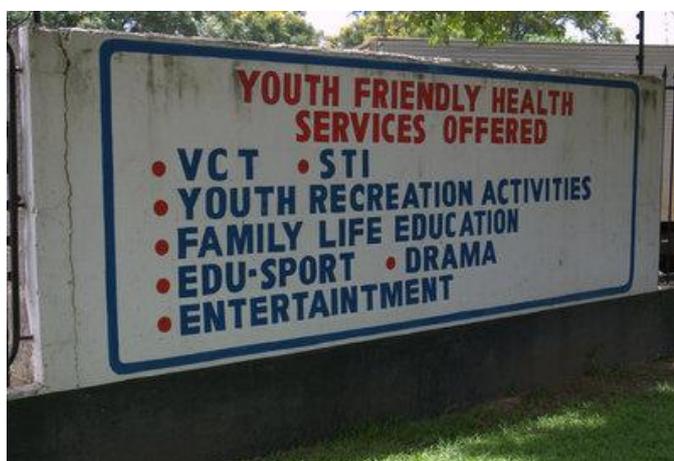
Elements of 'youth-friendly HCT'

Some of the programme models aimed at providing 'youth-friendly' testing services by revising certain aspects of more generally available services. SRH organisations felt that making clinic and HCT services more youth-friendly improves access to and utilisation of SRH services by young people.

Youth-friendly testing services were described as non-judgmental, non-coercive, and confidential. One might expect these qualities to be present in any HCT processes but the perception was that this was not always the case. Typically counsellors at general health service sites were perceived as having judgmental attitudes towards clients, often failing to keep their information confidential. In contrast, effective HCT counsellors at youth-friendly services were described as being empathetic and able to establish rapport with their clients, helping them to feel supported.

The term 'Youth-friendly' does not necessarily imply that services are provided by young people but a number of organisations do in fact utilise youth peer-counsellors in order to make the experience more friendly and comfortable.

One nurse working at a youth-friendly facility felt that youth peer-counsellors are better able to relate to young clients than older counsellors. She was in her 'thirties' and felt close-enough in age to the youth she worked with to understand their worlds and establish good rapport with them; something she believed they appreciated and responded positively to.



Youth friendly services

An interesting model found in one of the countries under study was the partnering of an international SRH organisation with a Sfd organisation to establish a small clinic at the main Sfd project site, where young people regularly gather. They offer a range of SRH services targeting youth aged 16-24, including family planning, STI screening and treatment, PAP smears, medical male circumcision referrals, and pregnancy crisis counselling. A nurse explained that the services are much more readily used than local general clinics. They are encouraged to make use of the services. This is because they are located near where young people gather and services are specifically oriented to the needs of young people. Also important to young people is the need to avoid public scrutiny when attending a public clinic, and negative judgements that they could experience at the public clinic, in being seen as in need of reproductive or sexual health services.

However, this has come with the bias that sport in many contexts is largely dominated by boys and young men rather than girls and young women. Sport programmes that have been offered in Sfd programmes are dominated by previously male sporting codes such as soccer and basketball, while girl-friendly codes have lagged behind. Organisations have generally recognised these problems and made attempts to remediate them; for example, through introduction of games that are mixed in gender terms, introduction of more popular women's sporting codes such as netball and volleyball

and introduction of previously male sporting codes for females. However, the bias towards males remains a challenge in some organisations.

This problem is especially important given that HIV risk and incidence is much higher in young women than their male counterparts and in almost all countries the gap between male and female HIV prevalence rates only begins to narrow in the mid-twenties.

Promotion of HCT

The research revealed a number of strategies that sports and SRH organisations involved in SfD HIV/AIDS programmes use to encourage people to test. These include:

1. Youth counsellors providing HCT

Two organisations offer young people a choice of whether to speak to a youth or an adult counsellor, recognising that some prefer to test with someone older than them, while others may find it easier to talk to someone closer in age with whom they can relate. Providing both options was seen as positive.

2. Integrating HCT at all levels of the programme

One organisation promotes HCT in all aspects of the organisation's functions. Messaging about the value of knowing one's status is integrated into different activities, such as the mid-activity 'ten minute talks'. The unit also provides mobile HCT tents at all games and drama group performances; HCT is not only a tournament activity or culmination point of a curriculum.

3. Discussions with parents and guardians

Especially in countries where adolescents cannot legally consent to an HIV test, some organisations have had success discussing HCT with parents and guardians in order to elicit their support.

4. Support to individuals undergoing HCT

A sports organisation that does not provide HCT explained how they sometimes have sessions where HIV and testing are discussed and promoted through games, and also on a one-on-one basis when there is reason to believe HCT is particularly needed. Young people are sometimes referred for testing and accompanied to the HCT facility if they wish this; and they are given opportunity afterwards to engage in conversations about the experience of the test, without specifically asking about the result.

5. Integrating HCT preparation as part of life-skills education in schools

Providing life-skills education in schools is a common programme model; and HCT is included as a component of the life-skills curriculum. It is put forward as a decision that one must make and that doing this is a competence. One organisation also runs workshops for teachers that address HCT, in order to empower them to share accurate information with their students and to appropriately encourage HCT.

6. Graduating through HCT

In some organisations where the SfD curriculum is offered in a school context as part of the school's tuition programme, HCT is offered at a tournament at the end of the six-week modularised programme, and young people see the HCT as a form of "graduating" from the SFD programme.

7. Celebrity support

Though not a large part of the programmes we visited, there are some programmes that have utilised local celebrities and sports stars to encourage and model testing.

8. Peer education after testing

In some programmes there is specific encouragement for people who test HIV-negative to enter peer-education programmes for further information, in the hope that an HIV-negative status can be maintained by developing good SRH behaviours through support following testing.

9. Orienting on positive futures

Some organisations have taken a broader approach to HIV prevention, focusing not only on abstinence, condoms and the concept of prevention, but also on goal-setting, career planning, and tapping into young people's talents in building positive and future-oriented aspirations that move beyond mere avoidance of risk.

Extending experience beyond the realm of SfD

As SfD organisations develop competence, linkages and understanding of key issues affecting youth in a context of HIV/AIDS, they are able to extend their influence. Their experience is recognised and opportunities arise to engage in supporting young people at broader levels than on the playing field or at the tournament. Although governments appear to have been slow to recognise the health and well-being assets that are nested in SfD organisations, they are gradually being recognised and their experience has, in some cases, led to opportunities for broader influence.

One SfD organisation manages the National AIDS toll-free helpline where people can phone in and receive immediate counselling from trained counsellors, referral to other resources or get linked to existing organisational programmes. People who phone in are asked for their details, which are captured on a client form and assigned to a community care worker for follow up. Young people who do not have access to a telephone can handwrite a letter to the organisation and post it. The letter does not require a stamp as the post office charges the cost to the organisation at the receiving end. Once the letter is received, the case is referred to a counsellor for a home visit, referral and follow-up. This is an effective way of getting young people to engage with the services in a non-threatening way with minimal cost implications for the young person.

Incentivising testing

Incentivising HCT at tournaments, health care facilities and youth friendly services has become common as a way of promoting HCT among young people. Incentives are often in the form of material goods such as caps, t-shirts, branded wristbands, lucky-draw entries, water bottles, points towards winning the sporting tournaments and/ or cash transfers.

Organisations identified the lack of intrinsic incentives and motivation to test among young people as being a major barrier to HCT uptake, and for this reason most have devised incentives to promote it.

Incentives may bypass the self-motivation to test. This motivation is an important element in the use of HCT as a behavioural prevention foundation. Incentivisation raises questions about the importance of personal motivations for HCT. The implicit theory of change in HCT is that the person has an interest in knowing their HIV status, as part of a trajectory of wanting to manage risk, feel better and live healthier. However, incentivisation and personal motivation are not mutually exclusive, and caution only needs to be exercised to ensure that testing is done with an appropriate mind-set and with a degree of seriousness befitting the purposes of prevention or treatment-seeking counselling.

Some organisations don't provide incentives for testing and expressed the view that while incentivisation may be a successful recruitment approach, it 'misses the point'. Youth from one such organisation felt that young people should assess their own risks and then choose to test, rather than because they were incentivised to do so; testing for the right reasons is seen as an achievement in itself.

Some incentivising organisations reported that incentivisation leads to repeated testing by individuals at different sites, or even at the same event where various services providers are present. However, this is not necessarily a major or unavoidable problem and concern about it may distract

from the more significant concern about personal motivation to test.

Another concern about incentivisation was raised by members of one organisation that offers wristbands to young people who test. The intention behind offering wristbands is partly for those who have tested to show to others that they have tested and thereby normalise and de-stigmatisate testing. There is anecdotal evidence, both this instance and elsewhere³⁴, that providing wristbands has improved uptake of HIV testing and this strategy has now been adopted by a fair number of organisations, including some international mobile HCT service providers. However, coaches in one organisation felt that the wearing of wristbands creates unhelpful intrigue, prompting the question: “You’ve tested, so I wonder what your status is?” Some felt that wearing a wristband to show you have tested is sometimes interpreted as a sign that ‘I am HIV negative’. It was not clear why this interpretation was justified - that is, why people who tested positive would not wear their wristbands - but young people seem to understand it in this way. It was felt that this stigmatises those who do not wear wristbands; moreover, it was believed by some to lead to heightened risk as wearing a wristband means ‘I am negative’ and invites HIV risk behaviour. Whatever the facts of the matter are, it appears that the incentive has become embroiled in the melee of everyday HIV/AIDS discourse to the point of having become more a part of the problem than a part of the solution.

A general point to take out of this is that caution should be exercised when it comes to using social signalling to shape behaviour around HIV/AIDS. In this instance attempts to create a positive norm, making it ‘cool’ or otherwise appealing to apply peer pressures, may improve uptake; but it may also create unhelpful interest in each other’s behaviour, which can have unpredictable consequences.

This anecdotal material should not be used as evidence to downplay the need to promote and encourage testing, but it does clearly point to the need for a cautious appreciation of risks regarding appropriate motivations for HCT that can be built on as part of HIV prevention.

Pivotal role of coaches

The involvement of coaches in programmes is seen as a fundamental step in programme success. Coaches often assume numerous roles as programme implementers, positive role models, supportive and caring adults for the youth, as well as reporting on programmes.

Some organisations indicated that they had a vigorous coach selection process as they believed that the ‘right’ coach was someone who was respected in the community, was a role model for positive behaviour, and was accessible and approachable for young people. Using the ‘diffusion of innovation’ approach, one could argue that organisations select coaches and volunteers based on their leadership qualities in communities. Coaches are trained as positive role models to diffuse the desired behaviour change and set trends for young people they come into contact with. Those young people are then vectors for diffusing innovations among peers. Although organisations do not explicitly state this, their programme models of using coaches as positive role models for young people have these effects.

Caring for coaches

While coaches play an integral part in delivering programmes, referring young people to services and supporting young people, coaches’ own psychosocial development and needs are often not addressed by the employing organisations.

In tournament testing organisations, HCT is offered through mobile services at mass sporting events;

³⁴ Marum (2008)

coaches often played an integral part in preparing young people for HIV testing. In many instances, coaches have the task of preparing their young people psychologically for testing at the tournaments as well as providing support after the HIV test. Some organisations have curricula which allow coaches to engage young people in conversations about HCT and what to expect during the testing process. In the case of one organisation, coaches mentioned that they had received very little training to cope with problems such as spontaneous disclosures of child abuse; disclosure of HIV status; and family problems that arose in the course of education efforts, motivation for HCT, or after HCT services had been provided.

On a more positive note, in trying to anticipate spontaneous disclosures about HIV status, child abuse or family problems, organisations mostly insist that coaches complete an internal referral form which is then sent to an external provider for medical attention, psychosocial support or any child protection services needed by the young person.

This raises concern about the training of coaches; the burden and responsibility given to them in managing such sensitive matters for young people is questionable, both ethically and in terms of their ability to make judgements on psychosocial care and support needs. It may well be the case that coaches are over-extended in terms of their preparation and training.

Coaches play an integral part in using positive peer pressure to get young people to test as well as mitigating the effects of negative peer pressure for young people who either chose to test or not test at these events. In some instances coaches would be the first people to go and test while the young people would follow suit in their assigned teams. This type of positive peer pressure may go a long way in allaying young people's concerns about testing but also poses an ethical dilemma, particularly among vulnerable and naïve youth who look up to the coaches and feel pressured to test. This compromises young people's right to self-determination and autonomy regarding their HIV status.

In Health Information Centres and Comprehensive Health Facilities, coaches provide information and encouragement for young people to access HCT services. However, their role is limited to providing information on the location and nature of services in the community rather than being actively involved in service provision. Two organisations identified the need to develop the coaches and programme implementers beyond their roles as facilitators and link-points; equipping them to more deeply engage with and support the needs of young people.

Preparation of coaches for their roles

While HCT is usually offered through professional external service providers, sport coaches play a vital role in motivating youth to utilise HCT services. They also tend to take a greater share of responsibility than the external service providers for linking young people, who have recently received HIV-positive test outcomes, with additional service providers. Sports coaches also tend to lead the provision of HIV education for prevention.

However, many organisations and coaches shared the view that the training they had received for their roles was merely to deliver the programmes and to refer any problems arising as a result of HCT to the testing organisation or other service providers in the community.

Where support programmes were located far from the organisation's office, coaches seeking support found accessing information and resources difficult because of transport challenges. This left coaches feeling alienated, isolated and exploited as they had been promised training and technical support but had received very little from the organisation.

The coaches felt that they were the first point of referral for programme participants and at times the referral process was long and bureaucratic, leaving programme participants feeling failed by the coach, the organisation and the referral services.

The lack of support for programme implementers is not unique to this organisation. Other organisations, that have young people assisting with programme and curriculum implementation, reported that although these youth sometimes lack the proper skills to carry out their work, there is limited provision for ongoing development, capacity building and support.

Questions about coach skills

The problem of ill-equipped coaches is compounded when the promotion of HCT forms part of programmes.

Coaches often do not have the skills and capacity to talk about HCT or provide follow-up once a programme participant had disclosed an HIV-positive test outcome, yet they often assume this role.

In all cases encountered, although young people (coaches) are not actively offering HCT, they felt that they needed basic counselling skills to be able to support programme participants who were interested in going for an HIV test or had gone for an HIV test and wanted further support. This training was needed more in cases where young people had disclosed their HIV-positive status to the coaches.

