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# Capacity-building for knowledge generation: Experiences in the context of health and development

Anke van der Kwaak, Hermen Ormel and Annemiek Richters (Eds)



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## 7 Multi-country programme on social science research redesigned: The case for a Great Lakes Applied Research Centre

Annemiek Richters, Hermen Ormel and Anke van der Kwaak

### Abstract

During the last year of the Multi-Country Programme for Social Science Research on HIV and AIDS (MCP - see previous chapter), it was decided that it would be more strategic in terms of capacity-building in the field of applied qualitative research to work with a limited number of research institutes in a particular region in Africa, instead of a consortium of countries spread over the continent. Another major decision was that the 'call for proposals' approach as applied in the MCP should be replaced by an approach that would allow closer cooperation and exchange between the consortium members regarding research capacity development. For that purpose the choice was made to work from a common theoretical perspective and focus on a common research theme, while allowing enough space for each country to develop a specific research focus of particular relevance to the country concerned. This chapter describes the process towards setting up the Great Lakes Applied Research Centre (GLARC), its evolving approach to research capacity development, the selected theoretical perspective of "vulnerabilities and social capital", the theme of "discordant couples" as the first common research theme and the country-specific foci for the proposed research as presented in draft proposals. The outcome of the GLARC process so far is that due to a lack of resources no progress has been made in the cross-country implementation of the various proposals. However, some GLARC members succeeded in carrying out exploratory research on the topic of discordant couples, and the networking between members resulted in various bilateral research activities. Leadership, partnership and the existence of a network in which research and mutual learning is the focus cannot exist without resources in terms of financial support, logistical means and innovative thinking. Unfortunately, the latter can only to be shared and implemented when the first two are in place to sustain the process.

### 7.1 Introduction

From 2005 to 2008, the MCP was operational in five African countries (Botswana, Burkina Faso, Ethiopia, Namibia and Rwanda), supported by various Dutch universities and funded by the Netherlands' Ministry of Foreign Affairs and the Dutch Aids Fonds (Van Poelje 2012, in this volume). The MCP aimed to increase the national capacity for the management and implementation of social science research for HIV and AIDS in the participating countries and facilitate mutual learning and joint fundraising for social science research on HIV in sub-Saharan Africa. The added value of such multi-country research partnerships and, more specifically, the need to establish networks for social science research in the field of

HIV and AIDS have been repeatedly emphasized (Kippax and Holt 2009; GHIN and CREHS 2010).

During the MCP implementation process it became clear that the inception phase needed more time than envisioned, to come up with a solid proposal for a second phase of capacity-building in the field of HIV and AIDS social science research. In a one-year extension (2008–2009) the consortium membership changed and saw the inclusion of four new members (Burundi, Democratic Republic of Congo, Kenya and Uganda), while Botswana and Burkina Faso no longer participated. The rationale for this change was that capacity-building in the field of applied research would be more effective and strategic if applied to a limited number of research institutes in a particular region in Africa, instead of a consortium of countries spread over the continent. The newly chosen regional approach would allow for more frequent exchanges among the researchers, policymakers, end-users and other stakeholders from the various countries. In addition, it was expected that the participating countries would have similar research priorities, which would facilitate cooperation and exchange between countries in terms of research capacity-building.

Rwanda had played a key role in the coordination of the inter-country MCP process and had achieved much in terms of in-country capacity-building – substantial stakeholder participation, active involvement of the National AIDS Committee, identification of a common research agenda and implementation and validation of a number of studies. Given the partly new group of countries, it was decided that a focus on the Great Lakes Region, with Rwanda at the centre, would offer the best chance to achieve more common ground and cohesion: the national HIV epidemics in the region had a number of common characteristics, and across the countries there was a shared need for further capacity-building. Ethiopia could serve as a "resource country", since the quality of social science research conducted in this country was considered by far the best of the MCP group. Namibia would be linked to what was to become the Great Lakes AIDS Research Centre (GLARC), with the ultimate aim of starting an initiative similar to GLARC in Southern Africa.

In this chapter we will describe the capacity-building process as it developed in the fifth and last year of the MCP and in its aftermath. We will focus in particular on the main issues discussed by the MCP participants during the process, and its outcomes and challenges. We conclude with an overview of lessons learnt in terms of cooperation between the different consortium partners (South–South and South–North) and research capacity-building.

