

## Background Report

# Establishing a Global Knowledge Network on HIV Stigma and Discrimination Reduction



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## Introduction

Despite more than a decade of efforts to understand the causes of HIV stigma, raise awareness about its harmful effects and develop and implement programs and strategies to reduce it, stigma remains a seriously neglected issue in the global response to HIV. To address this critical gap, MAC AIDS Fund and the International Center for Research on Women (ICRW) convened a meeting in Washington, D.C. on November 17, 2008 that brought together 58 experts from the program, research, policy, advocacy and donor sectors to identify why HIV stigma has not gained sufficient ground in the global HIV response and what can be done to turn that around. At the meeting, participants reviewed what works to reduce HIV stigma and discrimination, identified key barriers and opportunities for a coordinated response, prioritized six key action steps to galvanize support for scaling-up stigma-reduction efforts globally and reached consensus around an action plan for moving these steps forward. Foremost among the action items agreed upon was the creation of a Global Knowledge Network on HIV Stigma and Discrimination Reduction.

Such a network would allow people involved in program design, research and advocacy on HIV stigma and discrimination reduction to share information, tools, and experiences; strategize on how to respond to research, program and policy gaps; and coordinate efforts to develop and expand program, research and advocacy strategies for reducing HIV and associated stigmas worldwide. Participants recognized that a global knowledge network would create efficiencies within the global community working to reduce stigma and discrimination and maximize impact through improved communication, coordination and partnership building. In addition, it would serve as a vehicle to move forward the other key action items identified at the November 17<sup>th</sup> meeting<sup>1</sup>.

The MAC AIDS Fund, the Elton John AIDS Foundation and UNAIDS are currently supporting a planning phase to inform the creation of a Global Knowledge Network on HIV Stigma and Discrimination Reduction. The first step in the planning process was to conduct background research on existing health and development networks to identify options for organizing the structure and key functions of the stigma knowledge network. This report summarizes the findings of the background research, which informed a planning meeting of 24 working group members representing 17 organizations and institutions (see Appendix D) held on September 9-10, 2009. Following the meeting, the background report was updated to reflect the discussions and outcomes of the working group meeting. Based on the outcomes of the working group meeting, a business plan for the various components and functions of the network is currently being developed. It is the intention of the working group members to continuously involve and engage those likely to participate in the network throughout the planning and network development process.

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<sup>1</sup> The action items identified at the November 17<sup>th</sup> meeting included: (1) create a global knowledge network on HIV stigma reduction; (2) design and implement a global communications strategy; (3) develop a compendium on what works to reduce stigma; (4) consolidate existing measures and measurement tools; (5) initiate a coordinated advocacy campaign; and (6) facilitate better coordination among donors. More information on the meeting can be found at: <http://www.icrw.org/Stigma/hiv-aids-stigma-meeting.html>

## Methods and Sample

The rapid, background assessment employed a mixed-methods approach to gather information on existing knowledge networks and suggestions for how the stigma knowledge network could be organized. These methods included a web scan, key informant interviews and a brief electronic survey. Data were triangulated to inform the findings and recommendations. This assessment was not meant to be representative of all those who might participate in the network, rather the intention was to:

1. Gain a better understanding of how some existing health and development networks are structured to meet their primary objectives;
2. Gather lessons learned from these networks in terms of challenges faced and seek advice on building a network and engaging stakeholders; and
3. Gather information from a diverse group of potential stakeholders and users of the network on key priority areas that the network should address to initiate the planning process.

### Web scan

To gather ideas from other relevant networks, a web scan was conducted to identify existing networks that work or worked in the areas of health, HIV and AIDS, international development and gender. In Google, the terms “network,” “knowledge sharing,” and “information sharing” were paired with the words “development,” “health,” “gender,” “women,” “HIV,” and “AIDS.” Network websites suggested by colleagues at ICRW and the five key informants interviewed were also included in the web scan. In total, 25 different networks websites were identified and reviewed (see Appendix C for list of network websites visited).

### Key informant interviews

Twelve networks identified in the web scan were contacted to set up key informant interviews. Nine networks responded and five interviews were scheduled. Of the remaining four networks contacted, two were not available during the data collection timeframe and two were not suitable as models for the stigma knowledge network after further communication with network organizers. All key informants interviewed had been involved in the establishment and ongoing maintenance of a knowledge network. Most of these individuals represented global knowledge or research networks; however a few were more regionally focused. Informants were recruited purposively from networks identified in the web scan and were selected to capture more detailed information and insights from a broad-range of network types. Representatives of the following networks were interviewed: the Population and Poverty Research Network, the Development Practitioners Forum, AIDSLEX, the HIV Vaccine Trials Network and the Intercambios Alliance.

Key informant interviews were conducted by phone between June and July 2009 using a semi-structured interview guide. The interview guide covered a broad range of topics including the initiation, structure and function of the health and development networks, the level of engagement with network members and suggestions for embarking on a process to create a knowledge network. The interviews ranged in length from 45 minutes to 1 hour and only one

interview was conducted per informant. Interviews notes were typed and analyzed using a thematic approach.

### E-survey

To ensure input from a broad range of stakeholders working to reduce stigma and discrimination globally, an 11-item electronic survey was employed. The electronic survey was designed by ICRW with input from working group members and included questions on demographic information (type of organization, area of expertise, geographic area, etc.) as well as questions to elicit thoughts about the primary functions of the network, useful components of a network website, motivation to use the network and facilitation of synergy among people of different sectors.