In addition, coaches often shared stories of their own lives to motivate young people to go for a test. In one case, a coach disclosed her HIV status to her team to motivate them to go for a test. Further, some coaches told young people that they were HIV- positive to the participants when actually they were HIV- negative. Whilst this was done with positive intentions and in the interest of motivating young people to test, it potentially discounts the realities of what an HIV-positive test outcome would mean. It also creates a dishonest and disheartening relationship between coach and young person where a young person who tests positive seeks support from their coach believing they can learn from his/her experience as an HIV-positive person.

Peer-educators for treatment adherence

SfD peer-educators are sometimes used as treatment adherence supporters or home-based carers. One community-based organisation uses peer-educators who have been trained by the hospital staff and lay counsellors to count ARV medication for other young people in the programme. These practices present a number of ethical and child protection dilemmas, namely:

- It is not clear how ethical considerations are dealt with when peer-educators begin to play a significant role in supporting treatment. Organisations seem to think that confidentiality is superseded by the need to get young people on treatment and adhere to treatment.
- It is not clear who the burden of care should fall to in situations where people fall through the cracks of conventional health care services, and community based organisations pick up the burden of care, even when they are not adequately equipped for this, and it is not part of their core mission.
- The use of volunteers also raises numerous ethical dilemmas in terms of who should know about the patient's status, how that person is trained to deal with their assumed role, and what measures are put in place in order to safeguard the interest of the client and volunteers.
- There appears to be little recognition of risks of vicarious trauma among peer-educators, who in some instances deal with complex problem situations with no easy solutions, and support for peer-educators and volunteers appears to have been afforded insufficient attention.

Linkages and management of referrals

- As has been pointed out in the literature review, HCT is often a stand-alone service and provision of services to walk-in clients poses challenges to the management of referrals. Since the outcomes of HCT relies in many respects on clients being referred and gaining access to the services of other organisations, the nature and linkages that exist between service providers is critical.
- This is all the more so in contexts where services are distributed across a range of providers each providing particular services – HCT, support groups, reproductive health consultation, syndromic STI treatment, PMTCT services, and so on – in different venues. The term ‘functional integration’ is apt here. It refers to integrating service delivery points to ensure a client’s continual engagement with service delivery systems, recognising that from the point of view of the service user, integration must primarily be around utility. This requires developing well-articulated referral networks and consistent norms and standards of practice across functionally-related services.
- Fieldwork showed some interesting linkages between SfD organisations and organisations that provide sexual and reproductive health (SRH) services; recognising and respecting where expertise resides elsewhere and developing pathways to access rather than aiming to provide it internally. One respondent described how it worked well to partner with local SRH organisations because “their specialty is testing, ours is sport”. A good relationship and cooperative agreements around provision of services were seen as a necessity; although the degree of formalisation and functionality around such relationships varies.
- Doubts about the degrees of functional integration of SfD services and other services are justified; especially when HCT is provided by mobile providers, who may not really understand the local service delivery networks. Similarly, SfD organisations often provide programmes at some distance from where they are based. When the tournament is over, they leave the area with little or no further contact with the young people that they have left at the point of providing HCT.
- Coaches often move from school to school and thus cannot offer long-term monitoring and support to every young person they have referred into the network of service providers, unless they live in the same area as the young person. Thus, the services they provide after HCT are limited to early support and attempts to encourage use of other services.
- The availability of other service providers and the adequacy of linkages is an important issue that has posed some limitations on service quality. The volume of young people tested can be overwhelming and in one instance 900 young people were tested over a two-day tournament period. The volume of people exceeds the capacity of organisations to manage referrals adequately and also means that follow-up is likely to be patchy and unsatisfactory.

Quantity versus value

Those receiving HCT at tournament events are not necessarily only young people who have participated in the coaching programme. Pressure to complete a large number of ‘tests’ on the part of HCT service providers leads to brief testing sessions and possibly loss of quality of counselling. This compromises the potential value of HCT for those young people that have been particularly prepared to undergo HCT as part of their ‘graduation’.

- Some SfD organisations have online tracking databases that they use to refer and monitor cases of referral between organisations. Two of the organisations ensure that once young people have been tested at the tournaments, they are referred to the necessary services for counselling, treatment, and support. Young people who have been referred elsewhere for services are entered onto an online database which captures the services they require and

the name of the partner organisation and professionals handling the case. A coach is then assigned to track and monitor the progress of the case through the various stages of referral until the necessary services have been rendered.

- In this case, when it comes to treatment and care, the local health institution or partner organisation, by agreement, assumes the responsibility for on-referral and the coach merely offers support and monitoring of the young person's frame of mind. This is in many respects a suitable outcome from the point of view of SfD organisations.
- However, local organisations are not always equipped for the challenges of providing care and support in a satisfactory way and services are often not well networked. Some SfD organisations admit to being concerned about leaving 'behind' the young people they have worked with who have tested HIV-positive at the end of the programme.
- There is a strong need for SfD organisations to ensure that support and service systems are fit for the purpose of providing a system of essential services that appears more-or-less functionally integrated to the young person being referred; contributing to building these when they are weak or do not exist.

Provision of broader SRH services

International SRH organisations such as Planned Parenthood, Marie Stopes, New Start, and local NGOs, often partner with sports organisations to provide basic SRH services at events. These tend to include HCT, condom distribution, and provision of health information. Other SRH services are referred to the organisations' clinic (if applicable) or to government clinics. A health practitioner described how tournaments are a difficult environment in which to provide quality SRH services, given the lack of privacy, time, and facilities. They therefore only provide HCT and condoms; other services are catered for at their youth-friendly clinics instead.

All the organisations encountered refer people who test HIV positive to government clinics for management of HIV (CD4 and viral load tests and treatment, if needed). With the exception of one organisation, organisations did not provide follow-up HIV counselling after the immediate post-test counselling and most did not provide services in the form of post-diagnosis counselling and support groups.

One organisation that provides both SRH services and a youth programme specifically explained that when they refer HIV-positive young people, they encourage them to come back and share their experience at the clinic and also encouraged them to come to the SRH centre for assistance with STIs or family planning if needed.

The relationships between organisations working together in these ways generally appeared to work well and be mutually beneficial. NGOs that provide SRH services are able to reduce congestion at local clinics and there appeared to be quite good local-level arrangements which are particularly effective when the services are presented as youth friendly. One of the SfD NGO partners with a range of local government clinics that refers HIV-positive children to access after-care and psychosocial support.

SfD organisations often partner with other youth organisations, in addition to SRH NGOs, particularly during sports tournaments. There are also instances of 'exchange programmes' between NGOs for the purpose of sharing skills. A concern was expressed from one site that this process sometimes results in other projects taking their programme ideas and replicating them without permission or collaboration.

More serious challenges can also arise, such as when an international organisation planned to provide termination of pregnancy services from a SfD location but was not allowed to by the SfD organisation as it was seen as unacceptable by the community.

Despite this, it was generally found that ad hoc arrangements have been satisfactory for the needs of collaboration and referral between organisations at the local level. There was no strong sense of conflicting of interests and organisations appeared to see the need for adaptation towards mutually beneficial ends.

3.4 Conclusions and recommendations

In a field marked by innovation and adaptation recommendations can only be cautiously offered, as different arrangements and approaches will be suitable for some contexts but not others.

Practitioners and funders should look at these recommendations in terms of how SfD programmes can effectively and ethically promote HCT as an integral part of their programmes, with the aim of serving HIV prevention and treatment outcomes.

Building the capacity of coaches

Coaches are an invaluable asset to many organisations but are often in need of further education as well as support. Organisations' effort to develop coaches should be supported and there are opportunities in some countries to support the development of a semi-professional category of youth development practitioners tied to sports development agendas and programmes. There needs to be more systematisation around this, both towards recognition of skills of practitioners and building standards and training programmes in this area.

Organisations need to build the capacity of coaches so they can cope with challenges emerging from their interaction with youth in the programmes. Organisations need to train coaches in basic counselling skills and education on the legal framework in which the organisation (and thus the coaches) operate.

Organisations need to provide adequate quality supervision and debriefing for coaches and staff involved in direct programme delivery.

Caring for peer-educators and coaches

Organisations using peer-educators and/or coaches in treatment adherence, care and support should take cognisance of vicarious trauma and develop safety mechanisms for those involved. Research and growing literature on the mental health state of people who care for those infected with HIV seems to indicate that although there are benefits to the person with HIV in having a caring and supportive environment in which treatment is taken, the carers often suffer mental anguish and depression as a result of caring for an ill person. The effects are compounded when young people care for their peers and parents (as is often the case with child-headed households). This must be given consideration and carers assigned to support HIV-positive people should be provided with opportunities to debrief and share the burden of their experiences with others who can empathise and support them.

Developing appropriate partnerships

- Organisations that form partnerships to offer HCT through mobile services should establish long-term agreements, rather than ad hoc arrangements or collaborations.
- SfD organisations should strive to have strong relationships with SRH services, and HIV/AIDS treatment services and programmes for supporting people living with HIV. The closer the association with such services the better and on-site centres for provision of services appear to work particularly well. Where on-site services are absent (as is commonly the case),

preparatory work must be undertaken to ensure that the appropriate services are readied for the increase in referrals and demand for treatment and care brought about by the large numbers of young people tested at the culmination of SfD programmes.

- The WHO Global Health Sector Strategy 2011-2015 recognises that although the total reported number of HCT procedures has risen significantly, further efforts are needed to ensure wider access to HCT, timely diagnosis, and referral to prevention and treatment. SfD programmes offer ideal opportunities to reach young people with HCT services shaped to their needs and should be seen as an effective way of engaging this group in HCT.
- SfD organisations should advocate for the recognition of their contribution to HIV prevention and treatment through their education and HCT activities. They should show that they have developed substantial expertise in community and location-level skills-building for HIV prevention and care referral, and are an effective way of reaching underserved young people. Opportunities for partnerships have been realised at local level and efforts should be made to achieve higher-level partnerships for community-level service provision.

Funding for integration

A general consensus among the organisations was that if SfD organisations are to offer HCT, it should be managed carefully and integrated into a broader package of services that include treatment, care and support.

As an alternative to directly offering HCT, funders need to support efforts that foster integration of services offered to young people. It has been suggested above that functional integration is the first level of need, considering that services are often provided by a range of organisations, and there is no reason to believe that this is about to change. Rather, building linkages, information systems, forms of accountability and joint planning, would be desirable.

4 Ethics of HCT in SFD

4.1 Universal HCT guidelines

International framework to guide the practice of HCT is set out in the World Health Organisation (WHO) training manual for 'voluntary HIV counselling and testing'³⁵ and a manual to guide provider-initiated HIV testing and counselling in health facilities³⁶. These documents describe standards of practice and ethical guidelines for HCT.

Although country guidelines do differ in some important respects (see Appendix 5), the essential elements of HCT as laid down by the WHO guidelines are more or less adhered to by most countries at least in principle. The following characteristics are expected of HCT practice³⁷:

- **Voluntary:** The decision to have a test should not be coerced and the prevention value of HCT requires that a person *wants* to know their HIV status.
- **Confidential:** Information shared during counselling must not be shared with others unless the client states the desire for information to be communicated to a family member, partner or close friend.

³⁵ Who (2004)

³⁶ WHO (2007)

³⁷ UNAIDS (2002); WHO (2007)

- **Mandatory pre- and post-test counselling:** Counselling must be offered to any client considering taking an HIV test. Pre-test counselling is meant to provide an opportunity for clients to explore their risk of HIV infection, how to reduce it, and help clients decide whether or not to take the HIV test. Clients are informed of their HIV test result during post-test counselling where they are assisted in exploring their responses to the outcome.
- **Testing:** The presence of antibodies against HIV in the blood, saliva or urine indicates a diagnosis of HIV. Positive test results are confirmed using additional tests.
- **Informed consent:** The client agrees to HIV testing by giving their consent on the basis of understanding the procedures to which they consent.
- **Privacy:** The physical environment must allow private discussions between client and counsellor. The service provider must maintain privacy in maintaining clients' personal details.
- **Referral:** Clients must have access to prevention, care and support services as available. Referrals should be made with respect for the client's confidentiality and their consent.
- **Counsellors:** Characteristics of counsellors include being non-judgemental, empathetic, respectful, and supportive. Staff with counselling duties must be trained in HIV counselling techniques.
- **Equality:** HIV-positive people should not be discriminated against.
- **Adherence:** The service should adhere to local and national protocols, laws and regulations governing the provision of HIV services.
- **Monitoring and evaluation:** Counselling and testing services should be monitored and evaluated, both quantitatively and qualitatively to ensure the services are of high quality.

Adherence to standards of good practice can be assumed to be variable and contingent on quality of training, adequacy of facilities, availability of referral resources and management practices. There has been remarkably little research on standards of practice of HCT and it remains questionable whether rapid and widespread roll-out of HCT has upheld these expectations. The ethics, quality of service and effectiveness of HCT are at issue.

HCT practitioners throughout Sub-Saharan Africa occupy a critical position: they are intermediaries between the rule-making of international and national policymakers and the norms of the communities in which they live and work, as well as conditions determined by their organisations and the environment in which they provide services.³⁸

The contexts of HCT, and particularly community and event-based HCT, can result in failure to comply with many of the above features of sound HCT practice. This may include, but is by no means limited to: social pressure from counsellors or peers; brief and poor quality counselling sessions; lack of privacy; counsellors who are family or friends; socio-cultural settings that influence consent; and lack of facilities to refer to for follow-up services.

There has been some study of ethical dilemmas and erosion of standards of practice in the context of longitudinal HIV/AIDS studies³⁹, but other than a 2002 study in South Africa⁴⁰, there has been little research on HCT standards of practice and it is an area in need of attention. There has been little documentation or research on the challenges of adapting country protocols as HCT has gone to scale and increasingly been implemented in non-clinic settings; where practice has been adapted to suit practical demands and socio-cultural concerns.

³⁸ Angotti (2010)

³⁹ Angotti (2010)

⁴⁰ Magongo et al. (2002)

In the SfD field, where HCT may be delivered in large numbers at crowd events and in makeshift settings, there is considerable risk of ethical transgression and departure from acceptable standards of HCT practice. Whether transgressions have occurred was not specifically investigated, but under the circumstances there are inevitably some risks and these must be mitigated.