### 7.2 Capacity development: The process

The philosophy, objectives and capacity development approach of the MCP's extension phase (fifth year) were in line with those of the first four years. In addition to consolidating what had already been achieved, a major additional specific objective was the development of a proposal for a regional collaborative centre that would give substance to the follow-up phase of the MCP. To achieve the objectives for the extension phase, two workshops were held in Kigali (November 2008 and March 2009) and a third at the Royal Tropical Institute (KIT) in Amsterdam (May 2009). Besides discussing the future of the collaborative network and its research agenda, capacity-building for social science research remained a priority of all workshops and separate strategy meetings. Sessions on health systems strengthening, research among young people, mental health and sociotherapy were given, but emphasis was also placed on putting a monitoring and evaluation (M&E) system in place and how to plan with milestones. The development of a log frame was part of this.

During the first workshop the vision of GLARC was extensively debated, against the background of the lessons learnt from the MCP's first four years. The vision as it evolved in the process leading up to a GLARC proposal (see below) reflects the vision which was steering the MCP process from the beginning as well as the work experiences of the work-shop participants who had been involved in the MCP all along.

## 7.3 Capacity development: The content

Regarding research programming, two options for proceeding with research in the context of a multi-country study programme were examined: the call for proposals approach and the multi-country studies approach (see Annex 7.1). It was decided to build on the strength of both options and thus not continue with the call for proposals approach as applied in the previous MCP phase in each country separately. Workshop participants opted for a setup that would allow for closer cooperation and exchange between the consortium members regarding research. For that purpose, the choice was made to work from a common theoretical perspective and focus on common research, while allowing enough space for each country to develop a specific research focus that would be of particular relevance to the country concerned.

A free listing exercise resulted in four possible research themes being proposed for GLARC with a list of sub-topics for each.

Family planning and HIV and AIDS	Marriage and HIV and AIDS	HIV and AIDS and (post-) conflict situations	Sexuality and HIV and AIDS
Cultural aspects Role of grandparents Role of aunties Community participation Adolescent orientation Vulnerabilities	The role of faith Cultural aspects The role of community Poverty and socio- economic aspects Vulnerabilities	Migration Gender-based violence Rape Impact on health system Compliance with anti- retroviral therapy Religion Nutrition Family distortion	Teenagers Young adults Generational Sexual orientation Disclosure Risk and responsibility
		Coping mechanisms Therapy and counselling	

### Table 8 Proposed GLARC research themes and sub-topics

Post-workshop discussion with various stakeholders, particularly within Rwanda, resulted in a list of key theoretical concepts that could guide the future research programme (with one or more of the themes listed in Table 8 as its focus). The list included the concepts of vulnerabilities, accountability, value of life, risk perception and behaviour change. In addition, some desk review was done regarding these concepts and their relevance. The results were presented during the second workshop. There it was observed that the concepts of risk perception and behaviour change seemed over-used in the field of HIV and AIDS. They were, therefore, laid aside. The concept of value of life, originally chosen as a key concept for the proposed research, was considered to be an aspect of the much broader concept of vulnerability that came to the fore later (see below). It was, therefore, decided not to include the concept of value of life in the title of the research programme.

Eventually, the concepts of vulnerability and social capital were chosen as the most relevant for tackling the selected research themes. The theme of discordant couples was considered to be a neglected research topic in each participating country, while allowing enough flexibility for researchers to work on country-specific issues. It could also be considered as a theme cross-cutting the themes and sub-topics listed in Table 8. Each participant was asked to write a draft on the aspects of the theme of discordant couples they found relevant to research in their respective countries. The idea was that once GLARC were operational, a research theme to subsequently address in its second year and years to follow would be selected.

Throughout the various workshops the consortium developed the different sections of the GLARC proposal. Also, it addressed and defined capacity-building in terms of knowledge generation and shared information through separate sessions on: M&E for research and research communication, health systems and HIV programmes, ethical issues, the concept of resilience with regards to HIV and AIDS, the philosophy and practice of community-based sociotherapy in Rwanda, and the electronic monitoring system for the surveillance of AIDS patients as used in Rwanda. The objective of the finalizing KIT workshop (May 2009) was to present and discuss the outcome of the work achieved during the MCP extension phase in the company of donors, KIT personnel, representatives of non-governmental organizations (NGOs) and Dutch knowledge institutes and individuals interested in the topic. The draft GLARC proposal was finalized soon after (KIT 2009).

# 7.3 Capacity development outcomes: Vulnerabilities and social capital among HIV-discordant couples

The main outcome of the extension phase was the proposal for GLARC. It suggests that GLARC should be a regional membership-based and donor-supported research and capacitybuilding network whose mission is to promote dialogue and interaction between researchers, HIV practitioners, the private sector and policymakers in the Great Lakes Region and Ethiopia with a view to enhancing the impact of social science research in the field of HIV and AIDS on policymaking and development planning. Here we present only the part of the proposal that focuses on the content of the proposed research.