The survey was administered using Survey Monkey to 325 individuals and two listservs between July and August, 2009. The distribution list was compiled purposively based on ICRW and other working group members' knowledge of people from different sectors supporting or working to reduce HIV stigma and discrimination. The survey was not intended to be representative of all potential users of the network. The distribution list included people who attended the November 17, 2008 stigma meeting at ICRW, grantees of the World Bank's South Asia Region Development Marketplace on HIV Stigma Reduction, non-governmental organizations implementing stigma-reduction activities in Vietnam and individuals recommended by working group members, external review group members and respondents interviewed in another recent global survey conducted by ICRW on barriers to scaling-up stigma reduction efforts. In addition, the survey was sent out through two listservs: the International Community of Women living with HIV/AIDS and the Africa Region Stigma Trainers listserv, run by The International HIV/AIDS Alliance. Reminders were sent to recipients twice during the data collection process and data collection ended on August 17, 2009. In all, 114 people completed the survey (99 from the main distribution list and 15 from the two listservs). As the number of individuals in the listservs was not known, the estimated response rate based on the main distribution list (325 individuals) was 30.5%. Survey responses were securely downloaded from Survey Monkey, after which data cleaning, univariate and bivariate analyses were conducted using STATA 10.0.

Survey respondents represented a broad range of organization types, areas of expertise, regions and target populations (see Table 1 in Appendix A). The largest proportion of respondents worked for non-governmental organizations (56.0%), followed by country governments (14.0%), UN agencies (13.2%) and PLHIV networks (12.3%). Other organizations represented included: universities, health sector providers, independent consultants, private companies and donors. Half of the respondents reported being advocates, followed by program implementers (48.2%), researchers (33.3%), health providers (17.5%), donors (17.5%), individual and community activists (14.0%) and community leaders (11.4%). While all regions of the globe were represented in the e-survey, the most commonly reported regions of work included: East Africa (37.7%), West Africa (35.1%), Southern Africa (31.6%), Southeast Asia (30.7%) and South Asia (27.2%). The majority of respondents reported working with communities of people living with HIV (83.3%). Other common target populations included opinion leaders (60.5%), the general population (56.1%), men who have sex with men (51.8%), women and girls (51.8%),

female sex workers (48.2%), orphans and vulnerable children (41.2%) and injection drug users (37.7%).

## Findings

The following section presents the key findings from the background assessment.

### Key Network Functions

E-survey respondents were asked to rank the following six functions based on what they envisioned the primary focus of the stigma knowledge network should be: (1) knowledge sharing, (2) research and advocacy, (3) capacity building, (4) coordination and implementation, (5) fundraising, coordinating and administering funds and (6) some combination of these five functions. The majority of respondents ranked knowledge sharing as the first priority (42.2%), followed by some combination of the five (17.6%), capacity building (13.7%), research and advocacy (12.7%), coordination and implementation (8.8%) and fundraising, coordinating and administering funds (4.9%) (see Figure 1 in Appendix B). Among those who ranked the 'some combination' response, 24 provided suggestions for which functions should be combined. The three function areas mentioned most frequently were capacity building (74%), knowledge sharing (65%) and research and advocacy (65%). Table 2 shows the percentage of respondents ranking the top three functions by organization type. While most of the respondents working for NGOs felt that knowledge sharing should be the first priority of the network, among those self-identifying as working for CBOs, most ranked capacity building as what they envision the primary function of the network to be. Similarly, the majority of independent consultants ranked knowledge sharing as the primary function, while individual and community activists were concerned mainly with capacity building. Among respondents working for networks of people living with HIV, the percentage ranking knowledge sharing and capacity building as the primary functions were roughly the same. While fewer organizations highlighted research and advocacy as the primary function of the network, it was clearly an important component for many, including donors. These findings seem to indicate that a combination of the knowledge sharing, capacity building and research and advocacy functions is most likely to appeal to a broad range of potential network members across various sectors and organization types.

### Network Structures

Network leadership and membership strategies varied among the 25 networks reviewed in the web scan, but structures fell broadly into three categories: (1) heavily structured; (2) moderately structured; and (3) lightly structured. Most networks fell under the highly or moderately structured categories, while a few had more simple structures. Networks in all three of these categories tended to be coordinated and managed by one organization. The lead organization, sometimes viewed as the Secretariat, usually dedicated two to ten staff members to work on initiating and maintaining the network and fulfilling the determined goals, objectives and activities of the network. The main factor used to distinguish between lightly, moderately or heavily structured networks was the amount of input the lead organization received from other structural components. Other factors included how network members were engaged (i.e. online versus face-to-face communication) and the criteria for membership in the network.

In the heavily structured networks, the lead organization typically coordinated the work of other partner and/or member organizations and individuals. In networks that had a Secretariat, there was also typically a core group of partners working to push forward specific thematic areas. This could entail having core partners lead the development and implementation of a thematic area, with funding from the core network resources. Heavily structured networks also tended to have an advisory committee and/or board, which monitored the activities of the network and provided strategic guidance to the Secretariat for the networks' activities. Advisory board and committee members were generally elected and represented the network's core partner organizations and/or experts in the field of study. Heavily structured networks typically engaged members in both online and in-person forums, such as maintaining a strong network website and organizing annual or biannual conferences or meetings. Primary examples of networks that were more heavily structured included the [Global Health Policy Research Network](#), the [AIDS Vaccine Advocacy Coalition](#), [Danish Development Research Network \(DDRN\)](#), the [British Columbia Rural and Remote Health Research Network](#), the [Global Health Workforce Alliance](#), the [Ghana Information and Knowledge Sharing Network \(GINKS\)](#), and the [InterCambios Alliance](#).