4.2 HIV testing and child protection laws

Legislation upholding children's rights and child protection has been passed in many Southern African countries, recognising the autonomy of children and adolescents to consent independently to HIV testing; that is, without parental consent. This is subject to minimum ages below which young people are deemed not competent to independently provide consent. (See Appendix 5 which summarises HCT guidelines per country, including age of consent.)

In some African countries, the age of consent for HCT is as low as 12 years; and in all countries children younger than 12 require parental consent. In countries where the age of consent is 16, pregnant and/or married minors younger than 16 are able to give consent without parental involvement as they are deemed competent to provide consent for themselves.

Ages of consent for HCT are generally lower than the ages at which young people reach majority. This follows the realisation that the need for parental consent for HIV testing may create barriers to adolescents accessing HIV prevention and SRH services; because adolescents may not want their parents to know that they are sexually active. It is also motivated by the reality that many adolescents in high HIV-prevalence contexts do not have parents or legal guardians to consent to them accessing HCT services.⁴¹

The Southern African Development Community (SADC) policy regarding children and adolescents under the age of consent emphasises that:

- Testing of a child should be done only if it is in the best interest of the child.
- No child under the age of consent for HIV testing should be subjected to testing unless consent is given by a parent/ guardian. Testing a child without parental/ guardian consent is a violation of law.
- A medical practitioner may test a child for medical management without consent only in cases where a parent or legal guardian is not available.
- Testing must be accompanied by pre- and post- test counselling and results should be kept confidential.
- Definition of a child is specific to each country and the legal age of consent to HIV testing is stipulated by each country.

The WHO⁴² has recently developed guidelines on HIV disclosure for children up to 12 years. Among other recommendations the guidelines encourage a step-wise process over time, the need to support the management of stigma in school and other environments, and competence in supporting caregivers to disclose children's own HIV statuses to them in supportive ways. This again highlights that learning that one is HIV-positive is not an event in time, but involves a process of deepening understanding and engagement with the meaning that being 'HIV-positive' has, and how this evolves over time. Facilitating the process in children places particular demands on service providers and caregivers. Considering that children do participate in SfD HIV-awareness activities

⁴¹ Hikuam (2006)

⁴² Who (2011)

and sometimes undergo HCT⁴³ as part of this, there is a need to think very carefully about the advisability of including HCT, and to approach the prospect with due caution.

4.3 Ethics in SfD practice

Informed consent

SfD organisation staff, coaches and at times, the counsellors, emphasised that young people had to make the decision to test on their own without being coerced or pressured. Programme staff and volunteers/coaches are the ones who provide education to young people on the process of making the decision to undergo a test. However, the onus of ensuring that young people are adequately informed prior to signing or verbally giving consent was largely assumed by the HCT counsellor or service provider.

Some young people said that they either had to sign a form or give verbal consent to undergo the test. In most cases, young people are aware of their right to withdraw from the HCT process at any stage of the process.

Questions about informed consent for HCT are to some extent contested by child protection advocates as well as some organisations providing services. The psychosocial maturity of adolescents can vary regardless of age, but whilst it is likely that some young people may have the emotional and practical preparedness to appreciate the implications of testing at any age, this is less likely amongst younger adolescents. In some countries the legal age of consent is as young as 12 years (see Appendix 5). Given the significance of receiving an HIV-positive diagnosis on testing and the importance of prevention counselling, it is questionable whether children this young are in a position to make good use of the HCT process. It is also questionable whether they are likely to fully appreciate the decision they have taken to test and how it may impact on their lives, despite being legally permitted to consent to the test.

Organisations involved in HCT promotion and delivery need to be sensitive to the developmental needs and maturity of young people and should strengthen post-test support and safety-net measures.

SfD organisations are strategically positioned to offer these services as young people readily engage in their services and have relationships with staff and volunteers. Stigma and discrimination related to being seen in HIV-positive support groups is minimised.

Confidentiality

Interestingly, coaches often do not know about or inform young people about limits to confidentiality. In these cases, young people often have to learn through experience, often negative, that limits to confidentiality do exist. This is often the case where community members see young people at HCT centres, or where counsellors have to report cases of abuse that emerged during the pre- and post-test counselling; or when gossip is spread by health care professionals regarding a particular young person's test outcomes.

Often organisations cited that they maintain the confidentiality of HIV test outcomes by ensuring that HCT counsellors do not disclose the client's status. However, the issue of confidentiality is far more complex and often exists beyond the control of the client and the counsellor. Confidentiality is often not maintained within the limits of organisations because of reporting procedures;

⁴³ For example, de Jesus et al. (2009) report a South African tournament testing event where 10 (3.9%) of the 258 young people undergoing HCT in a single day were under 14 years old.

unprofessional behaviour among counsellors who gossip about clients; child protection rights overriding confidentiality requirements for clients who are minors; and other service consumers (who are not bound by the ethic of confidentiality) telling people in the community about who they saw at the HCT centres.

The use of peer pressure

Most of the organisations' staff interviewed identified positive peer pressure as a useful general approach to social learning. However, peer pressure is generally discouraged when it comes to HCT and decision-making about whether to undergo an HIV test or not. Programme participants are usually encouraged to make the decision 'on their own'.

An approach quite commonly adopted promotes the notion that peers should encourage each other to make their own choices when it comes to testing. There were some SfD staff that felt inclined to place greater emphasis on individual testing rather than testing in the public domain (e.g. tournament testing). They also felt that promotion of strict adherence to confidentiality and professional ethics encouraged a more appropriate mindset in prospective HCT candidates.

In reality, peer pressure emerged as a major influence, especially in tournament testing organisations. It was reported that peer-educators and coaches go first to test and then say: "I've tested, now you go". This was seen by some as coercive and detrimental for young people who had not psychologically and emotionally prepared themselves for testing. The negative effects of 'positive' peer pressure are further compounded when testing forms part of winning a trophy or material prize for a team. Then the entire team feels compelled to undergo an HIV test so their team can stand a better chance to win the trophy or prize.

It was reported that peer pressure may subtly coerce young people to test without forethought, and possibly without personal motivation and preparedness, detracting from the prospect of using the counselling component to good effect. It was also reported that subtle social coercion may pressurise peers to feel that they should disclose their test outcomes to each other; and positive peer pressure for disclosure may at times undermine a person's needs for privacy, especially in the context of an HIV-positive diagnosis. There was evidence to suggest that some participants experienced the motivation to test as pressurising and stressful. There clearly needs to be careful modulation of motivations on a person-by-person basis.

Well-meaning coaches are faced with situations where they have to motivate young people in an effort to increase HCT uptake, and they may fall back on poorly thought-through strategies to encourage young people to test. It must be said that the motivation of coaches is also driven by testing statistics targets which are seen as the measure of programme success rather than seeing the larger picture of behaviour change, through pre and post test counselling, and onward referrals.

It is important to note that sometimes organisations are not aware of the actions of coaches; questions need to be raised about organisational levels of monitoring of the way in which the highly sensitive matter of HCT is promoted in young people.

This caution aside, the more general picture is that organisation staff and young people interviewed shared the view that peer pressure had never been exercised to force young people to disclose their status to their peers. In fact, in some cases young people were encouraged to disclose only to someone they trusted or to seek support from coaches in the event of receiving an HIV-positive test outcome. Disclosure was encouraged only in instances where the young person was willing to be a positive role model to peers by providing examples of how 'positive living' had affected them.

Disclosure

Almost all the organisations, across countries, encouraged voluntary individual disclosure of their

health status as part of 'Positive Living', however, most of these organisations were not equipped to deal with or provide the necessary support for the person disclosing. Young people who disclose their HIV statuses are often ostracised, discriminated against and at times chased away from their communities. The threat of disclosure is often greater than the benefits.

Breaches of privacy

Breaches of privacy sometimes occur through attempts to promote more open communication; for example:

Coaches in one organisation often retell a story of a 15-year old who disclosed her HIV-positive status during a weekly group discussion. That young person's story is now used as an example to other young people to disclose without her specific consent, creating pressure on young people to share their own experiences and yet also raising the prospect that their own experiences may one day be shared in their absence.

This raises the need to for coaches to think more deeply about the management of privacy in situations of open discussion.

In addition, some governments provide nutrition fortified peanut butter for people on treatment, which also often leads to forced disclosure for people on medication as they have to take the peanut butter home to their families. In a similar case, one organisation has partnered with the Salvation Army which provides food parcels to people living with HIV. Food parcels are taken home to families who are all aware that food parcels are only provided to people living with HIV. Often the fallouts of this type of disclosure are so severe that young people are chased away from their families and communities. Further, young girls and women who are known to have HIV are not permitted to marry in their villages. For example, one counsellor shared that in her support group she had an HIV-positive man that was romantically pursuing the daughter of one of the women in the support group. The woman then disclosed the man's status to her daughter in order to protect her from the HIV man. The counsellor had not acted on the issue as she did not know how to respond. In this case, the mother had chosen to protect her child over the rights of the HIV-positive man and thus disclosed his status. An alternative route would have been to engage the man in dialogue, possibly with the help of the counsellor, to stop pursuing the matter or disclose his own status to the girl and let her decide.

In some organisations, if a young person confides in staff who are responsible for providing care and support, e.g. food, funds, medication, housing; senior staff will confide in each other about a young person's status in order to assist each another with their response. There are implicit confidentiality concerns with these kinds of interactions; ideally this kind of sharing should only occur with the young person's consent, but staff admitted that these discussions often happen without the knowledge of the person concerned.

Coach testing

In the tournament testers, coaches and/ or facilitators are often the first people to go and test in an effort to demystify the process, to lead by example, and to allay the fears of youth wanting to test. Coaches often disclose the outcomes of their HIV test, usually when the test outcomes are negative. While the intent behind the action of the coaches may be regarded as noble and encouraged by some, it presents numerous issues regarding confidentiality and the use of pressure. Firstly, coaches' access to confidentiality is limited by pressure (internal and external) to disclose their status in order to get more young people to test at the event. Secondly, coaches disclosing their status may put pressure on young people to also disclose their results after testing. Thirdly, peer pressure is legitimised in this context as learners might feel it's justified to expect their peers to disclose their test outcomes if their role models are doing so.

In one organisation, young people raised concern about some of the coaches who were used as role-models. Some of the young people felt that it was good to use coaches as role models but felt coaches were often seen not portraying the values and behaviour they encouraged in young people. For example, a coach known to be married was seen having an intimate relationship with someone else led young people to question whether the teaching on the risks of multiple concurrent partnerships and being faithful were applicable only to them and if so, why. Professionalism among staff employed to interact with young people is key but when negative role-modelling takes place, the risks are far-reaching for those young people who aspire to be like their coaches.

Motivating and incentivising young people to undergo HCT and positive peer pressure

There was a strong sense from the organisations visited that testing must be voluntary, and that young people are able to and should decide for themselves whether to test after developing a clear understanding of the benefits and psychological consequences of testing. One staff member felt that 'information is power' and felt that as an organisation their mission was to provide information, rather than to be prescriptive in telling young people what they should do or requiring that they test in order to participate.

This is somewhat at odds with motivating and sometimes incentivising young people to test and creating 'positive peer pressure to test'. This was picked up by a number of members of Sfd organisations who felt that the motivation to test should be derived from a genuine process of reflection and risk identification, rather wanting to acquire material things or to follow one's friends.

The provision of incentives may often be construed as coercive, especially when targeting young people who would not necessarily have the means to otherwise acquire these goods. Furthermore, the pressure to have something to 'show' for the testing may coerce some youth to undergo testing which they would not have done otherwise.

4.4 Conclusions and recommendations

Development and adoption of ethics protocols

When older people interact with young people around sensitive issues, where there is group engagement in learning about sensitive topics, and where programmes expose young people to life-skills education, a range of ethical issues come to the fore. It has been noted above that Sfd organisations are faced with many subtle ethical dilemmas, and in some instances they are not aware of them.

To address the significant ethical issues raised above, Sfd organisations should review their ethical frameworks and develop an awareness of the national and international standards that should guide the practice of HCT.

Organisations must have policies outlining standards of practice, including ethics. To reinforce perceptions of the importance of ethical standards, the need to abide by these standards should be included in staff contracts, along with consequences to any breach of these policies.

Coaches as well as other programme staff and volunteers, need to be trained in ethical practice when promoting and offering HCT and an ethical code should also be communicated to clients.

Organisations need to provide opportunities for clients to report unethical practice and act decisively on reports of unethical practice.

Funders should insist on organisations proving that they have ethics protocols in keeping with national and international standards, and oriented on client rights and service provider responsibilities. A way to achieve this is to set, as a requirement of funding agreements, that all organisations submit a policy on standards of practice for providing access to HCT through direct

service delivery or facilitating provision through another service provider; and a code of practice with details of how standards are implemented and monitored within organisations.

Cautious incentivising to test and avoidance of any pressure

The meaning of incentives must be understood; including the motivational set and reasons that are generated when promoting HCT. These must be in keeping with the overall purpose of HCT, rather than simply in keeping with the aim maximising the numbers of people tested.

Cautious approach regarding encouragement to disclose HIV status

For an HIV-positive person to live a happy and healthy life it is not necessary for them to be publicly open about their HIV-status. They will likely need to disclose their status to some people and it may be counter-productive to disclose their HIV-status to others. This is a point of correction that needs to be taken up by many SfD organisations.

Managing and mitigating risks

The risks of young people discovering their HIV-positive status without necessary support should not be discounted. Ultimately the context of peer-support and the context of conviviality associated with sports days and games, will pale into insignificance for young people who walk away with the news that they are HIV-positive.

The organisations are not naive about this, but coaches often do not know the outcomes of tests and responsibility is devolved to health services. The ethical duty to provide a continuity of support and care necessarily cannot fall to a single agency but it is of paramount importance that any efforts to promote testing should be done with a clear referral and support plan in place; even if it is not provided by the SfD organisation.

5 Outcomes of use of HCT in SfD

5.1 Research on HCT outcomes and value

There has been relatively little published research on HCT outcomes, considering the prominence of HIV testing in national HIV prevention strategies in most countries with generalised epidemics.

Behavioural prevention value of HCT

Reviews and studies of the contribution of HCT to behavioural HIV prevention are equivocal about its value.⁴⁴

A systematic review⁴⁵ of research on the impact of HCT on risk behaviour in developing countries shows mixed findings, ranging from significant reduction in HIV incidence among women who attended antenatal clinics and whose partners also underwent HCT, to no effect on HIV incidence among male factory workers.

