Stigma Reduction Initiative with Faith Leaders

Technical Learning Booklet
Stigma Reduction Initiative with Faith Leaders
The Global Network of People living with HIV (GNP+), along with their partners, the National People Living with HIV (PLHIV) networks agreed to work with the Catholic Agency for Overseas Development (CAFOD) on a three-year pilot Stigma Reduction Initiative (SRI) with faith leaders. The pilot took place with existing CAFOD partner organisations in three African countries, with technical support from National People Living with HIV (PLHIV) Networks, building on the implementation of the People Living with HIV Stigma Index. ¹

The diagram below provides a general picture of the process of the SRI. The order of steps will not necessarily be the same in each country and some steps may occur concurrently. This Technical Learning Booklet will focus on the stages outlined in green to provide guidance for further programming. These steps were chosen as they mark the key stages in the SRI process.

For more detailed information on the SRI, including templates of useful documents, please see the list of references at the end of this document. The technical learning shared in this booklet is based on the experience of GNP+ and CAFOD’s SRI, conducted in three African countries.

1 http://www.stigmaindex.org
ONE: CAFOD identify partners

The SRI took place with CAFOD partners in Ethiopia, Kenya and Zambia, where the PLHIV Stigma Index had been rolled out nationally, with technical support from National PLHIV Networks.

<table>
<thead>
<tr>
<th>CAFOD Office</th>
<th>CAFOD Partner</th>
<th>National partner network of GNP+</th>
<th>Geographical Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>CAFOD Ethiopia</td>
<td>Adigrat Diocesan Catholic Secretariat</td>
<td>Network of Networks of HIV Positives in Ethiopia (NEP+)³</td>
<td>Adigrat, in 5 districts of northern Ethiopia with urban and rural settings</td>
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<tr>
<td>CAFOD East Africa (Kenya)</td>
<td>Catholic Archdiocese of Mombasa</td>
<td>National Empowerment Network of People Living with HIV/AIDS in Kenya (NEPHAK)⁴</td>
<td>Mombasa, a coastal city in the south east of Kenya</td>
</tr>
<tr>
<td>CAFOD Southern Africa (Zambia)</td>
<td>St Theresa’s Mission Hospital</td>
<td>Network of Zambian People Living with HIV (NZP+)⁵</td>
<td>Ibenga, a small town in Mpongwe District in the Catholic Diocese of Ndola</td>
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</tbody>
</table>

Key steps in the development of partner-network relationships

- Develop **Memorandums of Understanding** (MoUs) between CAFOD and the National PLHIV Networks. To ensure ‘meaningful’ participation of PLHIV Networks make sure that agreements include the necessary resources (financial and in-kind) to support such involvement.

- Ensure that these MoUs include:
  
i. **The level of expertise and oversight required from each organisation** e.g. National PLHIV Networks agree to advise existing CAFOD partners on selection of interviewers and participants, to train the interviewers, and actively to engage on activities of the steering committees;

  ii. **Detail of technical support and assistance** e.g. interviewer training workshops or one-to-one mentoring of interviewers;

  iii. **Ethical considerations** e.g. matters of informed consent, confidentiality and data protection; and

  iv. **Financial considerations** e.g. CAFOD partners agree to remunerate the National PLHIV Networks for their technical assistance

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² It is a pre-condition for this SRI initiative that the PLHIV Stigma Index has already been implemented within the country.
³ [http://www.nepplus.org/](http://www.nepplus.org/)
⁴ [http://nephak.or.ke/who-we-are/](http://nephak.or.ke/who-we-are/)
TWO: Ethical approval is sought

According to the regulations stipulated by the founders of the PLHIV Stigma Index, “those responsible for conducting the survey should make sure that it conforms to the country’s ethical and data protection requirements”.

How to obtain ethical approval for a research project:

- Prepare a thoroughly-researched, well-written proposal with all recommended attachments e.g. approval for funding, questionnaires, consent forms, recommendation letters, previous research reports, activity reports.
- Secure funds for the application.
- Work in partnership with other influential stakeholders e.g. if required to obtain ethical clearance from a research institution, include a member of academic staff on a steering committee.
- Consult with partners including GNP+ and National PLHIV Networks, who have a wealth of experience with ethical issues in researching sensitive topics, including stigma. Work with them to obtain ethical clearance.