Among those reviewed, networks focused on a specific research agenda tended to be more moderately structured. These networks were typically led by one organization who either worked directly with a core group of partners or closely with the network funder to fulfill the objectives of the network. Moderately structured networks did not typically have an official steering committee or advisory board, rather they often sought advice from key experts as needed. Alternatively, as in the case of the [Global Network for Women's and Children's Health Research](#), the global steering committee was responsible for setting the research agenda for the network with input from network members. Depending on the nature of the network and its funding mechanisms, some coordinated the formation of working groups or funded specific research through large and small grants programs. Examples of networks following this more moderately structured model include: the [Population and Poverty Research Network](#) and the [Alliance for Cervical Cancer Prevention](#). Membership in these networks was often restricted and organizations or individuals that wished to join the network requested entrance from the Secretariat or submitted a proposal for research funds. These networks typically placed more emphasis on engaging members through in-person meetings and conference calls as opposed to online.

Lightly structured networks were usually housed and led by one non-profit organization whose aim was to facilitate knowledge-sharing and networking between members. These networks typically focused their efforts on building an online community interested in a particular topic and providing relevant knowledge and information in an easily available and useable format. The [Knowledge Management for Development \(KM4Dev\)](#) network is an interesting social networking website that encourages new membership and web-based communication between members. The [Development Practitioners Forum](#) and [AIDSLEX](#) are new networks that also encourage membership and facilitate networking and dialogue between members. All of these networks were lightly staffed and relied on volunteers and network members to maintain the activities of the network. In addition, these web-based networks had volunteer steering committees that helped support the needs of network members, build the community and give advice and recommendations about the network website. Typically, steering committee

members volunteered a minimum of two days per year to the network, which could include e-mail communication, conference calls or taking on specific tasks based on interest. Membership in these networks tended to be open to any interested persons, as opposed to being restricted to individuals from certain sectors or with specific expertise.

### Network Website Designs

Among the network websites reviewed in the web scan, most were organized to inform the user about the purpose of the network and its major activities. They tended to be non-interactive and provided news and upcoming events to members and other interested parties. Many of these websites provided users with resources, facts and significant publications in the network's subject area. If the network invested in capacity building efforts, the website also typically provided information and enrollment directions for trainings hosted by the network. Examples of networks with websites structured in this fashion included: the [AIDS Vaccine Advocacy Coalition](#), the [InterCambios Alliance](#), the [HIV/AIDS Network Coordination Office](#), [JASS](#), the [HIV Vaccine Trials Network](#), the [British Columbia Rural and Remote Health Research Network](#) and the [Sexual Violence Research Initiative](#).

For many networks, the sole purpose of the network and its website was to share relevant and new information with individuals who work in a related field of study. Many knowledge sharing websites posted information provided by the network's lead organization. Alternatively, the leading organization might vet information submitted by outside users before posting it on the website. Network websites sharing information in this way included: the [Science and Development Network](#), the [Promising Practices Network](#) and [Eldis](#).

In addition to providing information and resources to network members and website users, some network websites were built to encourage networking among members and to facilitate discussions between members. These websites were interactive and provided different forums for two-way dialogue, knowledge-sharing, and communication. Some websites were purely interactive, such as [Knowledge Management for Development \(KM4Dev\)](#), [AIDSLEX](#), and [Stack Overflow](#) while others combined interactive media forums and non-interactive information-sharing pages. Examples of websites that combined communication strategies include: [Research Advocacy Network \(RAN\)](#), [Knowledge Sharing Project \(KSP\) on Poverty Reduction Strategies and Millennium Development Goals](#), and the [Development Gateway Community](#).

E-survey respondents were asked which website components would be most useful to them. The majority of respondents (71.1%) stated that a comprehensive database or repository of resources and tools would be most useful. Other components frequently selected included an interactive e-forum where people can ask questions and get answers (60.5%), linkages to program information and resources by geographical area (59.6%), announcements and links to conferences, other events and funding opportunities (56.1%) and a comprehensive database of technical experts and trainers (54.4%) (see Figure 2 in Appendix B).

### Motivations for Participation in the Stigma Knowledge Network

In terms of what would motivate people to participate in the network and use the network website, two-thirds of e-survey respondents cited networking opportunities and partnership building. Other common responses included a comprehensive website containing pertinent

information, tools and resources (64.9%), practical tools and methodologies that are easily accessible (62.3%) and the possibility of expanding the reach of projects, programs and advocacy through linkage with other sectors (59.6%) (see Figure 3 in Appendix B).

Key informants also suggested a number of ideas for creating incentives and fostering momentum to keep people engaged in the network, including: making the network as interactive as possible by giving people from varied professions a range of opportunities to interact (face-to-face as well as online), having a wiki style component to the web-site, so members can post and edit content, continually seeking feedback on the network and network website from members, finding 'rock star' experts to participate via blogs and 'ask the expert' sessions, fostering a sense of belonging to a group of peers to ensure a successful e-forum and having web content available in multiple languages.

### Suggestions for Fostering Cross-sectoral Collaboration and Communication

In both the e-survey and the key informant interviews, respondents were asked to provide advice on how to foster collaboration across the various sectors the stigma knowledge network hopes to engage. There were a myriad of suggestions with some reoccurring key points.

The main re-emerging themes, included:

- Having clear network objectives and a clear focus on the role of each of sector in pushing forward the objectives from the beginning;
- Holding conferences and workshops on a regular basis to build a "community spirit" and foster the personal relationships necessary for collaboration;
- Identifying sector leaders and coordinators, including having regional focal points; and
- Having good website moderation (i.e. to assess what and where different postings should go, etc.)