There is certainly no strong or consistent evidence of behavioural changes such as reduced number of partners, abstinence, or increased condom use following HCT among people who test HIV-

⁴⁴ Dube et al. (2005); Glick (2005); Solomon et al. (2004)

⁴⁵ Denison et al. (2008) These authors note that weak study designs and limited replication compromise the strength of evidence.

negative. To the contrary a prospective cohort study in Zimbabwe found that “Increased sexual risk following receipt of a negative result may be a serious unintended consequence of VCT”.⁴⁶ This study points to adoption of riskier behaviour following testing in terms of numbers of partnerships in the last month, the last year, and in concurrent partnerships. Other studies have shown no significant change in HIV risk behaviour following HIV-negative diagnoses, either towards increased risk behaviour or increased risk-reduction behaviour.⁴⁷

On the other hand there is fairly consistent evidence from research studies that HCT tends to promote risk-reducing behaviour change following HIV-positive diagnoses.⁴⁸ The reasons for this have not really been established as the evidence is from survey-type studies and there has been little research on understanding the pathways to these reported changes. Studies tend to have focused on measuring risk-behaviour outcomes following discovering HIV-status, with little recognition of the role of counselling in the HCT process, which is likely a key variable in determining outcomes.

It may well prove the case that the quality and content of counselling following HIV-positive and HIV-negative test results may make the critical difference to outcomes. If a person discovers that they are HIV-negative following significant HIV risk-behaviour, there is some chance that discovery of their status will discount or even endorse their risk behaviour. But the fact that they choose to test shows that they have some concern about their status and discovery of their HIV-negative status could provide a platform for a new beginning without uncertainty.

The critical point is that the prevention value of HCT for both HIV-positive and HIV-negative diagnoses is strongly reliant on the quality of reflection, information provided, skills learned and decision making that is part of the counselling process, rather than on people simply knowing their HIV status.⁴⁹ Risks can be minimized with appropriate pre- and post-test counselling and the discussing of personal HIV prevention risks and prospects in a private and confidential environment must be regarded as a major HIV prevention opportunity. However, clearly knowledge of HIV-status is not in and of itself a prevention method, but it is an entry point to adoption of personal HIV prevention measures.

Overall the literature shows that the quality and type of counselling provided are critical to the effectiveness of HCT as a prevention method, and shaping this to the needs and contexts of clients is important.⁵⁰ Otherwise counselling can amount to no more than dissemination of commonly available information, overlooking the real challenges of negotiating HIV prevention behaviour in existing and new relationships. Adopting new HIV prevention behaviours may be expected to breach sensitive relational issues and it may impute mistrust. It requires collaboration with an ‘other’, in situations which may be complicated and difficult to negotiate because of power issues, or because a partner has not reached a similar position of seeing the need for HIV protection.

HCT leading to prevention through ART and SRH management

One area that has accrued strong evidence is the role of HCT in identifying people who are eligible for anti-retroviral therapy (ART). Lowering of viral loads through well-managed ART leads to very significant reduction of the likelihood of onward transmission of HIV. High plasma viral loads are associated with increased infectiousness⁵¹ and conversely higher numbers of people with HIV

⁴⁶ Sherr et al. (2009, p. 851)

⁴⁷ Turner et al. (2009)

⁴⁸ Pettifor et al. (2010); Sherr et al. (2007); Turner et al. (2009)

⁴⁹ Dube et al. (2005); Sherr et al. (2007)

⁵⁰ WHO et al. (2008)

⁵¹ Padian et al. (2008)

receiving ART has the potential to reduce population level-HIV incidence, since effective treatment reduces viral loads and the infectiousness of infected individuals.⁵²

Given this HCT has an important prevention benefit in identifying people needing ART, provided that the referral linkages from testing to treatment are well established and managed, so that ART eligible people are not lost to follow-up.

However, retention in HIV health care before a person's health has deteriorated to the point of being eligible for ART is poor, particularly for younger individuals, males and those at an earlier stage of infection.⁵³ Further work to optimize and evaluate care and monitoring strategies is required to realize the full benefits of people increasingly knowing their HIV statuses. This requires development of support for people who are HIV-positive but in need of ART, and provision of preventive and promotive health care services to retain them as users of health services.

HCT is also a critical service for entry into programmes for preventing mother-to-child transmission of HIV (PMTCT). There is strong evidence of the effectiveness of prevention of mother-to-child transmission (PMTCT) programmes.⁵⁴ However, PMTCT requires a great deal more than pregnant women discovering their HIV-positive status. It requires a range of changes at an individual, social network and family level, as well as appropriate biomedical and psychosocial interventions. HCT is an entry point and its value is only realised when it is used as part of a package of services and supports.⁵⁵

HCT and prevention for HIV-positive people

As has been pointed out above, HIV-infected persons who are aware of their HIV status tend to reduce behaviours that might transmit HIV to others to a greater extent than people who are HIV-negative.

However, even in the case of HIV-positive people there is no reason to believe that undergoing counselling and knowing one's status in itself would result in the prevention outcome of reduction in onward transmission of HIV and re-infection. The prevention outcomes observed in specific studies show that achieving HIV prevention through the behavioural choices of HIV-positive people relies heavily on the quality of counselling rather than simply knowing one's serostatus.⁵⁶

The balance of evidence suggests that HCT will have a significant epidemiological impact on an epidemic only if it attracts large numbers of sexually active HIV-positive individuals.⁵⁷ Furthermore, "it is likely that prevention effects will be strongest when HCT is provided to infected individuals and discordant couples".⁵⁸

This raises the need for programmes focusing on HIV prevention; sometimes called 'prevention for positives'. Current practice sees HIV prevention for people with HIV as best served under the rubric of 'combination prevention', as part of a broader basket of essential health and social services, including treatment.

HCT for couples

⁵² De Cock et al. (2008); Dodd et al. (2009);

⁵³ Lessells et al. (2011)

⁵⁴ Denison et al. (2008); Amouzou (2007); UN secretary General (2008)

⁵⁵ Mfecane et al. (2009)

⁵⁶ Foss (2007)

⁵⁷ Glick (2005)

⁵⁸ Menzies et al. (2009, p.369)

HCT for couples has been shown to have promising prevention prospects; and has been effectively used in contexts of reproductive decision making. However, there are challenges in promoting HCT in long-term relationships because of the perception that such relationships are generally 'safe' and because of the social risk of exposing marital infidelity through HCT.⁵⁹

HCT policies and guidelines do not make special provision for HCT services tailored to couples and HCT counsellors need to have special skills to engage in prevention counselling with couples. There is a need to refine and tailor ways of delivering HCT to couples and there has not been much progress on this needed development thus far.

HCT and sero-discordant couples

Data show that in mature, generalized HIV epidemics, a large proportion of new HIV infections occur within HIV-discordant couples.⁶⁰ Furthermore, the proportion of sero-discordant heterosexual couples in most sub-Saharan countries is much higher than the proportion where both members of the couple are HIV-positive.⁶¹

The first large HIV prevention trial in Eastern and Southern Africa involving HIV discordant couples, found that almost half (49%) of couples across all study sites and among all couples with one HIV infected partner were discordant.⁶² This makes prevention in sero-discordant couples a priority, as a non-infected partner in a sero-discordant relationship is at very high risk of infection.

Greater emphasis is thus needed on couple HIV testing and counselling. There has been evidence available since the early 1990s showing a significant reduction in sero-conversion among HIV sero-discordant⁶³ couples who were counselled about the need for HIV-prevention following couple testing.⁶⁴ The provision of HCT among sero-discordant couples leading to awareness of sero-discordance was reported in one study as having led to a 53% reduction in HIV infection in couples.⁶⁵ It was also found that HCT significantly reduces the prevalence of unprotected sex with non-primary partners.

There is also strong evidence from a number of countries that providing couple testing and counselling increases acceptance of HIV testing by pregnant women.⁶⁶

Sexually active women are generally easier to target for HCT as they tend to use reproductive health services more regularly. It is however also important to target men, especially in the context of societies with male-dominated relationships, where men are likely to have the stronger influence on a couple's behaviour subsequent to HCT. Targeting couples promises to increase levels of engagement of men in HIV prevention. In this regard SfD offers an opportunity to target men, although young men engaging SfD activities are less likely than older men to be involved in long-term sero-discordant relationships.

The promise of HCT for promoting HIV prevention in sero-discordant relationships is unfortunately not supported by protocols or strategies in many countries, although it is now almost universally regarded as an effective and needed prevention approach. There are also well-developed training

⁵⁹ Coates et al. (2008)

⁶⁰ Wawer et al. (2005)

⁶¹ WHO (2009)

⁶² Lingappa et al. (2008)

⁶³ Sero-discordance refers to situations where only one partner is HIV-positive.

⁶⁴ Allen et al, (1992); Allen & Serufilria (1992); Kamenga (1991)

⁶⁵ Bunnell et al. (2006)

⁶⁶ WHO (2009)

materials and protocols ready for adaptation to country and locality conditions.⁶⁷

Mental health aspects of HCT

The experience of learning one's HIV serostatus is psychologically taxing⁶⁸, and *the* diagnostic testing procedure and receiving the test results are associated with moderate to intense levels of anxiety and distress for the client. This raises the need to look more deeply at the mental health aspects of HCT and implications for SfD programmes that provide or utilise HICT services.

Reviews⁶⁹ of research on the mental health of people living with HIV reveal levels of mental health disorders way higher than found in the general population, with depression being the most common individual problem. Those employed, educated and receiving antiretroviral treatment have been found much less likely to be beset by mental health problems. Being female, experiencing poor health, receiving poor-quality health services, and a lack of material and emotional support from family and friends were associated with greater psychiatric morbidity.

There are significant emotional problems associated with receiving 'HIV-positive' test results, including depression, anxiety, self-blame, negative self-perception, perceived stigmatisation, suicide ideation, fear of dying, post-traumatic stress disorder, deterioration in relationships, abandonment and lack of support.⁷⁰ Therefore, there is a need not only for supportive counselling on receiving an HIV diagnosis, but also a need for the opportunity for further counselling to enhance coping strategies and facilitate disclosure following receiving HIV-positive test results.⁷¹

There is good reason to believe that the mental health consequences of discovering one's HIV status, given poor support to those who are HIV-positive, undermine the likelihood of adopting HIV-prevention behaviour. Testing without follow-up support, for example through education and support groups, means lost opportunities for HIV prevention.⁷²

While many organisations have built relationships and networks to provide functionally integrated services for treatment, care and support to people living with HIV, greater attention needs to be paid to the quality of psychosocial care, particularly for HIV-positive youth. This is clearly born out in the recommendations of almost all research studies on the mental health aspects of HIV and AIDS.

A consistent level of support is needed until the newly diagnosed person has adjusted. A study of people's biographies following testing HIV-positive shows a tendency for some people to be avoidant following the shock of discovering their HIV-positive status, and it may take many months or years before they are able to disclose their status to others, including partners; suffering considerable stress because of their secret.⁷³

Psychosocial support that can be either intensive or non-intensive and usually comes in one of the following forms:⁷⁴

- **Basic counselling-** Dealing with initial reactions and repercussions on receiving an HIV-positive diagnosis and developing strategies for psychosocial adjustment; usually provided

⁶⁷ Couples HIV counselling and testing intervention and training curriculum [web site]. Atlanta, United States Centers for Disease Control and Prevention, 2009 (<http://www.cdc.gov/globalaids/Resources/prevention/chct-training.html>, accessed March 2012).

⁶⁸ Worthington & Myers (2003)

⁶⁹ Brandt (2009); Young (2011)

⁷⁰ Lyketsos & Treisman (2001); MacPhail et al (2008); Wolfe et al. (2006); Young (2011); Brandt (2009)

⁷¹ MacPhail et al (2008); Skogmar et al. (2006)

⁷² Kelly et al. (2010); Freeman et al. (2008);

⁷³ Kelly et al. (2010)

⁷⁴ Perk et al. (2001)

by HCT service provider counsellors, social workers, trained volunteers, peer-educators, HIV support groups and friends.

- **Education-** Educating HIV-positive clients and couples about ART, HIV prevention, healthy living, and dealing with stigma; conducted by someone with specialised knowledge on living with HIV, HIV prevention, and health care for people with HIV.
- **Psychotherapy and psychiatric support-** Assisting in the case that the client/youth has major psychological maladjustment that impairs daily functioning; requiring the services of a specialised social worker or psychologist, and possibly medication to ease depression, anxiety and panic attacks.

The necessity for such services and support needs to be appreciated in mass-testing drives, testing 'events', workplace testing, mobile HCT and community-level HCT campaigns. Without successful referrals to support services and opportunities for further counselling, the intended outcomes of HCT, and particularly the HIV prevention outcomes, stand a good chance of not being realised.

HCT and stigma reduction

Although HCT has been assumed to be a strategy for stigma reduction, there has been little research on the effects of large-scale HCT drives on HIV stigma. The theory of change associating HIV with stigma reduction is that as more people enquire about their HIV-status and discover their HIV-positive status, stigma will be reduced through a process of normalisation of HIV status. However, the process of de-stigmatisation requires witnessing HIV-positive people being positive about their lives, and managing their health in effective ways; rather than people simply knowing their status. Here, as elsewhere, the efficacy of HCT requires the effective provision of other services that assist people to build up their resources and resilience in living with HIV.

HCT as a vehicle for disclosure

Disclosure of HIV-positive status is by no means a common outcome of HCT. People may, and often do, fail to disclose their status to those close to them, and even to sexual partners, for a number of years.⁷⁵

A number of studies have reported that young people's failure to disclose their HIV-positive status to parents was largely fuelled by wanting to hide the implication that they were sexually active, and also to avoid the sense of disgrace that they felt they would bring to their families as it became known that they were HIV-positive. This may be the case even when they trust their parents will be supportive.⁷⁶ Amongst young people disclosure is more common among peers and close friends rather than to family members and older people generally.⁷⁷

HCT as an entry point

HCT is practiced in a wide range of settings, and while there are national guidelines on HCT in most countries, questions must be raised about how HCT is practiced and whether the manner of practice is fit for serving HIV prevention purposes. At face value, the settings – ranging from sports venues to music concerts and shopping centres – are clearly determined by reach rather than appropriateness of setting, possibilities for referral and follow-up counselling, management of distress and optimisation of prevention decision-making.