### 7.3.1 Theoretical framework of vulnerabilities and social capital

In the GLARC proposal the use of a theoretical framework of vulnerabilities and social capital is presented for the study of the complex factors that either prevent or facilitate behaviour change. An underlying idea of this framework is that an individual's reaction to HIV- and AIDS-related issues and adoption of a particular behaviour are not influenced by the quality of the available information alone, but also by biographical factors such as people's perception of the value of life and perception of death, by relational dynamics and by social contexts in which relationships occur and individual life trajectories develop. Another presupposition is that studies done from the perspective of a vulnerability framework point to the need for interventions aimed at enablement and empowerment. GLARC would engage with these kinds of interventions from the perspective of social capital development.

### 7.3.2 Vulnerability

The heuristic matrix of vulnerability that is suggested to guide the research proposed in the GLARC context contains three levels: the social trajectory level (biographical fragility or identity vulnerability), the level on which two or more trajectories intersect (relational vulnerability), and the social context (contextual vulnerability). Delor and Hubert (2000) argue convincingly that any in-depth, comprehensive study of vulnerability should include in its focus these three levels, the particular links among them and their respective impacts on HIV- and AIDS-related behaviour. To study complex situations of vulnerability, they use the framework as presented in Table 9, defining an objective and a subjective dimension of vulnerability. Within both dimensions, the three levels of vulnerability are distinguished.

Level of reading of a situation of vulnerability	Objective dimensions	Subjective dimension
Trajectory level	Life cycle, age, gender, social mobility, social identity etc.	Subjective time, life project, perception of the future, *value given to life and death etc.
Interaction level	Partners' characteristics (ages, serological status etc.), setting of inter- action etc.	Subjective representations of the partner, perceptions of condoms according to sero-status etc.
Context level	System of collective norms, institutions, gender relations, inequalities etc.	Subjective perceptions or norms, personal interpretation and expectation of punishment etc.

Table 9	Framework with	examples of	fa range	of vulnerability factors
Table 5	Traine Work With	champies of	arange	or vanierability ractors

Source: Delor and Hubert 2000:1561 (\* added to the original framework)

The various elements of vulnerability can be resituated in the process of identity construction, which can be described as a process aimed at maintaining, expanding or protecting the living space in which a person is socially recognized. Situations of vulnerability are the circumstances – in terms of specific moments and areas – during which this vital exercise is the most painful, difficult and perilous. Since the first GLARC research proposed focusing on sero-discordant couples (see below for a justification of this choice), let us take such a couple as an example. The wife is living with HIV and the husband remains HIV-negative. She has been raped by soldiers and witnessed brutal war violence, which made her lose an interest in the future. Her husband forces sex upon her. Part of her family has been killed or went into exile; her remaining social network is small, and the social relations within this network are poor. It is mainly through in-depth qualitative research that we can learn to understand the behaviour of this particular woman, including her reasons for not wanting to disclose her HIV status to her husband and her still having a number of children with him even though she does not show much interest in children. While discussing this case and other specific vulnerabilities in post-conflict settings, the value people attribute to life and death was singled out as a factor that would need particular attention. It was then added to the framework of vulnerability factors.

GLARC studies, it was proposed, would focus on vulnerabilities of different population groups. Qualitative research approaches would be used to gain insight into the link between situations of vulnerability to various risks and situations of tension or upset balance in the complex system of relations with oneself, with others and with the world. We hypothesized that interventions to improve social relations would have a positive effect on changes at the other two levels and result in behaviour change that would contribute to the appropriate prevention, care and treatment in relation to HIV and AIDS. Based on this hypothesis we adopted the theoretical framework of social capital to approach the operational aspect of the research programme.

### 7.3.3 Social capital

The key element of the concept of social capital is that 'relationships matter' (Field 2003). In most social capital studies a distinction is made between *bonding* and *bridging* social capital. Within these two types of social capital a distinction between *structural* and *cognitive* social capital, both operating at micro (individual person or family) and macro (neighbourhood, community, formal or informal group) levels, is also made. The structural form of social capital comprises the extent and intensity of social links or activities, and the cognitive form covers the perceptions of support, reciprocity, sharing and trust. HIV prevalence has a negative effect on social capital, which in turn hinders the development process (David and Li 2008).