Other less commonly mentioned suggestions but good points to consider, included:

- Establishing a steering committee with representatives from all sectors;
- Reducing the language barrier by making communication and web-content available in multiple languages;
- Providing a weekly or monthly e-blast of information;
- Having a cutting-edge web-site with pages specific to each sector, but which are accessible to the other sector members;
- Ensuring that research is linked to program implementation and is presented in a digestible format for policy makers and advocates to keep policy makers and donors on board; and
- Engaging concerned officials of national AIDS control organizations from various countries.

### General Suggestions and Words of Wisdom

The e-survey respondents and key informants were also asked to provide suggestions on what has worked well in other networks they are familiar with and to provide general words of wisdom that working group members should consider while embarking on the network

planning process. In general, feedback was very positive and there was much excitement about starting a cross-sectoral knowledge network on HIV stigma and discrimination reduction.

The most frequently mentioned themes included:

- Having good e-moderators and providing weekly summaries of discussions;
- Having regular updates, monthly updates with new tools, etc;
- Having explicit goals and purpose and clear responsibilities of partners; and
- Having in place an organization that properly coordinates the network, including:
  - A full time coordinator for the compilation and management of resource materials; and
  - Ensuring some scientific rigor and monitoring of the information posted on the website.

Other good points included:

- Stay nimble and flexible, yet with clear lines of responsibility;
- Take a phased approach to the establishment of the network and expand on an incremental basis;
- Be prepared to interact with network members so they will interact with each other;
- Have a common cause that provides confidence that members are part of something significant;
- Provide concise information, keeping things short and simple, user-friendly;
- Build capacity by serving as a resource pool;
- Develop and prioritize goals on the issues that most at risk populations identify as primary obstacles to uptake of health prevention and care services for further HIV stigma reduction activities; and
- Hold an annual 'awards of merit' program that would serve the network's profile, showcase strong work and innovation, and, via the event keynote, be a platform for agenda setting.

## Recommendations

Based on the background assessment, it was clear that the most pressing needs for enabling stigma and discrimination reduction globally are: a forum for sharing knowledge (e.g. around best practices, tools, existing resources, etc.), mechanisms for strengthening capacity to conduct stigma and discrimination reduction efforts; and a forum to foster innovative research and advocacy. To address these critical needs, the working group members are proposing the following goals, objectives, thematic areas and structure for a global knowledge network on HIV-related stigma and discrimination reduction.

### Proposed Goals & Objectives:

The Global Knowledge Network on HIV-related Stigma and Discrimination Reduction seeks to:

- Goal I:** Bring together diverse stakeholders to share experiences, knowledge tools, and research around HIV-related stigma and discrimination.

Objective 1.1: Manage and disseminate information on reducing stigma and discrimination through the network web-site, including provision of tools, best practices and guidelines for planning and implementation.

Objective 1.2: Foster new partnerships across sectors through networking opportunities at conferences/meetings and linking network members with available human resources via the network web-site.

**Goal 2:** Foster innovative solutions and expand the reach of existing ways to reduce HIV-related stigma and discrimination.

Objective 2.1: Inform, educate and reach out to a range of audiences by promoting and creating demand for best practices to reduce stigma and discrimination and catalyzing key stakeholders to support, utilize and expand these practices.

Objective 2.3: Mobilize network members and provide tools to advocate for increased funding to support integrating stigma and discrimination reduction into all HIV programming

**Goal 3:** Facilitate research across disciplines to expand the evidence base of the impact of HIV-related stigma and discrimination reduction efforts.

Objective 3.1: Identify and advocate for a global cross-sector research agenda by engaging network members and other stakeholders to participate in e-forums, electronic surveys and network working groups.

Objective 3.2: Link network members and evaluation experts to improve monitoring and evaluation of stigma reduction programs and to promote evidence-based advocacy.

#### Proposed Thematic Areas:

Based on the findings from the background assessment and discussions at the September working group meeting, the following thematic areas of focus are proposed for the Global Knowledge Network on HIV-related Stigma and Discrimination Reduction:

1. Improving and Expanding Evidence-based Programming
2. Strategic Research to Strengthen the Evidence-base
3. Communication and Advocacy

While the network will not directly implement activities, the idea is that the network would foster the knowledge sharing and linkages needed to catalyze HIV-related stigma and discrimination reduction efforts in these three areas.