⁷⁵ Kelly et al.(2010)

⁷⁶ Horizon (2001); MacPhail et al (2008); Paxton (2002);

⁷⁷ Deribe et al. (2009)

Multiple HCT strategies with different costs and efficiencies can and should be used to meet the need for universal HCT access.⁷⁸ But in each case it must be assured that HCT is part of a functionally integrated comprehensive approach to prevention.

HCT cannot be isolated as an intervention. As an output on its own it stands as an opportunity that must be built on.⁷⁹ It is a part of a basket of HIV prevention services which must be in place if it is to realise its value.⁸⁰ The overall prevention outcomes of HCT are optimised for both HIV-positive and HIV-negative diagnoses when it is offered in conjunction with other interventions and follow-up services and referrals. Required services include ongoing counselling, psychosocial support, viral-load tests, tests of CD 4 counts, and access to treatment.

5.2 Research on the reach and outcomes of HCT in SfD programmes

There is very little research literature on HCT in SfD contexts.

One study⁸¹ aggregated data from 2006 to 2010 from a multi-country SfD programme, showing that 16,000 young people had been tested at 68 VCT soccer tournaments in South Africa, Lesotho, Zambia, Malawi, and Namibia.

Rapid diagnostic tests were used and 816 individuals (5.1%) tested positive were immediately referred to a care and treatment partner. Of those undergoing HCT, 52% were males and roughly half were adolescents aged 15-24. Importantly, the majority accessed HCT for the first time. Individuals surveyed preferred testing at HCT tournaments to the local clinic, as it reduced the risk of stigma and involved support by friends. The effective partnerships between SfD organisation, testing partner, and care and treatment provider are also reported as programme achievements.

There is evidence from South Africa⁸² that high levels of HCT uptake can be achieved on a single day where young people are convened for facilitated educational sports activities. In the documented case 258 young people underwent HCT, 43% of who were between the ages of 15 and 19 years old. This was achieved through partnership of a government health department, a mobile HCT organisation and a national SfD organisation. It is reported that 18 of these young participants (7%) were diagnosed as HIV-positive on this particular day. It is also reported that appropriate referrals were made for health and support services for those diagnosed HIV-positive, although there is no report on whether these referrals were followed through.

At face value the above studies looks very encouraging. With effective coordination HCT soccer tournaments can play a valuable role in helping countries achieve HCT. Of particular significance is the enrolment of men and adolescents in HCT, as they have to this point lagged behind women and older people respectively, in terms of ever having tested.⁸³

However, as successful as the above achievements may be in their own terms, there is little understanding from research such as this of results at the outcomes level; for both HIV-positive and HIV-negative HCT diagnoses.

For HIV-positive test results, questions remain about the success of referrals and possible loss to follow-up. People who have been diagnosed HIV-positive and referred to other health and social services may not make contact with services to which they referred. For HIV-negative test results,

⁷⁸ Menzies et al. (2010)

⁷⁹ Kennedy et al. (2010); Turner et al. (2009); Kurewa et al. (2011); Foss (2007)

⁸⁰ Allen et al. (1992); Kamenga (1991); Foss (2007)

⁸¹ Kaufman et al. (2010)

⁸² de Jesus et al. (2009)

⁸³ Kaufman et al. (2010)

there is uncertainty about what HCT achieves in terms of prevention outcomes, as has been discussed in Section 5.1 above.

A major gap in terms of understanding HCT outcomes is the number of people with HIV who enter health and support services following HCT. The proportions of young people testing positive in some SfD programmes (7% in South Africa⁸⁴; and a 5.1% average in Southern Africa, Lesotho, Zambia, Malawi, and Namibia⁸⁵) imply a significant number of people needing follow-up testing and HIV-related care and support. But, since responsibility for providing these services shifts from the SfD organisation to other civil society or government service providers, the SfD organisations have relatively little involvement in this component and SfD organisations are not able to point to outcomes.

Two quasi-experimental studies on sports-based HIV prevention programmes in Zimbabwe⁸⁶ and Tanzania⁸⁷ found significant effects on HIV-related knowledge, reported attitudes, intentions, and perceived control in condom use. A cross-sectional study⁸⁸ found that participation in a sport-based HIV prevention program in Kenya was associated with greater self-reported condom use at first and last sex, as well as higher reported frequency of condom use. Similar findings have been reported in a Caribbean study.⁸⁹

These results look encouraging in terms of HIV prevention outcomes. However, they rely on self-reported outcomes and there are no independent measures of STI or HIV incidence to support the hope that they may make an impact at this level.

It is important to appreciate that randomised control trial studies based on structured life-skills programmes have failed to produce evidence of HIV incidence reduction, although they have shown some promising reductions in risk behaviours.⁹⁰ One study concluded that “The challenge remains to find effective HIV prevention approaches for young people in the face of continued and unacceptably high HIV incidence, particularly among young women.”⁹¹

There has been no study to this point which has looked specifically at the effectiveness of SfD interventions in reducing incidence of HIV or related infections (e.g. STI and Herpes Simplex Virus).

There has also been no study measuring the effects of HCT on youth HIV reduction behaviour and uptake of treatment services.

A multi-country randomised control trial is currently in planning in Southern Africa that aims to include HIV testing to measure the impact of the intervention on HIV incidence. This promises to provide much needed understanding of the effectiveness and value-added of SfD methodologies and HCT.

5.3 Fieldwork findings related to HCT outcome in SfD programmes

The fieldwork did not set out to specifically research HCT outcomes, although some general remarks can be made on the basis of observations.

⁸⁴ de Jesus et al. (2009)

⁸⁵ Kaufman et al. (2010)

⁸⁶ Clark et al. (2006)

⁸⁷ Maro et al.(2009)

⁸⁸ Delva et al. (2010)

⁸⁹ Kaufman et al. (2012)

⁹⁰ Jewkes et al (2008); Cowan et al. (2010)

⁹¹ Cowan et al. (2012, p.25410)

Knowledge about SRH issues and services

The field visits found that young people who participated in SfD programmes had broad knowledge about HIV risks and prevention measures and other sexual and reproductive health issues. They also had some understanding of local hospitals, clinics and NGOs as sources of information and services.

There was no opportunity to compare their knowledge levels to that of equivalent young people not exposed to SfD programmes, but it was clear from what they said that much of what people knew they had learned from the programme.

However, information about HCT, treatment, post-test support and emergency post-exposure prophylaxis was often limited, and sometimes incorrect or non-existent.

Participants appeared to have some insight into additional support services which exist in their communities, but this was quite limited. While young people are informed about what to expect when seeking HCT services, treatment support groups and post-test clubs were not known about by some.

Testing outcomes

There were perceived benefits of youth SfD organisations providing HCT rather than a health service, which were largely related to youth being more comfortable in that environment. Youth can engage in activities there and feel safe in a confined space, rather than exposed as they would be at a clinic, where the fact that they tested could be witnessed by others. An SfD organisation was seen as having an advantageous position in terms of confidentiality as there are many reasons other than testing that a young person might come to the centre.

Organisations mentioned that it was important for young people to know their status as it enabled them to take action. The different test outcomes are dealt with differently. If a young person has a positive HIV test outcome, they are counselled on the consequences, positive living, pre-treatment, ART, support groups, and a referral is made to a nearby clinic. If a young person has a negative result, HCT counsellors advise that they should return for a follow-up test as they may be in the window period; and discuss the types of behaviour changes necessary to maintain an HIV-negative result, including the importance couple testing and consistency condom use. Young people who would like to discuss their test outcome, SRH, STI's and pregnancy are referred to services where they can receive follow-up sessions.

The follow-up session is seen as useful as it was said to be difficult to transmit information at the moment when someone finds out they are positive or negative. Providing information to and discuss coping strategies, disclosure and treatment support options with people with a positive result during a follow-up session, rather than immediately, was seen as preferable as it allows the person space to recover from the initial shock of an HIV-positive finding and process information better. Ultimately it is up to the individual whether they choose to access counselling and SRH services after testing positive.

Treatment, care and support

While organisations may offer HCT either as a direct or outsourced service, very few organisations actually undertake providing treatment, care or support for people who test HIV positive. Ongoing treatment and support tends to be the burden of partner organisations or government health institutions, rather than the responsibility of 'plus sport NGOs'. However, there were some interesting variations found across the research sites of how this vital service can be provided, which are described below.

Post-test clubs and HIV support groups

There was little evidence of post-test clubs run by SfD organisations for young people who had undergone HCT. The idea of post-test clubs has been developed in a range of other settings, usually aimed at providing peer-support to people who have tested HIV-positive.

Young people who had had a positive test outcome in SfD programmes visited were typically referred to special health facilities for treatment and, where possible, to support groups for people living with HIV and AIDS not specifically associated with SfD organisations.

One organisation hosts a post-test club for youth who have undergone testing. Members are invited to join after testing regardless of their HIV status. The post-test clubs focus on providing additional information regarding prevention, treatment and support for young people. The group is facilitated by young people and provides an interactive forum where individual views are expressed and peer support is fostered. Another organisation had a post-test club for HIV negative young people that doubled as a peer-education group with a focus on staying HIV-negative.

Post test-clubs

Post-test clubs for young people are seldom key parts of programmes. However, when they are offered, they provide essential information and a safe space for young people to discuss critical issues and questions they may have after undertaking an HIV test.

This is an area of practice which should be better documented and further discussed, especially regarding young people, for whom there are very often not specific support services, and who often do not feel comfortable going to regular health clinics to have questions answered.

It is a potentially important addition to programmes which could be used to ensure support to young people beyond the exit door of the counselling room.

Although SfD organisations did not often specifically host post-test clubs specifically related to the event of HCT, some of the organisations engage in support for people who are HIV-positive, in a range of ways.

One organisation engages in HIV-support by hosting the National AIDS Toll-free Helpline and has an agreement with the national post office to accept letters without stamps addressed to the Helpline, which is then paid on the receiving end; to support young people who live in remote areas.

We also encountered a promising model for the integration of sports within HIV support groups. The organisation forms partnerships with some local clinics throughout the city to assist their associated HIV support groups in developing sports programmes. The organisation provides funds, training, equipment, transport, and coaching to the groups. Football and netball were typical activities, with some also playing volleyball and indigenous games. Often support groups had two mixed-gender teams, one for adults and one for youth, sometimes involving more than 100 individuals from one clinic.

Some of the support group members perceived sport and exercise as being a core element of 'living positively', which promotes treatment adherence. Some also noted that the quality of interaction among group members was greater during sports activities than ordinary support group meetings, presumably as a result of the camaraderie that develops on the field. The interaction between support group members involved in sport was seen as building friendships and as an effective way of dealing with stress. One woman described how when she plays football and netball: "I don't even feel like I'm HIV-positive. I feel nice. I don't even think about other stuff in life. We laugh, we joke. We feel happy...".

HIV-positive children's programme

One organisation runs a vibrant children's programme for around 60 HIV-positive children (ages 5-15 years) many of whom were infected at birth. The programme runs three times a week and is led by a member of staff who is HIV-positive, supported by several child mentors. Activities combine sports, games and recreation with information about treatment, how the virus affects their bodies, and how to stay healthy. The programme allows young people to meet and socialise with others who are also HIV-infected.

There is an associated programme for guardians that help them understand their children's health and treatment needs. Child mentors from the programme also visit the children's homes to support families and to promote treatment adherence for the children. They are specifically concerned to detect environmental factors that could affect adherence, such as whether medication is taken in secret, whether medication is taken in accordance with food intake recommendations, and whether there are other emotional problems that could affect adherence.

It can be ascertained from the above that although not necessarily connected to post-HCT support, SfD organisations are responsive to the needs of young people with HIV; and have developed what appear to be promising approaches for applying SfD as a means of engaging and supporting young people with HIV.

Youth friendly and youth specific professional services

The youth-oriented educational activities leading to HCT were perceived as inconsistent with the consulting room atmosphere of the HCT service delivery context. This is by no means always the case, but it was generally felt that an effort should be made to have HCT offered by young professional staff; this is a step further than requiring that staff be able to understand and relate to young people. It was felt that whereas promotion of HCT is done by young coaches, HCT services are often not offered by people that the clients can easily relate to.

Asked about standards for SRH services, SfD organisations tended to use the term 'youth-friendly', emphasising having the range of health, information and HCT services centralised to one location where young people frequent, and having a staff of young professional people.

Some young people said that HCT services should be offered in a setting where only young people frequent, such as youth clubs or centres. There were, however, mixed feelings about this and others felt that HCT was better-offered at a health care institution where they were guaranteed to be seen by medically trained personnel as opposed to the semi-skilled NGO staff members that often provide services in other settings.

There was a general sense of mistrust of health care professionals amongst young people. They tended to feel that health care personnel sometimes acted unprofessionally, failing to maintain confidentiality and expressing judgemental and critical attitudes. It was felt that this is a major barrier to utilising HCT and SRH services. In one country, young people would travel out of their communities to town or neighbouring areas to utilise HCT services and to receive SRH treatment because they did not want the nurses at local clinics talking about their status or their health problems in their communities.

On the other hand, SfD programme implementers described how young people are often more interested in playing sports than hearing about HIV/ AIDS and that a balance needs to be struck between engaging and empowering young people on important matters, and entertaining and

appealing to them. The two poles of development and engagement are represented to some extent by the aptitudes of coaches who are sometimes good at facilitating sport activities but are not as competent in addressing HIV/AIDS information questions and supporting nuanced development of life-skills solutions to HIV/AIDS. There is certainly evidence of coaches being able to fulfil both functions but the organisations were pointing to the ongoing challenge of meeting both demands.

A related point is the meaning of the strong HIV/AIDS focus that has taken root in many organisations, and which has been at least partly motivated by funding availability. A leader of one organisation expressed a concern that his organisation had grown to focus on life-skills education to the detriment of sports, creating a need to get back to providing good quality sport opportunities, which he believed had an important developmental function in itself.

Managing HCT as a prevention intervention

Respondents noted a number of gaps and needs related to programmes, as well as problems experienced in dealing with particular HIV-prevention questions. There are areas where capacity to address particular issues needs to be improved and where useful ideas in current HIV-prevention thinking are not being deployed.