The hypothesis regarding the importance of access to social capital for behaviour change to occur is supported by experiences with sociotherapy as implemented in Rwanda (Richters et al. 2010). Participation in sociotherapy by people living with HIV reduced their isolation and hopelessness and contributed to their regaining self-respect and being recognized by others as a valuable human being. Sociotherapy stimulated its participants to go for testing, change their eating patterns and care for others. The increase in social capital also led to a reduction of sexual violence in intimate relations. The hypothesis that social capital is positively related to HIV control, in terms of reducing incidence, is also supported by a study undertaken in rural Zimbabwe, which explored the role of social capital and school education in avoidance of HIV among young women (Gregson et al. 2004). The conclusion was that participation in local community groups is often positively associated with successful avoidance of HIV, which in turn is positively associated with psychosocial determinants of safer

sexual behaviour. A last example that supports the importance of social capital for behaviour change is the "community conversation" implemented by CARE in Ethiopia. This intervention functioned as a catalyst for stigma reduction and behaviour change (Getaneh et al. 2008).

In our discussion on the possible contribution of the strengthening of social capital to the reduction of vulnerabilities to HIV it was recognized that particular forms of social capital do not reduce that vulnerability but increase it instead. For instance, strong social bonds within extended families may foster gender norms and identities that obstruct the development of the psychosocial qualities and behaviours that are needed to successfully avoid HIV infection. This form of social bonding has been described by some authors as 'anti-social capital' (Gregson et al. 2004:2122). Another issue to consider is that sexual liaisons with multiple partners may serve to increase the size and diversity of an individual's sexual relationships and as such increases their social capital (Thornton 2009). This case could also be considered anti-social capital. We concluded that by using the concept of social capital as a key concept in our proposed programme for research, there would be a need to be attentive to positive and negative aspects of social capital in terms of HIV prevention and care for people living with HIV and AIDS.

## 7.3.4 Vulnerabilities and social capital among HIV-discordant married or cohabiting couples

The research topic for the first phase of GLARC was "vulnerabilities and social capital among HIV-discordant married or cohabiting couples". HIV infections in sub-Saharan Africa are mostly attributable to heterosexual transmission. On the basis of survey and clinical data collected in urban Zambia and Rwanda, it was estimated that 60–90 per cent of new heterosexually acquired infections occurred within marriage or cohabitation (Dunkle et al. 2008). However, even though HIV-discordant partnerships are a risky context for women and men, most HIV services in Africa currently deal primarily with clients as individuals.

The HIV-positive partner in a sero-discordant couple is often confronted with the challenge of, for instance, disclosing his/her HIV status to his/her spouse, relatives and/or friends and making a decision whether or not to become (for the first time or again) a biological parent. While voluntary counselling and testing and behaviour change interventions aimed at couples have shown to reduce HIV transmission among sero-discordant couples, the premise of GLARC is that given the contextual vulnerability of the partners in these couples, various kinds of community interventions enhancing the social capital of these partners may be even more effective towards HIV prevention (Kwagala et al. 2008). The same applies to contraceptive use among these couples. With the availability and increased access to anti-retroviral drugs (for anti-retroviral therapy (ART) and prevention of mother-to-child transmission) in certain sub-regions of the Great Lakes Region, sexual activity and the desire for biological children have increased, also among sero-discordant couples. With fertility rates already high, integration of HIV prevention and family planning efforts is advisable (Odhiambo 2007).

The spread of HIV in the countries involved in GLARC may be specifically affected by people's high mobility in the region and by (related) sexual violence outside and within

marriage. Three country examples may illustrate this. Rwanda has a large prison population at high risk of HIV transmission through men having sex with men. This, in turn, results in the risk of ex-prisoners infecting their wives or new partners. In Kivu province in the east of the DRC, the civilian population is moving from place to place in search for peace, while military groups and rebels move frequently for various other reasons. A leading cause of HIV in this region is sexual violence by the military and rebels. Women who are HIV-positive as a result of rape may infect their partners. Many of these women, however, move within the region but also to neighbouring countries to avoid stigma and to search for survival opportunities, which include new marital and cohabitation relationships. In Kenya, postelection violence forced many families to move from one region to another, leading to separation of the families. This resulted in disruption of the use of ART. Cases of rape and new infections have been documented among the internally displaced persons who are living in camps. Further studies are needed to document sero-discordance, given that the recent Kenya AIDS Indicator Survey carried out in 2007 showed that in Kenya in relationships of people living with HIV who are married and know their partner's HIV status is 44 per cent (National AIDS and STI Control Programme 2008).