#### Proposed Structure:

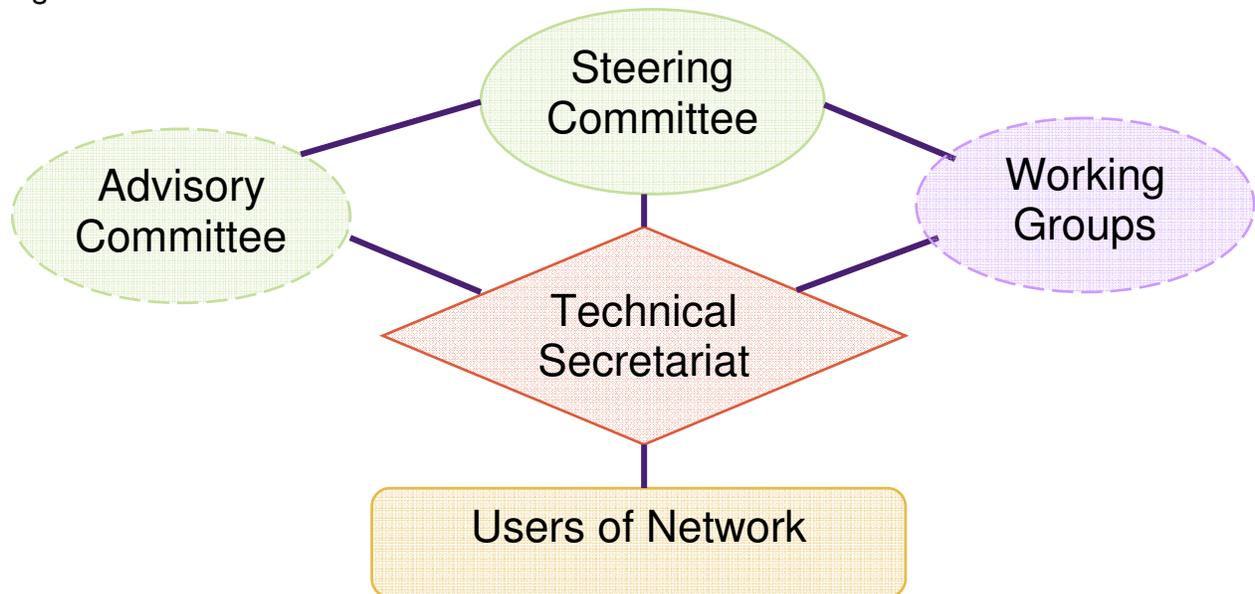
To move forward activities in each of these thematic areas at the global level, the following more heavily structured network is proposed (see Figure 4 on the following page)<sup>2</sup>. In this structure, a technical secretariat would engage and receive input from both a steering committee, consisting of representatives from a few core partner organizations, and an

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<sup>2</sup> This diagram is not meant to depict hierarchy (i.e. the users of the network are equally important as the other components, even though they are included at the bottom of this diagram).

advisory committee, consisting of key stakeholders from all relevant sectors (i.e. networks of people living with HIV, implementers, researchers, advocates and donors). Participation of steering committee members would require time and resource availability, whereas advisory committee members would be engaged on a voluntary basis. Members of the executive committee and the technical secretariat would serve on working groups that would fundraise and push forward work in each of the three thematic areas. General membership would be open to all interested persons, who would register online to participate in e-forums, receive newsletters, email updates and event announcements.

Figure 4.



While the thematic areas would most likely remain consistent, institutions participating in some of the structural roles (i.e. the Secretariat and Advisory Committee) could rotate on an agreed upon timeframe (i.e. 4-5 years).

## Appendix A: Tables

Table I. Selected e-survey respondent characteristics.

| <i>Respondent Characteristics</i>  | Total<br>(%)<br>(N=114) |
|------------------------------------|-------------------------|
| <b>Type of organization</b>        |                         |
| Non-governmental organization      | 36.0*                   |
| Community-based organization       | 14.0                    |
| Country government                 | 14.0                    |
| UN Agency                          | 13.2                    |
| PLHIV Network                      | 12.3                    |
| University/educational institution | 9.6                     |
| Health sector provider             | 7.9                     |
| Independent consultant             | 7.0                     |
| Individual/community activist      | 6.1                     |
| Private company                    | 6.1                     |
| Bilateral donor                    | 6.1                     |
| Multi-lateral donor                | 6.1                     |
| Private foundation                 | 6.1                     |
| Legal/law firm                     | 1.8                     |
| <b>Area of expertise</b>           |                         |
| Advocate                           | 50.0*                   |
| Program implementer/practitioner   | 48.2                    |
| Researcher                         | 33.3                    |
| Health provider                    | 17.5                    |
| Donor                              | 17.5                    |
| Individual/community activist      | 14.0                    |
| Policy maker                       | 12.3                    |
| Community leader                   | 11.4                    |
| <b>Regions of work</b>             |                         |
| East Africa                        | 37.7*                   |
| West Africa                        | 35.1                    |
| Southern Africa                    | 31.6                    |
| Southeast Asia                     | 30.7                    |
| South Asia                         | 27.2                    |
| Central Africa                     | 17.5                    |
| North America                      | 14.0                    |
| South America                      | 13.2                    |
| Caribbean                          | 13.2                    |
| Central America                    | 11.4                    |
| Eastern Europe                     | 10.5                    |
| Middle East                        | 10.5                    |
| Pacific Islands                    | 7.9                     |
| North Africa                       | 7.0                     |
| Western Europe                     | 7.9                     |
| Australia and New Zealand          | 4.4                     |

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**Type of communities respondents  
are working with**

|                                 |      |
|---------------------------------|------|
| People living with HIV          | 83.3 |
| Opinion leaders                 | 60.5 |
| General population              | 56.1 |
| Men who have sex with men       | 51.8 |
| Women and girls                 | 51.8 |
| Female sex workers              | 48.2 |
| Orphans and vulnerable children | 41.2 |
| Injecting drug users            | 37.7 |
| School children                 | 30.7 |
| Male sex workers                | 29.8 |
| Transgenders                    | 24.6 |
| Transgender sex workers         | 24.6 |
| Street adolescents              | 15.8 |

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\*Note: percentages will not add up to 100 as respondents were allowed to select more than one response category.