Be mindful that ethical clearance can be a long process and may delay the research time-frame. Avoid this scenario by leaving enough time to secure ethical approval.

6  http://www.stigmaindex.org/17/ethical-research/the-interview-process.html
7  Photo: A group of interviewers in Mombasa, Kenya
THREE: Selection and training of interviewers by PLHIV networks

The PLHIV Stigma Index: User Guide stipulates that interviewers must be members of a national network of PLHIV. They must be either be HIV positive, and open about their status i.e. comfortable about disclosing it to others, or personally affected by HIV. This is so as to provide interviewees with a supportive environment, as well as to encourage them to talk more openly about their own experiences.

When selecting interviewers, consider the following:

- Recruiting interviewers through National PLHIV Networks, support groups and community structures;
- Using the media to advertise e.g. local radio;
- Referring interviewers on to National PLHIV Networks if they are not already connected;
- Interviewers’ educational level e.g. literacy – interview the interviewers;
- Interviewers’ experience of living and working in the community/neighbourhood;
- Ensuring that male and female interviewers of various ages are trained so that, where possible, interviewer and interviewee can be ‘matched’.

“I was just taking research as something done by professionals. I didn’t know a person like me could do research”
(Male PLHIV: Interviewer, Kenya)

When training interviewers, consider the following:

- National PLHIV Networks should work in partnership with the CAFOD partner to provide the training, as part of the technical assistance agreed in the MoU;
- Where the training takes place e.g. is it local or will interviewers need to travel?
- When the training takes place e.g. not clashing with religious days
- How long the training will last and how many interviewers can be trained at any one time;
- The exact nature of the training workshops. It is helpful to provide an overview of the context of the SRI, including the expected goals and outcomes. Provide training on human resources, confidentiality, psychosocial support, how and where to make referrals to legal networks, health services, possible income generating activities and educational opportunities.
- How much work will the interviewers be doing? A realistic expectation is 20 interviews over 2 weeks.
Be aware that the number of interviewers may decrease over time, as people move away or lose interest. Be prepared to train extra interviewers, or provide annual training between data collection rounds.

FOUR: Steering committee is created

Steering committees to be created from representatives from all stakeholders in the project, (community members, faith leaders, health personnel, CAFOD partner) ensuring meaningful participation of women and men of all ages and those living with and affected by HIV

- Steering committees to meet at least quarterly to review progress

FIVE: Selection of interviewees

Selection and recruitment of interviewees

Interviewees must be people either living with or affected by HIV who are members of a National PLHIV Network or who have a link to a Network in some way. As such, recruitment can take place through referrals from health professionals, or through HIV support groups, networks or clinics.

When selecting interviewees, consider the following:

- Recruiting interviewees through National PLHIV Networks and local support groups or community structures;
- Recruiting interviewees via referrals from local health professionals or anti-retroviral therapy clinics. Referrals must only be made with the patients’ permission;
- Including the interviewers themselves as interviewees;
- Ensuring a representative balance of both PLHIV and those affected
- The potential ethical issues involved in interviewing children and youth, particularly in relation to informed consent – think of other ways of involvement if possible;
- How big the sample size should be. In Ethiopia, SRI staff used statistical data from health bureau showing the number of PLHIV in each district. This data were used to determine the sample size (number of interviewees) for each district.

Be mindful of which groups and/or particular individuals you may be missing in your survey. These may include key populations such as those with disabilities, men who have sex with men and injecting drug users.
**Informed consent and confidentiality**

- At the recruitment stage, participants must be informed of the aims and purpose of the Stigma Reduction Initiative. This includes how their personal data will be used and stored. Any information sheets must be translated into the local language.

- Interviewers then ask participants to consent to provide personal data through completing the Stigma Index Questionnaire. All participants must give either written or verbal consent, and this must be recorded as part of the data collection process.