### 7.3.5 Towards a multi-country programme

As part of the preparation for a future multi-country programme on sero-discordant couples and HIV, a brainstorm took place about specific research questions and research designs. A selection of preliminary research subtopics included:

- the vulnerabilities that prevent disclosure of HIV status among sero-discordant couples (perceived responsibilities and guilt in cases of rape, extra-marital sex, polygamous marriages etc.);
- traditional practices in rural areas that can be adopted to reduce vulnerabilities (for example, the practice of elderly women who in the past counselled families when new situations arose and succeeded in prevention of stigmatization);
- decision-making processes within sero-discordant couples regarding conception and contraception;
- a comparison of use of and access to family planning methods between discordant and non-discordant couples;
- determinants of joining associations and networks of people living with HIV by serodiscordant couples compared to HIV-positive concordant couples;
- attitudes, whereabouts and reactions of children of sero-discordant couples after disclosure of their own HIV status and their parents' status;
- the impact of social capital strengthening on HIV prevention among sero-discordant couples;
- the possibilities of introducing a social capital approach to HIV prevention and care within health systems; and
- increasing health systems' accountability and responsiveness to vulnerable groups such as sero-discordant couples.

The results of the brainstorm process formed the basis for the development of countryspecific research proposals, which were presented, discussed and rewritten during a workshop held in Kisumu, Kenya, in May 2010 (KIT 2010). A summary of the results of this exercise in the form of draft proposals is presented in Annex 7.2. The Kisumu workshop took place a year after the MCP extension phase had officially ended. Meanwhile the idea had developed that once the GLARC proposal was funded, a week-long capacity-building research workshop would be held, during which the proposed preliminary country research projects would be tuned into each other. So as not to lose momentum, participants and resource persons of the network that was supposed to merge into GLARC (all based at higher institutions of learning in the region) received the suggestion to encourage students to take up the proposed research or to develop proposals under the identified themes. This suggestion resulted in students working on the GLARC theme of sero-discordant couples as operationalized in the draft proposals under the guidance of senior researchers in Rwanda, Uganda, Kenya and Ethiopia.

In Ethiopia, a study carried out by Daniel Tadesse under the supervision of Prof. Getnet Tadele resulted in an MA thesis (Tadesse 2011). The study found widespread misconceptions about HIV-discordance among sero-discordant couples, health care providers and counsellors, such as: the belief that the other partner was already infected, but the test did not show it; biological immunity to HIV; and prevention of HIV through ART. As a result of these misconceptions, many couples were confused and unlikely to take the necessary preventive measures or they were not interested in being tested. Although service providers informed and educated them, nevertheless many of the sero-discordant couples continued to engage in risky sexual behaviours. However, it was also found that for some couples the presence of HIV did not bring about any change in their relationship. Still, they experienced a variety of psychosocial problems such as fear of infecting and being infected, blame, neglect, guilt and uncertainty. Their coping strategies were found to be safer sex, abstinence, communication, disclosure, silence, secrecy, cooperation and religion. Social capital was found to be a double-edged sword. While informants claimed they were receiving instrumental, informational, appraisal and emotional support from relatives, friends and acquaintances, these same groups of people were found to be a source of stress and anxiety.

## 7.4 Capacity development: Challenges

Apart from the above-mentioned activities, the GLARC process is more or less on hold. Due to budget cuts in development cooperation in the Netherlands, funds were no longer allocated by the Ministry of Foreign Affairs and Aids Fonds. Although the centre in development very much represented a network of partners working in South–South and South–North alliances, and a regional approach to social science research on sexual and reproductive health and rights (thus broader than the HIV focus before) still seems necessary and urgent, no funding was obtained through applications to global and regional calls for research proposals. The justification for working as a regional centre still holds to the present day. The region has a common geography and history, a history of effective collaboration for capacity development and common weaknesses regarding social science research and policy gaps. The topic of sero-discordant couples offers an opportunity to address cross-region issues regarding sexuality, decision-making, power and quality of life/positive living; the common objective then is to improve quality of life and care (by the community and by service)

providers). It should also be noted that both topics (regional approach, content topic) address issues in the context of shared socio-political structures and fragile states. Although partnerships were emphasized, and a group of institutions had already worked together with a strong focus on research and capacity-building and joint linking and learning, no funds have become available yet. Opportunities remain limited to exchange visits between some GLARC partners and occasional collaborative initiatives.