Table 2. Percentage of respondents ranking knowledge sharing, research and advocacy and capacity building as the most important function of the stigma knowledge network, by organization type area of expertise/sector.

|                                    | (n)* | Ranked Knowledge Sharing #1<br>% | Ranked Research and Advocacy #1<br>% | Ranked Capacity Building #1<br>% |
|------------------------------------|------|----------------------------------|--------------------------------------|----------------------------------|
| <b>Organization type</b>           |      |                                  |                                      |                                  |
| NGO                                | (40) | 40.0 <sup>§</sup>                | 10.0                                 | 12.5                             |
| Donor                              | (21) | 33.3                             | 19.0                                 | 9.5                              |
| CBO                                | (16) | 18.8                             | 12.5                                 | 25.0                             |
| UN Agency                          | (15) | 40.0                             | 0.0                                  | 20.0                             |
| Country government                 | (15) | 33.3                             | 6.7                                  | 6.7                              |
| PLHIV network                      | (14) | 35.7                             | 0.0                                  | 28.6                             |
| University/educational institution | (11) | 36.4                             | 9.1                                  | 0.0                              |
| Independent consultant             | (8)  | 50.0                             | 12.5                                 | 12.5                             |
| Health sector provider             | (8)  | 25.0                             | 0.0                                  | 12.5                             |
| Private Company                    | (7)  | 57.1                             | 0.0                                  | 14.3                             |
| Individual/community activist      | (7)  | 28.6                             | 0.0                                  | 42.9                             |
| Legal/law firm                     | (2)  | 0.0                              | 50.0                                 | 0.0                              |
| <b>Area of Expertise/Sector</b>    |      |                                  |                                      |                                  |
| Advocate                           | (57) | 29.8 <sup>§</sup>                | 8.8                                  | 14.0                             |
| Programmer                         | (55) | 43.6                             | 7.3                                  | 16.4                             |
| Researcher                         | (38) | 42.1                             | 15.8                                 | 7.9                              |
| Donor                              | (20) | 35.0                             | 15.0                                 | 15.0                             |
| Health provider                    | (19) | 31.6                             | 0.0                                  | 21.1                             |
| Community activist                 | (16) | 31.3                             | 0.0                                  | 43.8                             |
| Policy maker                       | (14) | 50.0                             | 14.3                                 | 0.0                              |
| Community leader                   | (13) | 30.8                             | 15.4                                 | 23.1                             |

\*Total number of respondents affiliated with each organization type.

§ Row percentages will not total 100% as only three of the 6 possible function areas are displayed in this table.

## Appendix B: Figures

Figure 1. Percentage of e-survey respondents ranking function areas as the number one function of the network (N=102).

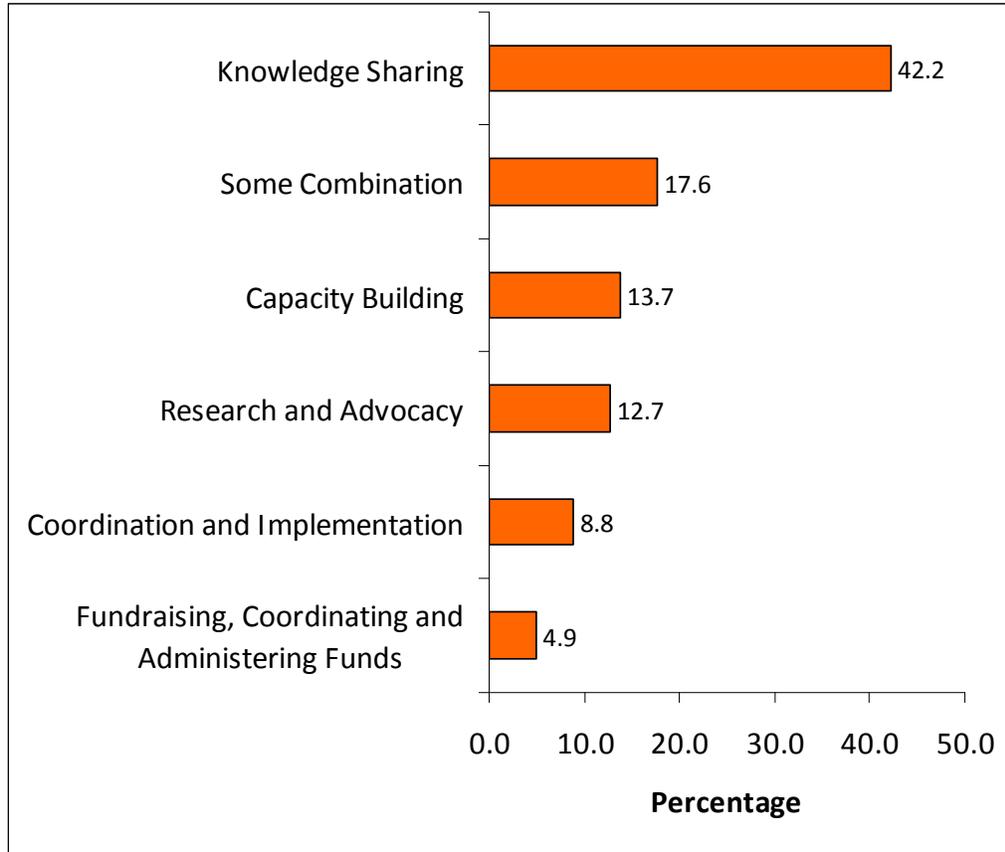


Figure 2. Most useful website components for the stigma knowledge network (N=114).