- 1) It was felt by young people that had participated in SfD programmes that all young people in these programmes should be taught SRH life-skills, with HIV forming a substantial component. The life-skills components should emphasise the need for testing and seeking early medical attention. Furthermore, it was felt that the life-skills programmes should be in a curriculum that is structured; as not all programmes have well structured curricula.
- 2) The involvement of people with HIV in prevention tends to have been neglected and almost completely overlooked in some SfD HIV/AIDS programmes. It is one of the key concepts in new HIV-prevention thinking to support the role of people with HIV in prevention efforts. They have a role to play in preventing onward transmission of HIV, in preventing re-infection, and in exercising appropriate reproductive health choices to avoid vertical transmission of HIV. It is also important to emphasise the significant prevention achievements of effective ART.
- 3) A concern arose regarding whether testing HIV negative will lead some young people to continue engaging in risk behaviours, rather than serve a preventative function. This related both to instances in which someone expected to test positive but did not, as well as to peers who discover that someone they know has had a lot of unprotected sex but tested negative; *'HIV is not real. If this person is negative, then HIV can't exist.'* This is an important issue which likely arises from misconceptions about the likelihood of becoming infected in a single sex act and lack of knowledge about the dynamics and conditions associated with higher risks of infection. There was evidence in relation to this issue, and elsewhere, that coaches are not always well-appraised of ways to address these tricky questions; although they appear to be adept at imparting basic HIV/AIDS knowledge.
- 4) Limited resources led some programme staff to feel their programmes do not reach as many people as they could. The ability to organise more sporting activities and to make HCT more accessible through having mobile HCT units and counsellors, would increase effectiveness.
- 5) Coaches often do not have the skills and capacity to talk about HCT or provide follow up once a programme participant had disclosed an HIV-positive test outcome, yet often they assume this role. It was felt by some beneficiaries that coaches should be trained in basic counselling to deal with more sensitive issues.
- 6) Young people who have undergone HCT previously, and who may want to test only to know their status, avoid doing so because they don't want to go through 'counselling' again. Policies and advice on repeat HCT is needed, to guide both service providers and young people about the value of the counselling component.

5.4 Conclusions and recommendations

Given the need to adapt HCT to opportunities and circumstances, there is no perfect model for offering of HCT, treatment, care and support; although at country level there are generic guidelines for provision of services.

The following conclusions and recommendations are made with a view to optimising the intended outcomes of HICT.

HCT practices

- The quality of pre and post-test counselling should be closely monitored, especially in tournament testing contexts where concerns have been raised around ethics, the time allocated to counselling, notification of opportunities for follow-up support, and the support available to assist young people to take up referrals.
- Referral to post-test clubs should be more broadly adopted and some SfD organisations already provide support to young people who are HIV-positive. Participation in post-test clubs should also be made available to people who test HIV-negative, as testing often highlights the need for more information and motivation to remain HIV-negative in the face of the risks young people are typically exposed to. In some contexts, running post-test clubs that include both people who have tested positive and negative in the group, has proven to be a viable approach that needs to be explored further. Inadvertent non-consensual disclosure of HIV status by attendance or non-attendance of post-test clubs might be avoided by not restricting attendance to those who test positive or negative.
- In addition to the post test clubs, young people who have a positive test outcome should always be referred to psychosocial support group for people living with HIV and again there are some useful innovations in this area already in place in SfD organisations
- Rather than offering HCT as a standalone service, it should form part of deliberate and systematic prevention, care and support initiatives.

Organisations and national policies should aim at achieving widespread use of HCT services and actively promote 'knowing your HIV status'. Achieving targets for numbers of people tested should not however come at the expense of failing to guide individuals through the HCT process in a sensitive and appropriate way, as it would likely undermine the theory of change used to position HCT as a prevention strategy (see literature review). It is therefore important to approach incentivised testing and positive peer pressure with caution.

Combination prevention

Combination prevention refers to the concurrent use of biomedical, behavioural, social and systematic/structural interventions in targeting specific modes and contexts of transmission. It is seen as one of the foundations of new HIV-prevention thinking.

The World Health Organisation has made a call for the need to develop and promote combination prevention, treatment and care packages for key populations in different epidemic types and settings. Some SfD organisations have shown themselves as capable of meeting the challenge of contributing to combination prevention through functionally connecting a range of services and in some of the settings visited in this study, they stood out as the only viable avenue to achieving this.

HCT is a key element of combination prevention and the implied theory of change is that HCT is an entry point to prevention. It lays the ground for prevention outcomes, whether biomedical (ART as prevention); behavioural and social (sexual risk management, disclosure of HIV status to partners); or attitudinal shifts supporting prevention (building the notion of

living positively with HIV, promoting more open discourses about HIV, de-stigmatising HIV).

However, achievement of such outcomes following HCT cannot be left to chance and unknown referral networks. It also cannot be assumed that a quick test in a tent on a sports field fulfils the intentions of HCT. It is not the test but what the test is part of that matters.

It is strongly suggested that programmes using tournament testing and those referring to outside HCT service providers, should closely monitor both the quality of testing and the consequences of testing social network and individual levels. The value of HCT involves appropriate referrals, and SfD organisations should closely assess the quality of services and referrals, the forms of ongoing support and services offered, and the responses of young people to testing.

A number of organisations offer HCT through partnerships with hospitals and HCT service providers. This model allows for complimentary prevention approaches to be delivered simultaneously; with health care providers able to offer biomedical interventions, while SfD organisations provide support through programmes that promote socio-behavioural change.

Linking VCT soccer tournaments to home-based clinic outreach initiatives is recommended to effectively integrate patients into care and treatment services.

Systematic and deliberate follow-up should be built into each service so that organisations are able to track a young person from entering the life-skills programme to when they exit the programme and are referred to services outside of the youth centre.

Comprehensive and functionally integrated services

“Delivery of services that are better integrated, decentralized and resourced is an urgent priority.”
(Global health sector strategy on HIV/AIDS, 2011-2015)⁹²

This report has dealt extensively with the need to achieve higher levels of functional integration of services and strong referral networks with referral tracking. Challenges have been noted in situations where HCT is provided as a mobile service and where the SfD organisation is providing programmes away from its usual base.

SfD organisations providing or facilitating the provision of HCT services should always only do this when they have taken measures to ensure that referral pathways have been understood by HCT service providers, and where referral partners will be contacted regarding referrals, and forewarned about HCT tournaments.

Post-test clubs

The introduction of post-test clubs for both HIV-positive and negative outcomes is promising and necessary. Although providing such services directly it is not always possible when a SfD programme has been conducted at a distant location, the SfD organisation should be in a position to promote the development of such services among local service providers and provide access to guidelines and advice on how post-test clubs are best conducted and managed. This aspect of working with young people has not been firmly taken up by local actors and facilitating such services would be an achievable extension of programme activities. Appropriate guidelines for post-test clubs have not been developed to the same

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extent as coaching manuals have, and this is needed to ensure that participation leads to the desired outcomes for both positive and negative participants.

6 Monitoring, evaluation and research in SfD programmes

Monitoring and evaluation (M&E) is a significant challenge to many organisations, some of which have had to undertake M&E activities due to the relatively high emphasis placed on M&E in health, and specifically, HIV programmes. The capacity for research is even more challenging, as it requires specific skills beyond that which might be expected of programme managers and implementers.

6.1 M&E

Organisations have been unclear about what to monitor, evaluate and report. For smaller organisations difficulties experienced in managing evaluation processes have been exacerbated by lack of a strong sense of the utility of M&E activities other than the need to report to funders.

Ironically, organisations cited lack of funding for M&E as a major reason why M&E was not afforded more attention in their organisations; even as they struggled to report their outputs to funders. Some organisations reported having to actively fundraise to support their M&E functions, which had not been built into programme budgets; or in one case because funders had said they were not prepared to fund M&E activities.

The significant work involved in M&E practice was seen as additional to the main purposes of delivering specific services to young people, rather than an integral part of it; although one of the more established organisations actively uses M&E data as a critical part of programme development and management.

The undervaluing of M&E is not a phenomenon specific to SfD organisations, and comes from an emphasis on reporting outputs as the main purpose of M&E, at the expense of more intrinsically valuable M&E practices that could help organisations improve their services and management. A result is that M&E tends to be seen as a bothersome requirement, the utilisation-value of which is not appreciated or developed within programmes.

In more grassroots-type organisations, M&E was mostly limited to observing and capturing data such as the attendance of young people in the programme, numbers of matches played, the number of tournaments hosted, wins at those tournaments, and similar data, the knowledge-building value of which is not always clear. There was limited and sometimes no capturing of the outputs of life-skills components or HIV testing conducted on-site by external service providers.

The numbers of people tested in the course of SfD programmes are counted by some organisations, but since testing is often conducted by external service providers they do not specifically have to report HCT delivery statistics and therefore do not collect these numbers systematically.

In some instances monitoring activities strongly under-represent the contributions of these organisations to HCT service delivery. For example, some SfD organisations do not conduct HCT sessions themselves, but they supply equipment or facilities and create the opportunity for testing through their programmes. Their contribution is to ensure that young people are prepared to undergo HCT and that they have access to appropriate services. Sometimes there is a more concrete connection to HCT service provision in that the organisations have the health information centres on their premises, although these are manned by outside organisations. In other cases where there is no health information centre as part of the programme, the organisations refer young people to SRH or other health and welfare services. In all of the above cases there are instances where organisations do not capture these referrals and forms of indirect support for HCT in M&E records.

M&E systems are commonly geared only to record directly delivered outputs, missing the opportunity to show their important and often indispensable roles in service delivery supply-chains and missing their contribution to important outcomes.

Some organisations are more engaged in monitoring their achievements. One organisation routinely administers pre-assessment questionnaires which gauge the level of knowledge among young people on the life-skills component and / or other key aspects of the curriculum, as well as attitudes and behaviours. Programme participants then participate in the programme and on completion of the programme a sample would complete post-exposure questionnaires. This assists in monitoring and maintaining the quality of interventions and coaching in particular.

6.2 Research

Please refer to Section 5.2 above where research on the reach and outcomes of HCT in SfD programmes has been summarised.

There is a mixed picture in terms of organisations initiating research processes themselves. There are some smaller organisations that have had aspects of their programmes researched; usually by visiting volunteers or post-graduate students. Some larger SfD organisations and networks have developed substantial international contacts and support from reputable universities and scholars in the research and development of programmes. In some cases programmes have been well theorised and tested, and organisations actively seek evidence and engage in harvesting of new learning as an intrinsic part of their functioning.

Most of the research reports on SfD programmes are largely descriptive although as mentioned above there have been at least three published studies on the HIV prevention effects of sports-based youth programmes.

It is encouraging that there is a small, but growing body of international literature on the effectiveness of HIV awareness and behavioural outcomes of SfD programmes. One organisation is currently planning a randomised control trial to test the effectiveness of its programme through a quasi-experimental design, including use of biomarkers to test the prevention efficacy of the intervention. This is being done in partnership with reputable research partners and must be regarded as a milestone in the development of SfD HIV and AIDS programming.

As has been pointed out above, the existing literature is equivocal about the effects of HCT, although coaches and others tended to be quite unquestioning of the value of HCT. They tended to believe that it was good and were supportive of it on the basis of it being a part of national plans and objectives. There were some who were more reflective and circumspect about the achievements of HCT. However, generally there was not a strong awareness or questioning of what precisely the contribution of HCT was; only a commitment to the idea that it is important for everyone to know their HIV status.

It has been pointed out above, that the research literature connects good HCT outcomes – in terms of HIV prevention, treatment, care, support and impact mitigation – to adequate support and referrals within a functionally integrated system of services. Without this there is some risk of harm, or at least limited or no effectiveness.

The effectiveness of HCT is strongly reliant on what happens to young people when they enter the health system or system of HIV support, or when they complete programmes; especially since HCT quite often happens at tournaments which mark the culmination of programmes. Given the transitory nature of SfD programmes in schools and other off-premise locations, the ultimate outcomes are determined to a large extent by conditions beyond the control of the coaches. Those programmes with health information centres are somewhat of an exception to the extent that they have opportunity to run ongoing HIV support groups and have a greater ongoing involvement with

the young people they serve.

There is remarkably little research on the ethical propriety of HCT services in SfD programmes. The management of HCT was undoubtedly the most problematic of programme activities in organisations visited. The most important questions relate to tournament testing and the range of risks associated with this. The review of literature shows that where there is limited opportunity to manage referrals and ensure follow-through support of participants, HCT may have limited or negative effects. One organisation acknowledges this, and one of the large organisations has become concerned about it to the extent of needing to employ a social worker to manage the quality of HCT and follow-up services and to develop strategies to resolve problems around tournament testing.

6.3 Conclusions and recommendations

Monitoring and evaluation

The theory of change that undergirds support for HCT in national strategies needs to be fully-understood by all SfD programmes. There needs to be further investment in supporting and building the capacity of staff to understand, monitor and track the outcomes of HCT provisioning.

This involves keeping track of programme quality and standards as well as ethical propriety. It also involves building better understanding of the role of HCT in HIV prevention and treatment and how this should be optimised without incurring the kinds of risks that follow attempts to achieve scale.

It is important to develop ways of optimising the outcomes of HCT and to develop appropriate indicators for this. Current indicators for HCT generally do not go further than understanding the number of people reached.

There is also a value in gathering data that is useful for developing HIV/AIDS services. For example, it is of value to know whether young people are undergoing HCT for the first time or undergoing a repeat HCT procedure; as this allows understanding of how young people are engaging with HCT as a vehicle for HIV prevention. It is also of value to generate data on the ages, gender and area of domicile of those undergoing HCT and the HIV outcomes of testing. This kind of monitoring data is important to appreciate the kinds of HIV prevention, treatment and care services that are appropriate; and it helps to understand who is not being reached and the need to extend services accordingly. Rather than collecting data for reporting reasons only, it is important for use in management and development of programmes. The data is also valuable for country-level planning of services on the part of health and other government departments, especially given the scale of services in some countries.

Research

It should be of concern to international supporters of SfD programmes that the innovations, efficiencies and prevention or care outcomes of HCT provision in SfD programmes have not been adequately researched.

To build on the achievements, innovations and prospects that have been described above there is need for more systematic research at a sector level, rather than only on a project basis.

Innovations in HCT provision should be subjected to research and monitoring, especially regarding confidentiality, subtle coercion, social network curiosity and speculation about the HIV status of others; as well as to ensure minimum standards in terms of case management and referral for people with HIV-positive testing outcomes.

7 Summary of conclusions and recommendations

The broad aim of the review was to critically analyse and provide recommendations on different approaches used in SfD programmes for the effective prevention and treatment of HIV and AIDS.