## 7.5 Conclusion

The outcome of the GLARC process so far is that due to a lack of resources no progress has been made in the cross-country implementation of the various research proposals. However, some GLARC members succeeded in carrying out exploratory research on the topic of serodiscordant couples, and the networking between members resulted in various bilateral research activities. On a more positive note, the experience taught participants that working together with a diverse but dedicated group of researchers from countries in the South and North definitely carries benefits in terms of capacity development: minds were sharpened, ideas challenged, skills built and concepts tested. The interaction between the African countries has been at least as important as the South–North exchange, and collaborative efforts between researchers and research institutes have continued. This book is definitely an outcome of this process. It has been inspired by it, and the creative and innovative thinking is there that can also be fed by virtual discussions and communications. The main lesson learnt is that, even if researchers and their institutions really become partners who share the urgency of studying important topics together, without funding the implementation of that urgency is not going to be feasible.

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## References

- David, A.C. and C.A. Li (2008) *Exploring the links between HIV/AIDS, social capital, and development*. Policy Research Working Paper 4679. World Bank, African Region. Available at http://www-wds.worldbank.org/servlet/WDSContentServer/WDSP/IB/2008/07/23/000 158349\_20080723111217/Rendered/PDF/WPS4679.pdf (accessed 15 June 2012).
- Delor, F. and M. Hubert (2000) Revisiting the concept of 'vulnerability'. Social Science & Medicine 50:1557-1570.

Dunkle, K.L., R. Stephenson, E. Karita, et al. (2008) New heterosexually transmitted HIV infections in married or cohabitating couples in urban Zambia and Rwanda: An analysis of survey and clinical data. *Lancet* 371:2183–2191.

Field, J. (2003) Social capital. Routledge, London and New York.

- Getaneh, H., Y.Mekonen, F. Esthetu, et al. (2008) Community conversation as a catalyst for stigma reduction and behaviour change: Lessons learned from a CARE project in Ethiopia. *Care Bulletin* 2:13–15.
- GHIN and CREHS (2010) *Multi-country partnerships: Adding value to research.* Global HIV/AIDS Initiatives Network (GHIN), Dublin/London, and the Consortium for Research on Equitable Health Systems (CREHS), London. Available at http://www.crehs.lshtm.ac.uk/ downloads/publications/partnerships.pdf (accessed 13 January 2012).
- Gregson, S., N. Terceira, P. Mushati, et al. (2004) Community group participation: Can it help women to avoid HIV? An exploratory study of social capital and school education in rural Zimbabwe. *Social Science & Medicine* 58:2119–2132.
- Kippax, S. and M. Holt (2009) The state of social and political science research related to HIV: A report for the International AIDS Society. International AIDS Society, Geneva. Available at http://www.iasociety.org/Web/WebContent/File/IAS\_Report\_on\_State\_of\_ Social\_and\_Political\_Science\_Research.pdf (accessed 13 January 2012).
- KIT (2009) The Great Lakes AIDS Research Consortium (GLARC): Research, research capacity development and research communication for evidence-based HIV and AIDS policies and programmes. KIT, Amsterdam.
- KIT (2010) Great Lakes Applied Research Consortium (GLARC) on social science research in the field of SRHR and HIV. Report of the research capacity-building workshop on vulnerabilities and social capital: Discordant couples and beyond. Great Lakes University of Kisumu (TICH), Kisumu, Kenya, 25–28 May 2010. KIT, Amsterdam.
- Kwagala, B., A. van der Kwaak and H. Birungi (2008) *Promoting sexual health in Uganda: The TASO Uganda sexuality counselling approach*. KIT, Amsterdam.
- National AIDS and STI Control Programme (2008) Kenya AIDS Indicator Survey 2007: Preliminary Report. Ministry of Health, Nairobi, Kenya.
- Odhiambo, G.J. (2007) *HIV sero-discordant couples in Kenya: Determinants, implications and solutions.* MA in Public Health thesis. KIT, Amsterdam.
- Richters, A., T. Rutayisire and C. Dekker (2010) Care as a turning point in sociotherapy: Remaking the moral world in post-genocide Rwanda. *Medische Antropologie* 22(1):93–108.
- Tadesse, D. (2011) Living in a sero-discordant relationship: Knowledge, challenges, and coping strategies among HIV discordant couples in Addis Ababa. MA thesis School of Graduate Studies of Addis Ababa University. Department of Sociology, Addis Ababa University, Ethiopia.
- Thornton, R. (2009) Sexual networks and social capital: Multiple and concurrent sexual partnerships as a rational response to unstable social networks. *African Journal of AIDS Research* 8(4):413–421.
- Van Poelje, R. (2012) Multi-stakeholder process and analysis: The case of the multi-country programme for social science research on HIV and AIDS in five African countries. In: Van der Kwaak et al. (2012), *Capacity-building for knowledge generation: Experiences in the context of health and development*, Chapter 6. KIT Publishers, Amsterdam.