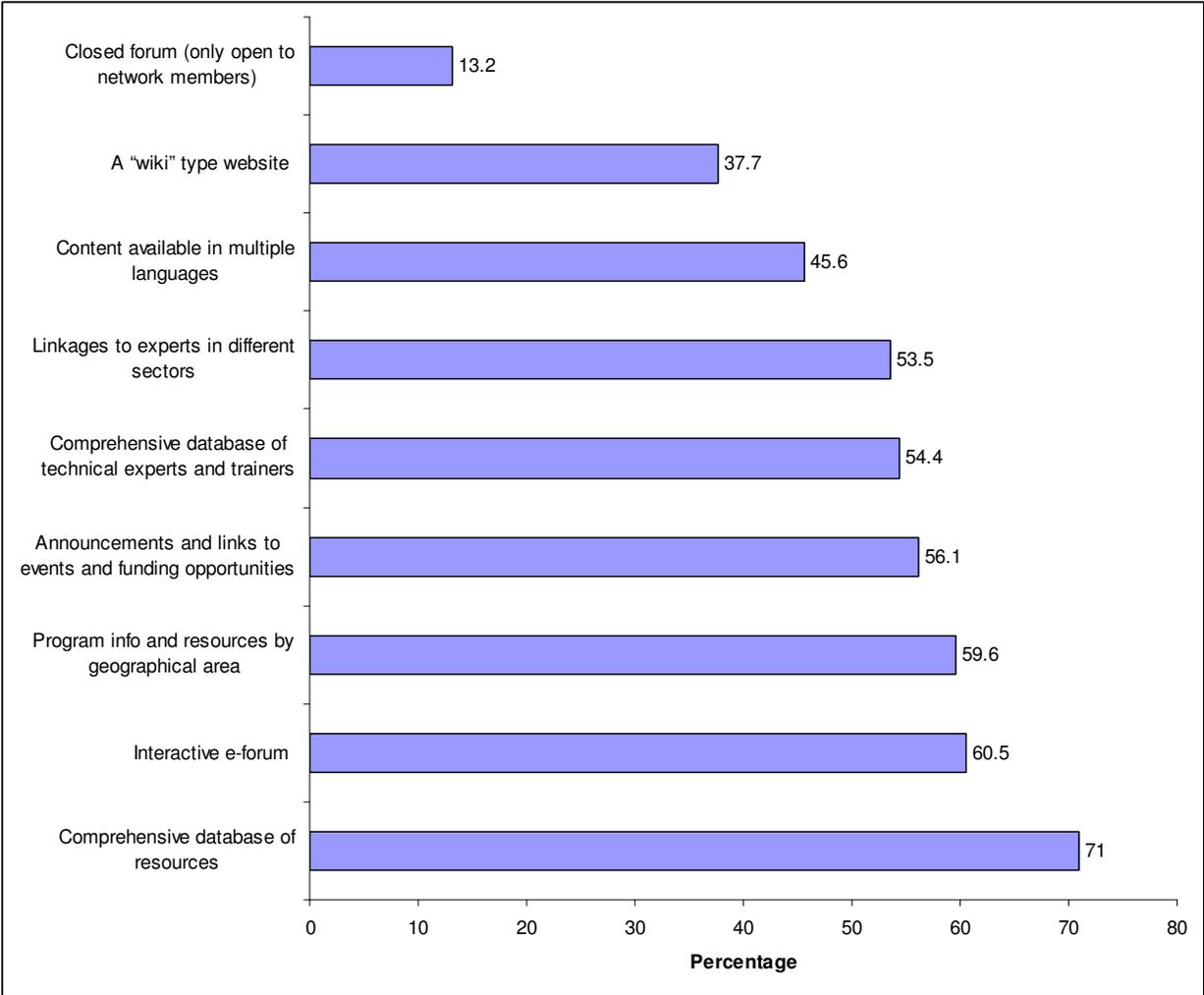
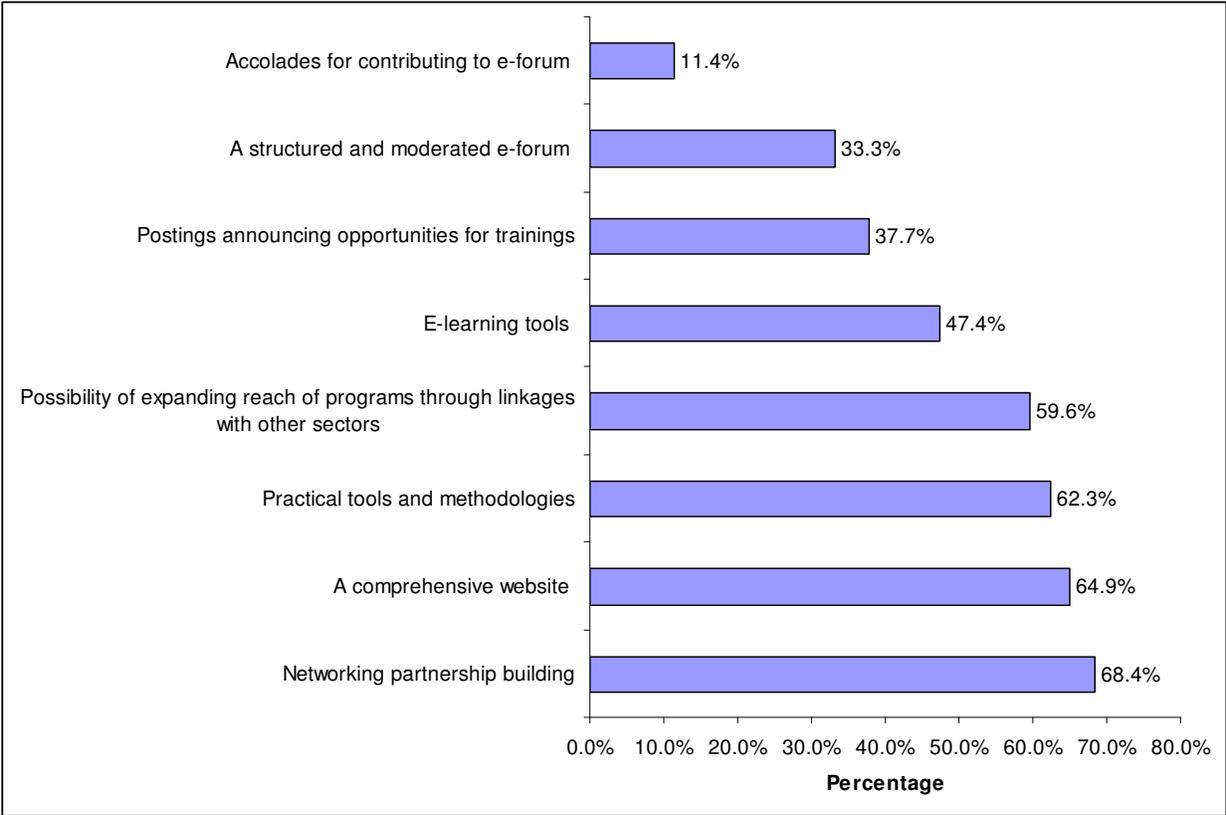