This review indicates that SfD organisations that promote and offer HCT have limited resources and capacity to offer holistic and comprehensive services to young people. The most common model of HCT is through mass tournament testing which takes place periodically, and which, because of its mass format, is likely to be most prone to quality problems.

The association of SfD programmes with Health Information Centres and Comprehensive Facilities has the greatest potential in terms of quality of services, follow up and integration; but often function in challenging contexts and are not sustainable without significant donor aid and government support. Government facilities offer HCT; however, young people have mixed feelings about utilising the services due to perceived attitudes of health care professionals which deter youth from using their services. Often the stigma of being seen accessing these services is a major deterrent for young people.

While innovations in practice exist; including, post-test clubs, support groups for HIV positive children, and the building of referral networks to organisations that specialise in care and support, greater work still needs to be done to strengthen this area of service provision.

Treatment is available at most government and private health care facilities, and SfD organisations often refer their clients to these services. SfD organisations often have partnerships with these service providers, but the relationships are often not consistent and sustained.

Informed consent and confidentiality are by far the most cited ethical considerations in the practice of HCT and the provision of treatment. In practice, SfD organisations still face challenges with strict adherence to principles of confidentiality, informed consent (especially with minors) and disclosure. The main challenges organisations face are knowing to negotiate the conflict of client rights, particularly when there is a report of child abuse and sexual violence; and organisational reporting needs. The limits of confidentiality, consent for disclosure and anonymity were often not explained to young people seeking HCT services. While the encouragement of 'positive living' is a goal for many organisations, pressure to disclose one's status because of the incentives attached was often problematic.

Material incentives to promote HCT may promote and increase HCT uptake in young people by allowing the motivation for testing to be masked, allowing 'everyone' to test. Thus, those who test are not singled out as being at risk by virtue of testing. However, it does not lay the foundation for the prevention work that should be set in motion following prevention counselling, whatever the outcome.

SfD organisations that promote and offer HCT services to young people need to build the capacity of those who provide health and other HIV/AIDS related services to them. Conscious efforts have to be made to provide safety nets for young people who undergo HIV testing, as well as educating and advocating for professional conduct among those directly offering HCT services. HCT should be part of an integrated package that includes treatment, care and support for young people. Funders need to direct efforts towards supporting increased integration of services, relationship building among partners and the training and development of coaches and those directly involved in service delivery.

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Appendix 1 – Participating SfD organisations

Organisation	Services
Organisation 1, Lesotho	<ul style="list-style-type: none"> ▪ Life-skills + sport ▪ Promote HCT and offered through partnerships with mobile clinics ▪ Income generating ▪ Work skills ▪ Training
Organisation 2, Lesotho	<ul style="list-style-type: none"> ▪ HBC ▪ Life-skills +sports ▪ Based at hospital and HCT offered there ▪ Promote HCT and offered through partnerships with mobile clinics ▪ Nutrition programmes ▪ Treatment adherence
Organisation 3, Lesotho	<ul style="list-style-type: none"> ▪ Life-skills +sport ▪ Treatment adherence ▪ Scaling-up of community interventions in hard-to-reach communities ▪ Promote HCT and offered through partnerships with mobile clinics
Organisation 4, South Africa	<ul style="list-style-type: none"> ▪ Life-skills + sport ▪ Training ▪ Promote HCT and offered through partnerships with mobile clinics.
Organisation 5, South Africa	<ul style="list-style-type: none"> ▪ Networking and capacity building ▪ Marketing of member organisations ▪ Small funding conduit ▪ Technical assistance to member NGOs
Organisation 6, Zambia	<ul style="list-style-type: none"> ▪ Life-skills & sport ▪ HCT on site ▪ Marie Stopes SRH on site ▪ Child and adult support groups on site (some treatment adherence) ▪ Some HBC to HIV+ young people ▪ Tournaments ▪ Strong youth participation element
Organisation 7, Zambia	<ul style="list-style-type: none"> ▪ Life-skills in schools and community centres ▪ Sports programmes for child and adult HIV support groups at clinics ▪ Sports with young people with disabilities ▪ Tournaments with HCT ▪ Girls programme ▪ Sport for OVCs
Organisation 8, Zambia	<ul style="list-style-type: none"> ▪ SRH service provider with sport as an add-on ▪ PPAZ football team; education/outreach to other football teams, including regular community ones ▪ Youth action movement / peer education ▪ Host tournaments and assists other tournaments with SRH/HCT ▪ Some sports facilities at youth-friendly clinics, in order to draw young

people in

- Strong youth participation model for programmes implementation and org decision-making
- Organisation 9, Malawi
- Promote HCT at tournaments
 - Sport and Life-skills education in schools and communities
 - Technical assistance to youth clubs
 - Advocacy and training on human rights
 - Agri-income generating projects
- Organisation 10, Malawi
- Consultancy of organisational development
 - Youth centres
 - Promote HCT at tournaments
 - Sport and Life-skills education in schools and communities
 - HCT services onsite through partner organisation
 - International volunteer placement
 - Advocacy for education, human rights and child protection.

Appendix 2 – Introductory letter to organisations



Request for participation in Comic Relief and UK Sport good practice study

The Centre for AIDS Development, Research and Evaluation (CADRE) (www.cadre.org.za) is a South African non-profit organisation that specialises in research, evaluation, and program design in the HIV/AIDS field.

CADRE is conducting a 'good practice' study for Comic Relief, in partnership with UK Sport, aimed at better understanding models and approaches which use sport (with a focus on soccer) as a means of conducting youth development aimed at producing health outcomes. The study has a particular focus on stigma reduction, health-promoting behaviours, HIV counselling and testing and up-take in HIV health care and support among young people. This research will inform Comic Relief's programmes, grant policies and general practices in the area of sport for development.

The research is taking place in 4 countries, namely South Africa, Lesotho, Zambia and Malawi where 2 organisations in each country will be covered.

CADRE would like to request permission to conduct fieldwork in your organisation. The research looks at the following broad questions:

1. What is your organisation's understanding of how positive change and particularly health outcomes (with a focus on HIV and AIDS) can be engendered in young people using sports as an entry point?
2. How does your organisation apply itself to bringing about such change? What are the key elements in your programme? Who is involved and what are the different roles?
3. How specifically does the programme engage youth in HIV testing and treatment and how are issues to do with ethics and confidentially managed?
4. How does your organisation harvest knowledge, learn from experience and build on successes? How do you know that you are achieving what you set out to achieve?
5. How has your organisation's focus grown or changed over time?
6. What are your support networks/partnerships in the field?
7. How does your organisation think it might obtain long term sustainability?

The research will require the following from your organisation:

1. A 60 minute interview with a senior staff member who knows the programme intimately
2. A 60-90 minute group discussion with a group of 6-8 participants
3. Shorter interviews with programme participants, implementers/coaches or programme partners on an informal basis.

Your organisation will be provided with the findings of the study and will be acknowledged for its contribution.

CADRE will make a small contribution (R800) to express our appreciation for the time your organisation has given to the research.

Appendix 3 – Participants per organisation

Organisation	No. of Participants	Position	Interview type
Organisation 1, Lesotho	1 participant	Managing Director	IDI*
	6 participants	Coaches	FGD**
	8 participants	Programme beneficiaries	FGD
Organisation 2 , Lesotho	3 participants	Senior programme staff	FGD
	6 participants	Coaches	FGD
Organisation 3,Lesotho	1 participant	Director	IDI
	4 participants	Coaches	FGD
Organisation 4 , South Africa	1 participant	Programmes Manager	IDI
	12 participants	Coaches	FGD
	1 participant	Programme beneficiary	IDI
	1 participant	Curriculum design and M&E	IDI
Organisation 5, South Africa,	1 participant	Provincial coordinator	IDI
	50 participants	CADRE researcher attended a planning meeting for Network	Planning Meeting
	3 participants	Programme staff	FGD
Organisation 6 , Zambia	5 participants	Peer-educators	FGD
	1 participant	Counsellor	IDI
	1 participant	Director	IDI
	1 participant	RH Provider	IDI
	2 participants	Senior staff members	FGD
Organisation 7, Zambia	1 participant	Senior Project Officer	FGD
	15 participants	Peer-educators/coaches	FGD
	9 participants	Support group leaders	FGD
	3 participants	Programme Staff	FGD
Organisation 8, Zambia	6 participants	Counsellors and Coaches	FGD
	1 participant	Head of Health Centre	IDI
	2 participants	Director & Project Manager	FGD
Organisation 9,Malawi	4 participants	Programme staff	FGD
	4 participants	Coaches	FGD
	2 participants	Programme beneficiaries	FGD
	3 participants	Programme beneficiaries	FGD
	2 participants	Programme beneficiaries	FGD
	1 participant	Programme beneficiary	IDI
	6 participants	Programme beneficiaries	FGD
Organisation 10, Malawi	2 participants	Programme staff	FGD
	1 participant	Programme staff	IDI
	1 participant	Counsellor	IDI
	1 participant	Executive Director	IDI

* IDI – individual interview

** FGD – focus group discussion

Appendix 4 – Schedule of questions

Programme Managers/ Coordinators

1. What is your organisation's understanding of how positive change, and particularly health outcomes (with a focus on HIV and AIDS), can be engendered in young people using sports as an entry point?
2. How does your organisation apply itself to bringing about such change? What are the key elements in your programme? Who is involved and what are the different roles?
3. How specifically does the programme engage youth in HIV testing and treatment and how are issues to do with ethics and confidentially managed? By whom and how is the testing done? Through what kind of arrangement?
4. How is disclosure managed? What about peer pressure when a group have all been tested? Surely there is pressure to know each other's status? What do you encourage in such situations? How do you prevent problems?
5. What does counselling and testing involve in HIV-positive and negative outcomes?
6. What are the consequences of not wanting to test?
7. What kind of follow-up counselling and support is available?
8. Ask them about treatment? What is their continuing responsibility to the young person? Do they support treatment adherence? What kind of HIV-positive support do they offer?
9. What about positive prevention? Post-test clubs?
10. How does the organisation support prevention? What methods and approach do they use? How do they know it works? Does it?
11. How does your organisation harvest knowledge, learn from experience and build on successes? How do you know that you are achieving what you set out to achieve?
12. How has your organisation's focus grown or changed over time? What have been their big learnings over time? Ask them about their turning points in the past? Are they considering any new moves?
13. What are your support networks/partnerships in the field?
14. What do they provide? How do they manage and maintain such partnerships? Are there problems? What would they advise other programmes about partnerships for testing, treatment and support?
15. How does your organisation think it might obtain long term sustainability? What is funding situation? Do they have ideas about sustainability? What opportunities are there?

Coaches/programme implementers

1. What is your motivation for being involved in the programme?
2. What role, if any, do you think the programme has in encouraging young people to go for HIV testing?
3. What support is provided to young people wanting to undergo HIV testing? What role do you play in that? What skills/training do you have to enable you to be in that role? What additional skills are required?
4. What are some of the challenges you encounter in supporting young people seeking HCT?
5. What improvements, if any, would you like to see in HCT and sport for development?
6. What is their experience of how young people have responded to testing with both kinds of outcomes?
7. How specifically does the programme engage youth in HIV testing and treatment and how are issues to do with ethics and confidentially managed? By whom and how is the testing done? Through what kind of arrangement?
8. How is disclosure managed? What about peer pressure when a group have all been tested? Surely there is pressure to know each other's status? What do you encourage in such situations? How do you prevent problems?

9. What does counselling and testing involve in HIV-positive and negative outcomes?
10. What are the consequences of not wanting to test?
11. What kind of follow-up counselling and support is available?
12. Ask them about treatment? What is their continuing responsibility to the young person? Do they support treatment adherence? What kind of HIV-positive support do they offer?
13. What about positive prevention? Post-test clubs?
14. How does the organisation support prevention? What methods and approach do they use? How do they know it works? Does it?
15. Do they believe that all this HIV and health stuff works well through the organisation or should it rather be done by the health services?
16. Also ask them about behavioural prevention practices and how these are received.

Programme participants

1. What is your motivation for participating in the programme?
2. Are there any particular changes you have seen in yourself since being part of the programme?
3. Have you ever considered taking an HIV test? *Why? Need to rephrase-sensitive. You hopefully won't read questions so all needs to be paraphrased into the conversation.* Is there any pressure to be tested? What do they think about the testing thing the way it is done in the club, and elsewhere? How do they think testing should be done/
4. How does testing affect people, as far as they know?
5. What kind of support do you need in order to go for HCT? Do you think the organisation is equipped to provide you with that support? How?
6. What needs to happen to make to enable you to consider going for HCT? - *Only if they said NO to 3.*
7. What about treatment? What happens if people need treatment or counselling? Does the organisation/club support this?
8. What do they think of the organisation's attempts to promote prevention? Does it work? *Ask for stories about this.*
9. What other services are you aware of that can support you should you ever decide to go for HCT? How? And how did you come to know about them?
10. Overall: the organisation's approach to this versus the health services, etc. Why not just use the health and other NGO services. Is it worth the effort?