## Annex 7.1

Two options for proceeding with research in the context of a multi-country study programme

	The typical process	Strengths	Constraints
A. Call for proposals	<ol> <li>Develop and circulate a call for proposals</li> <li>Panel review of concept papers/preliminary proposals</li> <li>Workshop(s) to strengthen proposals</li> <li>Panel review of full proposals</li> <li>Panel review of full proposals</li> <li>Review by Scientific and Ethical Review Group</li> <li>Approval by Coordinating Body and perhaps also funding agent</li> <li>Technical support and analysis workshop</li> <li>Workshops to develop papers and discrimination of findings</li> </ol>	<ol> <li>Respond better to local needs and interests and skills of local investigators</li> <li>Feeling of complete "ownership" by local investigators</li> <li>Flexibility in study design and timing</li> </ol>	<ol> <li>Difficult to monitor</li> <li>Difficult to provide technical assistance</li> <li>Difficult to compare results</li> <li>Difficult to synthesize results</li> <li>Prone to fragmented research</li> <li>Subject to delays in completing projects</li> </ol>
B. Multi-country studies	<ol> <li>and dissemination of findings</li> <li>Identify the topic of priority and potential investigators and resource persons</li> <li>Consultation to review the situation and agree on issues of high priority and study design and related issues</li> <li>Commission preparation of the protocol and instruments</li> <li>Investigators' meeting to review and revise the protocol, design and instruments</li> <li>Review by the Specialist Panel and Coordinating Body</li> <li>Regular monitoring, technical assistance</li> <li>Workshops at critical stages of implementation</li> <li>Meetings to disseminate results and implications of findings</li> </ol>	<ol> <li>Ensures good monitoring and quality output</li> <li>Progress in time</li> <li>Results are comparable</li> <li>Greater potential for publication</li> <li>Greater potential for impact</li> </ol>	<ol> <li>Requires more intensive staff/ consultant inputs</li> <li>Country (context) variations not fully accounted for</li> <li>Greater dependence of local researchers on Coordinating Body staff and consultants</li> </ol>

Source: Department of Reproductive Health and Research of the World Health Organization (WHO). Presented at the RAWOO (NL), Aids Fonds (NL), WHO, UNAIDS, Global Forum for Health Research (GFHR) and Council on Health Research for Development (COHRED) meeting that took place on 7 March 2003 at WHO, Geneva.

### Annex 7.2

## Summaries of draft research proposals developed by representatives of proposed GLARC member institutions

Burundi: Psycho-affective and socio-economic aspects of the vulnerability situation of discordant couples (Sylvère Seguru)

In Burundi in the cities, in contrast to the countryside, the percentage of women affected by HIV and AIDS is at least twice as much as that of men. In the capital, Bujumbura, 13 per cent of women and 5.5 per cent of men are infected. In the countryside the percentages are 2.9 per cent and 2.1 per cent, respectively. An underlying reason for the high HIV and AIDS prevalence in the country is the poverty among the population. HIV and AIDS in turn contribute, partly through the consequent stigma-related reduction in social capital, substantially to that poverty. Against this background the research focuses on the specific vulnerability of sero-discordant couples as a causal factor of the HIV infection and as a consequence of it. Particular attention will be paid to vulnerability in terms of the increase in poverty within the household, the loss of social capital of the spouses, the psycho-affective state of all family members and the relations between these three aspects of vulnerability. To start with, an attempt will be made to ascertain the prevalence of sero-discordant couples who are already identified as such. Research methods include individual interviews, focus group discussions and identification of psycho-affective problems.

Democratic Republic of Congo: Men's practices in response to the vulnerability of women who are sexually violated and live with HIV in North Kivu province (Edmond Ntabe)

This study addresses one of the major negative consequences of armed conflict: sexual violence, often coupled with HIV infection. The situation in North Kivu is compounded by asymmetric gender relations, which are reflected in women's limited ability to negotiate safer sex, and their fear of testing for HIV or disclosing their status due to anticipated repercussions. Women's vulnerability increases in contexts where men's multiple partnering is culturally condoned. The cultural emphasis on male dominance often encourages or enhances negative practices that increase female (and sometimes household) vulnerability. Men's perceptions and related practices regarding the vulnerability of sexually violated and HIV-infected women is an unexplored area in the Kivu region. The study, therefore, aims to: describe the vulnerability of sexually violated women and women living with HIV; explore the gender-based perceptions and responses of men (as spouses and partners) to this situation; and the role of social capital in relation to women's vulnerabilities and men's perceptions and practices will be made. Mixed-methods research, including a survey and focus group discussions, will be used for data collection.