Figure 3. Motivations for participating in the stigma knowledge network (N=114).



## Appendix C: Networks Reviewed for the Background Assessment

| Networks   | Website   | Interviewed? |
|--|---|--------------|
| AIDS Vaccine Advocacy Coalition  | <a href="http://www.avac.org/vax_update.htm">http://www.avac.org/vax_update.htm</a>   |              |
| AIDSLEX  | <a href="http://aidslex.org/english/Home-Page/">http://aidslex.org/english/Home-Page/</a>                                   | ✓            |
| Alliance for Cervical Cancer Prevention  | <a href="http://www.alliance-cxca.org/">http://www.alliance-cxca.org/</a>   |              |
| British Columbia Rural and Remote Health Research Network  | <a href="http://www.bcrrhrn.ca/">http://www.bcrrhrn.ca/</a>   |              |
| Danish Development Research Network (DDRN)   | <a href="http://www.ddrn.dk/index.php?side_id=7">http://www.ddrn.dk/index.php?side_id=7</a>                                 |              |
| Development Gateway Community  | <a href="http://www.developmentgateway.org/">http://www.developmentgateway.org/</a>   |              |
| Development Practitioners Forum  | <a href="http://www.devprac.org/">http://www.devprac.org/</a>   | ✓            |
| Eldis  | <a href="http://www.eldis.org/">http://www.eldis.org/</a>   |              |
| Ghana Information and Knowledge Sharing Network (GINKS)  | <a href="http://www.ginks.org/">http://www.ginks.org/</a>   |              |
| Global Health Policy Research Network  | <a href="http://www.cgdev.org/section/initiatives/_active/ghprn">http://www.cgdev.org/section/initiatives/_active/ghprn</a> |              |
| Global Health Workforce Alliance   | <a href="http://www.who.int/workforcealliance/en/">http://www.who.int/workforcealliance/en/</a>                             |              |
| Global Network for Women's and Children's Health Research  | <a href="http://gn.rti.org/">http://gn.rti.org/</a>   |              |
| HIV Vaccine Trials Network   | <a href="http://www.hvtn.org/about/index.html">http://www.hvtn.org/about/index.html</a>                                     | ✓            |
| HIV/AIDS Network Coordination Office   | <a href="http://www.hanc.info/Pages/index.aspx">http://www.hanc.info/Pages/index.aspx</a>                                   |              |
| InterCambios Alliance  | <a href="http://www.alianzaintercambios.org/?idioma=english">http://www.alianzaintercambios.org/?idioma=english</a>         | ✓            |
| International Community of Women Living with HIV/AIDS  | <a href="http://www.icw.org/">http://www.icw.org/</a>   |              |
| Jass (Just Associates)   | <a href="http://www.justassociates.org/associates.htm">http://www.justassociates.org/associates.htm</a>                     |              |
| KM4Dev (Knowledge Management for Development)  | <a href="http://www.km4dev.org/">http://www.km4dev.org/</a>   |              |
| Knowledge Sharing Project (KSP) on Poverty Reduction Strategies and Millennium Development Goals | <a href="http://www.uneca.org/africanprsp/Default.html">http://www.uneca.org/africanprsp/Default.html</a>                   |              |
| Population and Poverty Research Network  | <a href="http://www.poppovresearchnetwork.org/">http://www.poppovresearchnetwork.org/</a>                                   | ✓            |
| Promising Practices Network  | <a href="http://www.promisingpractices.net/default.asp">http://www.promisingpractices.net/default.asp</a>                   |              |
| Quebec Population Health Research Network  | <a href="http://www.santepop.qc.ca/index_e.asp">http://www.santepop.qc.ca/index_e.asp</a>                                   |              |
| Research Advocacy Network (RAN)  | <a href="http://www.researchadvocacy.org/about/index.php">http://www.researchadvocacy.org/about/index.php</a>               |              |
| Science and Development Network  | <a href="http://www.scidev.net/">http://www.scidev.net/</a>   |              |
| Sexual Violence Research Initiative  | <a href="http://www.svri.org/">http://www.svri.org/</a>   |              |
| Stack Overflow   | <a href="http://www.stackoverflow.com/">http://www.stackoverflow.com/</a>   |              |

## Appendix D: Working Group Members

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