- Due to the sensitive nature of the survey content, all participants must be assured that their identity and personal data will be kept confidential. Use numbers instead of participants’ names, and ensure that the code sheets are secure in a locked cabinet.

**SIX: Interviews and administration of the Stigma Reduction Initiative survey**

The Stigma Reduction Initiative survey was based on the standard methodology of the People Living with HIV Stigma Index Survey Questionnaire, developed by GNP+, ICW, IPPF and UNAIDS. For the SRI pilot, GNP+ worked with CAFOD to devise a questionnaire which built on the PLHIV Stigma Index to explore in detail the issues and challenges for faith leaders and faith communities.

**Side-by-side interviewing approach**

The PLHIV Stigma Index is designed to be an empowering and participatory experience for those involved. The people who developed the original Stigma Index suggested that the interviewee and interviewer should sit next to each other, so that they could fill it in together.

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8 [http://www.stigmaindex.org/13/ethical-research/ethical-research.html](http://www.stigmaindex.org/13/ethical-research/ethical-research.html)
9 [See The PLHIV Stigma Index: User Guide for more detailed information, accessed via the link in footnote 7](http://www.stigmaindex.org/13/ethical-research/ethical-research.html)
10 ICW: International Community of Women Living with HIV & AIDS [www.icw.org](http://www.icw.org) GNP+: [www.gnpplus.net](http://www.gnpplus.net) IPPF: International Planned Parenthood Federation (involved as originator and are no longer in partnership) [http://www.ippf.org](http://www.ippf.org)
Things to remember when administering the Stigma Reduction Initiative survey:

- Explain to participants that the survey will take 1.5 to 2 hours to complete.
- Ensure the language is appropriate. Keep it simple and explain terms in more detail if required.
- Provide monetary allowances for interviewers for transport, communication and bags.
- If interviewees need support, refer where possible. Give referral slips to interviewees so that they can take them to service providers. Follow up with service providers to find out if referrals took place.
- Be prepared to give advice and information on rights, laws and policies.
- After the survey hold a debrief session with interviewers. Provide certificates of participation for interviewees and interviewers. If interviewers have been involved for three years, state this on the certificate of participation. It may prove useful for supporting future applications for work or further education.

Ensure that the timing of the survey does not clash with public holidays, or particular seasons e.g. harvest that would prevent people from attending. Ensure advice is professional rather than personal, where necessary make referrals to other services.

SEVEN: Data input, cleaning and analysis

Background decision-making

- Determine whether your organisation has the necessary capacity and skills ‘in-house’ to carry out the data analysis involved in the Stigma Reduction Initiative.
- If not, it may be necessary to contract some of the more detailed work to a consultant, as a means of gathering specific information in-country, and providing technical support to your staff.
- CAFOD contracted the data analysis to Plurpol Consulting \(^{11}\), an international development consultancy based in New Zealand.

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\(^{11}\) [http://www.plurpol.org/joom/](http://www.plurpol.org/joom/)
Key considerations concerning the Stigma Reduction Initiative survey data

- Ensure that the Stigma Reduction Initiative survey forms are properly checked i.e. are they fully complete, legible and properly coded?
- Where possible use local consultants to clean data (check for discrepancies) and develop reports.
- Where it is not possible to employ local consultants for data cleaning and analysis, partners wish to emphasise that they are the owners of the data and that the reports must be developed in consultation with all partners e.g. CAFOD, CAFOD partner and GNP+. This builds capacity of all the stakeholders, but also engenders a sense of ownership of the project.
- Ensure that the consultant responsible for analysing and interpreting the findings is a competent user of a statistics software programme such as SPSS (Statistical Package for the Social Sciences).

Include any consultancy fees and associated costs (e.g. flights) in the overall SRI budget. CAFOD estimate that the cost of contracting an experienced international consultant for 15 days work can exceed £5000.