Ethiopia: Situation analysis of sero-discordant couples (Getnet Tadele)

This proposal focuses on the situation analysis of sero-discordant couples and the exploration of people's understanding of and beliefs about discordance, experiences after disclosure of sero-status, coping strategies and challenges. The proposal exhaustively traces the background to understanding of and responding to HIV from a global perspective from the 1980s, when the first cases of HIV were diagnosed, to the present. The theme of sero-discordance is presented, including the fact that in Ethiopia 85 per cent of couples living with HIV are in discordant relationships. The need to include HIV-negative persons in sero-discordant relationships among groups of people who are most vulnerable to new infections is stressed. Challenges that HIV-positive and HIV-negative partners within sero-discordant relationships face - such as sexual violence, emotional abuse, verbal threats and unprotected sex - are highlighted. The study aims to explore lived experiences of sero-discordant couples, specifically address-ing: understanding of sero-discordance; challenges of living in a sero-discordant relationship; effects of disclosure of status; and coping strategies for the couples, including the role of social capital in coping with sero-discordance. The proposed methodology is basically qualitative using in-depth interviews, case studies of sero-discordant couples of reproductive age that have stayed together for at least a year, and key informant interviews.

### Kenya: The impact of vulnerabilities on discordant couples in Kenya (Rose Olayo)

With reference to the national HIV and AIDS strategic plan, the proposal highlights the fact that the number of new infections (incidence) in Kenya is unacceptably high and that there are major differences in susceptibility among different groups. Particularly vulnerable are young girls as well as males and females in HIV-discordant relationships. The acceptability and use of condoms among sero-discordant couples is low, and knowledge on how to deal with sero-discordance among couples is limited. The situation is compounded by the diversity of cultural beliefs and practices that negatively impact decision-making and the well-being of individuals in sero-discordant relationships. The study will focus in particular on young sero-discordant couples. It aims to identify socio-cultural factors that influence HIV infection among them; assess their level of disclosure of HIV status; explore the outcomes of disclosure for them; and investigate the role of social networks in supporting them. HIV prevention strategies attuned to the needs of young people will be proposed as one of the outcomes of the study. Qualitative methods, such as key informant interviews and in-depth interviews, will be used for data collection.

### Rwanda: Discordant couples, vulnerability and social capital (Laetitia Nyirazinyoye)

The proposed study on sero-discordant couples, vulnerability and social capital is contextualized in terms of a post-conflict situation, characterized in Rwanda by significant social and cultural disruptions as a result of genocide, displacement, long-term return migration and high levels of family violence, including gender-based violence. Although the magnitude of sero-discordance in Rwanda is yet to be determined, it has been established that knowledge of sero-discordance can result in intra-couple conflicts, separation or divorce. On the other hand, lack of knowledge on sero-discordance increases the risk of HIV transmission. Research questions focus on: factors that facilitate and inhibit disclosure; outcomes of disclosure, including responses by the couple's children; use and access regarding family planning; determinants of joining associations and networks for people living with HIV and AIDS; mechanisms, services and resources available on a community level to promote healing relationships and family planning among couples; and behaviour, communication and change messages and strategies for sero-discordant couples and their relatives. Data will be collected through interviews with persons in sero-discordant relationships to be recruited at voluntary counselling and testing and prevention of mother-to-child transmission programmes at health facilities and at community level through community health workers.

### Uganda: Social capital, discordance and reproductive choices (Betty Kwagala)

Uganda, like other countries in the region, has experienced the brunt of both conflict and HIV and AIDS. The relatively high levels of sero-discordance among couples increased interest in preventing infection of the non-infected partners mainly through condom use or abstinence. The availability of anti-retroviral therapy (ART) and prevention of mother-to-child transmission has increased interest in childbearing, often at the risk of increased exposure to HIV infection. Contraceptive use other than condoms remains low. The study intends to analyse how social capital influences sero-discordant couples' reproductive intentions and choices regarding conception and contraception. More specifically, the study will focus on the influence of socio-demographic factors on contraception and conception; the influence of the quality of bonding social capital (at partner and family level) on voluntary membership of associations; and the influence of the quality of bonding social capital at partner, family, health provider, peer and association levels regarding reproductive choices concerning conception and contraception among sero-discordant couples. Recommendations will be offered for enhancing the quality of life of persons in sero-discordant relationships regarding reproductive health choices. The study will be exploratory and descriptive, using key informant interviews, focus group discussions, in-depth interviews with clients in sero-discordant relationships, and secondary data.