Appendix 5 – HCT country guidelines for minors

Country	Guidelines	Age of consent for HIV testing
Malawi ⁹³	<ul style="list-style-type: none"> Any person below 12 years who is sexually active, pregnant or married is considered to be a mature minor, therefore, is eligible for HIV testing consent. 	13
South Africa ⁹⁴	<ul style="list-style-type: none"> HCT for a minor under 12-years old must be done for medical management and treatment purposes only. Persons younger than 12 years must demonstrate an acceptable level of maturity if they are to be tested without parental consent. 	12
Lesotho ⁹⁵	<ul style="list-style-type: none"> Pregnant, sexually active minors may consent to testing at any age provided they understand the consequences and benefits of testing. 	12
Mauritius ⁹⁶	<ul style="list-style-type: none"> A person must be able to demonstrate capacity to understand the risks and benefits of HIV testing. 	Not specified
Mozambique ⁹⁷	<ul style="list-style-type: none"> Married, pregnant and sexually active girls below 16 years can give consent for testing. 	16
Namibia ⁹⁸	<ul style="list-style-type: none"> Minors should express maturity and capacity to understand the risks and benefits of HIV testing and consent 	14
Botswana ⁹⁹	<ul style="list-style-type: none"> If younger than 16 years, there must be demonstrable evidence of a medical need for HCT. Persons between 16 and 21 are offered an HIV test as part of routine health services, but still need parental/legal guardian consent. In practice, adolescents especially those aged 18 and over, are sometimes tested by giving verbal assurances that they have obtained their parents'/legal guardians' consent. 	21
Swaziland ¹⁰⁰	<ul style="list-style-type: none"> Parental consent required for HIV testing for those less than 15 years old. Inconsistent across service providers, as some do not enforce the need for parental consent and will provide service for children less than 15 years old, depending on circumstances. 	15

⁹³ Mwandira (2008)

⁹⁴ Department of Health, South Africa section 132 of the Child Act (2010)

⁹⁵ Zambia HCT report (2009)

⁹⁶ HIV and AIDS Act Mauritius (2006)

⁹⁷ Mozambique National AIDS Council Plano Estratégico Nacional de Combateao HIV/SIDA (2005-2009)

⁹⁸ UNICEF (2011)

⁹⁹ The Botswana Review of Ethics, Law and HIV/AIDS (BRELA) (2008)

¹⁰⁰ UNFPA (2007)

Zambia ¹⁰¹	<ul style="list-style-type: none"> ▪ Married and pregnant minors are considered to be mature minors/ emancipated minors, therefore can give consent. Zambia has age specific guidelines: ▪ 0-6 years- consent obtained from parents or legal guardians. ▪ 7-15 years- consent obtained from the child if they understand the risks and benefits of HIV testing. 	16
Kenya ¹⁰²	<ul style="list-style-type: none"> ▪ HCT done only for medical intervention for persons below the age of consent, therefore parental/legal guardian consent is needed. ▪ HCT solely for pregnant, sexually active girls and young mothers who are below this age. 	15
Zimbabwe ¹⁰³	<ul style="list-style-type: none"> ▪ HCT is strictly for persons below this age ONLY when they are living independently, sexually active or pregnant. 	16

¹⁰¹ Zambia HCT Report (2009)

¹⁰² UNICEF (2011)

¹⁰³ Ministry of Social Welfare Zimbabwe (2009)

Appendix 6– Models of HCT provision

Model	What we know	Issues for consideration
Free standing HCT centres/ Client-initiated HCT ¹⁰⁴	<ul style="list-style-type: none"> Operated by non-governmental organisations. Clients come exclusively for HCT. Results are obtained within ten to 20 minutes. Examples: New Start , AIDS Information Centre in Uganda, Planned Parenthood Worldwide, and Population Services International (PSI) 	<ul style="list-style-type: none"> Sometimes limited psychosocial and medical infrastructure to clients post testing. Associated with HIV, therefore sometimes stigmatised.
Provider-initiated HCT /Routine testing ¹⁰⁵	<ul style="list-style-type: none"> Client is offered HIV testing during regular health visits (routine HCT) or when the patient presents HIV related symptoms (diagnostic HCT for medical management and treatment). Client has an option to opt out/ decline the test or opt in/accept to take the test. Successful in Botswana, South Africa, Lesotho and other sub-Saharan countries.¹⁰⁶ 	<ul style="list-style-type: none"> Provider has power and authority over the client. Clients may be tested without establishing full consent as in VCT.¹⁰⁷ Adequacy of infrastructures and human resources for testing and skilled pre- and post-test counselling May not take into account the unequal and gendered context of society in which HIV testing occurs, as well as the high levels of prevailing HIV-related stigma, discrimination and other violations of rights. Clients are allegedly sometimes not provided the choice to ‘opt out’.¹⁰⁸
Integrated HCT ¹⁰⁹	<ul style="list-style-type: none"> HCT combined into existing health care settings; e.g. sexually transmitted disease clinics, TB clinics, family planning clinics, antenatal care facilities, men’s health clinics and primary health care clinics. Young people are often reluctant to attend formal health services; reproductive health services reach few adolescents. Effective for young people who present signs of STI’s, TB and who attend family 	<ul style="list-style-type: none"> It is not appealing to groups that do not readily go to health care facilities such as men and youth. Adequacy of infrastructures and manpower for testing, skilled pre- and post-test counselling determine the success of this model HCT and counselling services can be integrated into youth friendly health services easily and relatively inexpensively if HCT is already available in primary health care

¹⁰⁴ McCauley (2004)

¹⁰⁵ UNAIDS (2007)

¹⁰⁶ De Cock (2005)

¹⁰⁷ Obi & Ifebunandu (2006)

¹⁰⁸ Physicians for Human Rights (2006)

¹⁰⁹ McCauley (2004)

planning only.

Youth centres¹¹⁰

- Youth Friendly services provided by young people.
- Innovative approaches to integrating counselling.
- Youth culture—such as music and drama—has been developed in the United States and some African settings (e.g., Botswana, Uganda, Zambia and Nigeria).
- There is room to increase the delivery of counselling through these sites.

Integrated into school and college¹¹¹

- HCT Service offered to learners above the stipulated age of consent.
- Adopted by South Africa department of Health since 2011 (On hold due to ethical objections).¹¹²
- Best-suited for youths who are still at school.

PMTCT¹¹³

- Pregnant women offered a test for HIV during pregnancy, labour and delivery, or breastfeeding.
- Works best for youths who attend antenatal care.
- Complements couple's HCT.

Community /Mobile HCT¹¹⁴

- Mobile services such as vans or buses equipped with HIV-testing facilities.
- Designed to reach hard-to-reach places and groups such as sex workers, drug injecting users or employees at companies.
- Best suited for youth who reside on the

settings.

- There is no hard evidence to suggest that YFHS are effective or that YFHS successfully increases young people's use of health services.
- Cautions in using such sites for HCT—including ensuring confidentiality, testing quality and providing adequate referral.
- Networks for positive young people.

- Psychological impacts of testing at young age.
- Age of consent does not equate maturity to understand the risks and benefits of HIV testing.
- Issues of confidentiality and privacy are a challenge since testing is done on school grounds.
- Teachers are not equipped to counsel learners who test positive.
- Disclosure to partners is sometimes not feasible. Some clinics have limited resources.
- Feasibility of replacement feeding is not an option for most women and the individual's commitment to adhere to prophylaxes and medications.
- It can be costly as it requires more resources, equipment and manpower.
- Follow up after the testing is not easy since clients are anonymous.
- Service requires extensive community mobilisation to be

¹¹⁰ Boswell & Bargarley (2002)

¹¹¹ Boswell & Bargarley (2002)

¹¹² News24 (December, 2011)

¹¹³ McCauley, (2004).

¹¹⁴ Khumalo- Sakutukwa et al. (2008)

	streets, those who are sex workers, and drug injectors.	successful.
Home- based HCT¹¹⁵	<ul style="list-style-type: none"> ▪ Done at the client’s home by lay counsellors and community health workers who provide counselling and testing. ▪ Studies¹¹⁶ demonstrate that it is preferred to testing at the public health facilities given concerns about confidentiality. 	<ul style="list-style-type: none"> ▪ There are no data demonstrating potential positive impact of home testing in comparison to HCT. ▪ Results may be inaccurate or misinterpreted; it reduces uptake of appropriate pre- and post-test counselling and it does not facilitate referral for the individual¹¹⁷.
Self -testing¹¹⁸	<ul style="list-style-type: none"> ▪ Client does rapid test and the results are obtained in less than ten minutes. ▪ Designed to increase accessibility, availability, stigma reduction and to enhance confidentiality. ▪ Banned in South Africa due to lack of pre- and post-test counselling. It is speculated that it could lead to anxiety and ultimately suicide for those who test positive. 	<ul style="list-style-type: none"> ▪ Results may be inaccurate or misinterpreted. ▪ Lack of appropriate pre- and post-test counselling; and it does not facilitate referral for the individual¹¹⁹. ▪ There is no actual research evidence that correlates self-testing with disruptive behaviour or suicide¹²⁰.
Couple’s HCT^{121,122}	<ul style="list-style-type: none"> ▪ Designed for married and cohabiting couples to facilitate disclosure, communication on HIV, and prevention. ▪ Effective prevention for sero-discordant couples. 	<ul style="list-style-type: none"> ▪ Marital disruption; positive concordant couples may split up or experience the death of one partner. ▪ Data is notoriously unreliable for self-reported sexual behaviour; for example, in a Zimbabwe household study, about a third of the young women who were HIV-positive reported being virgins¹²³.
Premarital HCT¹²⁴	<ul style="list-style-type: none"> ▪ Done before the couple marries ▪ Mandatory in most countries such as Bahrain, Guinea and Ethiopia For both males and females are required to undertake mandatory HCT. There are no services mentioned attached to mandatory pre marital HCT. Currently 	<ul style="list-style-type: none"> ▪ Infringes upon internationally guaranteed human rights. ▪ Without regard for informed consent, confidentiality, and access to HIV counselling and information¹²⁶

¹¹⁵ Bateganya et al. (2007)

¹¹⁶ Fylkesnes & Siziya (2004)

¹¹⁷ Boswell & Bargarley (2002)

¹¹⁸ South African Medical Association (2007)

¹¹⁹ Boswell & Bargarley (2002)

¹²⁰ Richter et al. (2010)

¹²¹ Allen (1993)

¹²² Grabbe (2010)

¹²³ Kilembe (2010)

¹²⁴ Turyagyen (2000)

proposed model in Cambodia, Senegal and Zimbabwe¹²⁵

Private care HCT¹²⁷

- Private health practitioners such as private doctors, traditional healers, pharmacists to provide information and service of HCT.
- Preferred by young people.
- Can provide on-going medical care for people living with HIV/AIDS.
- Enhanced confidentiality and privacy
- High cost since the services are done privately.
- Limited staff and HCT services might result into poor quality counselling.
- Doctors, pharmacists, traditional practitioners and nurses are too busy to do thorough pre- and post-HCT counselling.
- There is potential to improve HCT in the private setting. Although there have been some small-scale increase in private HCT uptake.
- Efforts to train private practitioners to offer better HCT services, there has been little emphasis on improving HCT services for young people in the private sector¹²⁸.

HCT for insurance purposes¹²⁹

- Life insurance requires HIV tests to be done.
- Indirect mechanism that increases HCT uptake.
- Benefits are denied should the individual refuse to take the test.
- Not effective for young people because they are usually not the recipients of insurance services.
- This model has been labelled as discriminatory against people living with HIV/AIDS.

¹²⁶ Burns (2008)

¹²⁵ Open Society Institute (2009)

¹²⁷ Kakande (2002)

¹²⁸ Boswell & Bargarley (2002)

¹²⁹ Shilongo (2012)

Appendix 7 – SWOT analysis of HCT models

	Strengths	Weaknesses	Opportunities	Threats
<ul style="list-style-type: none"> ▪ Tournament Testers: 	<ul style="list-style-type: none"> ▪ Minimal cost implications for the SfD organisations, but reaches a greater number of people. ▪ Encourages partnerships among organisations that specialise in different services. ▪ Mass HCT testing also reduces issues related to stigma of testing as many people in the group collectively seek the service at such events. ▪ Normalises HCT for young people. 	<ul style="list-style-type: none"> ▪ The nature and quality of pre- and post-test counselling is often not adequate. ▪ Lacks safety mechanisms for people who have a positive HIV test outcome at events. ▪ Referral systems and follow up that can be offered in this setting is often not adequate. ▪ Systematic follow up of utilisation of referral systems is a major challenge. ▪ Positive peer pressure among youth groups is often a coercive factor in pressuring young people to test and disclose their status. ▪ HCT uptake is limited to event attendees. ▪ Poorly developed M&E systems. ▪ M&E is limited to testing statistics and not impact. ▪ People with disabilities (blind, deaf, mental health) are not well catered for. 	<ul style="list-style-type: none"> ▪ Services can be taken to the most remote areas. ▪ Offers opportunity for couple's testing. ▪ Increased collaboration and integration of services. 	<ul style="list-style-type: none"> ▪ Unpredictable funding patterns and access to resources. ▪ Is not sustainable in the format that it is currently implemented. ▪ Increased need for integrated services may make this model die out.
<ul style="list-style-type: none"> ▪ Health Information Centres 	<ul style="list-style-type: none"> ▪ Increases access of family planning and HCT for youth. ▪ Services are located in places that young people often frequent. ▪ Normalises HCT 	<ul style="list-style-type: none"> ▪ It is costly and time-consuming for organisations. ▪ It does not adequately address the organisation's on-going responsibility to young people who have had a positive test outcome 	<ul style="list-style-type: none"> ▪ Has potential for replication and scaling up in hard-to-reach communities. ▪ Offers opportunities to get young men involved 	<ul style="list-style-type: none"> ▪ Largely maintaining the status quo where family planning is mainly targeting women, to the exclusion of young men.

	<p>for young people.</p> <ul style="list-style-type: none"> ▪ Promotes health-seeking behaviour. ▪ Often, the service is youth oriented. ▪ Can diagnose STI's/TB and HIV co-infections and offer treatment immediately. 	<ul style="list-style-type: none"> ▪ Does adequately support treatment adherence. ▪ Uptake of referral services and follow up in is not easily measured. ▪ Does not adequately address the mental health fall-outs post receiving a positive HIV test outcome. 	<p>in HCT and family planning activities.</p> <ul style="list-style-type: none"> ▪ Potential to reduce teenage pregnancy, STIs and HIV rates among youth. 	<ul style="list-style-type: none"> ▪ Centralised location of services may make them inaccessible to people without financial means to travel. ▪ Does not adequately address the "fear of being seen" accessing SRH services.
<ul style="list-style-type: none"> ▪ Comprehensive Health Facility 	<ul style="list-style-type: none"> ▪ Supports treatment adherence and support. ▪ Promotes access and utilisation of health facilities by youth. ▪ Encourages health-seeking behaviour in young people through inclusion of youth friendly interventions. 	<ul style="list-style-type: none"> ▪ Very costly and resource intensive. ▪ Often does not adequately address the psychosocial needs of youth. ▪ Health is their priority, so SfD is often not given adequate attention and/ or resources. 	<ul style="list-style-type: none"> ▪ Can be easily replicated in communities that have local clinics or health care facilities. ▪ Potential for scaling-up services in hard-to-reach communities. ▪ Offers opportunities for developing and piloting minimum policy standards for counselling in a contained setting. ▪ Potential to promote utilisation of health care facilities by young men. ▪ Advocacy for youth-oriented healthcare services. 	<ul style="list-style-type: none"> ▪ Costly and unsustainable if services rely on aid. ▪ Attrition of medical personnel seeking better employment.