Important steps to follow when working with an external consultant

- Draw up a contract between the consultant and your organisation, in addition to terms of reference for the SRI. These written and signed agreements will enable both parties to know exactly what it expected from them, and how their work fits in to the overall project.
- Develop a time-frame for the project, which includes detail of tasks e.g.
  - Supporting the initial application of the Stigma Reduction Initiative survey: provide technical advice on criteria for selection of participants, training for interviewers and faith leaders and roll-out plans for the Year 1 survey.
  - Development of and support for the response strategy of faith leaders: Analyse data collected from the Stigma Reduction Initiative survey and report on findings. Work collaboratively with in-country steering committees, CAFOD’s country co-representative and faith leaders to review findings and enable faith leaders to develop stigma reduction strategies.
  - Continue to support the interim (Year 2) and final (Year 3) applications of the Stigma Reduction Initiative survey.
  - Analyse and report on the findings of the Year 2 and 3 Stigma Reduction Initiative surveys.
• Supporting the facilitation of meetings between interviewers, steering committees and faith leaders to consider findings and identify next steps, adjustments or affirmations of faith leaders’ stigma reduction strategies.

• Contribute to the overall evaluation of the project, through co-facilitating one inter-country meeting of SRI Representatives.

EIGHT: Report findings shared

Reporting the findings: An iterative process

■ Use a standardised template to develop reports and ensure that there is a balance of narrative explanation, qualitative discussion and quantitative interpretation.

■ Use clear language throughout.

■ Develop a comprehensive version of the report, which includes all the graphs, but also a condensed version which is easier for sharing, depending on the audience.

■ Include direct quotes from interviewees and case studies in the report.

■ Ensure that the quality of report is peer reviewed at local and international level.

■ Partners may request an initial report that outlines the interesting or notable frequencies.

■ Following this, it is important to meet with partners to ascertain how they want the report written up i.e. mainly narrative with appendices of the graphs and tables, with full technical language and all graphs/tables, or somewhere in between.

12 Photo: Faith leaders, PLHIV and CAFOD partners and staff at the final inter-country SRI review workshop in Kenya, May 2014
"We were told that our data collection was excellent but we didn’t get the info – I would really like to know the findings”
(Female PLHIV: Interviewer, Ethiopia)

Sharing the reports: A collaborative process

- Share reports with steering committees, faith leaders and community members (specifically interviewers/ees). Encourage these stakeholders to express their reflections and thoughts on the findings. Be aware that many community members may not be literate and so verbal feedback and discussions would be preferential.
- Share the reports with participants i.e. interviewers and interviewees
- Ensure that a wide range of stakeholders receives copies of the report e.g. INERELA, AIDS councils, Ministry of Health, Ministry of Agriculture (Services that get referrals)
- Share reports on an online platform e.g. CAFOD’s HIV & AIDS Virtual Network 13
- Ensure that there are sufficient resources allocated for feedback and meetings
- Ensure feedback meetings are scheduled for times of day or year when most/all community members are likely to be able to attend

NINE: Faith leader action plans developed, implemented and monitored

Supporting Faith Leaders

- Support faith leaders in developing action plans to reduce stigma and discrimination in communities. Ensure PLHIV and those affected by HIV are involved. There are many supportive materials e.g. Called to Care 14 series for this purpose. Support may take the form of:

13 For more information on HAVNet, please email Jane Lennon, CAFOD’s HIV Knowledge Management Coordinator: jlennon@cafod.org.uk
14 http://www.stratshope.org/order.htm
• Conducting training for faith leaders in theological reflection related to HIV. INERELA 15 have a document that is supported by quotes from Scripture and spiritual aspects of HIV to link to their day to day work.

• Conducting training for faith leaders on Knowledge Attitudes and Practices for themselves and comprehensive education on HIV prevention by appropriate institutions e.g. health centres and health personnel, INERELA+ and National PLHIV Networks

• Conducting training for faith leaders on psychosocial counselling and non-judgemental listening. Encouraging them to conduct pastoral visits to households of PLHIV and those affected.

• Supporting faith leaders to denounce HIV-related stigma and discrimination in their sermons, through radio, other media and public platforms e.g. schools and prisons.

• Encouraging faith leaders to go for HIV testing and/or treatment to set an example to their congregations.

• Enabling faith leaders to advocate for HIV testing and treatment, and to speak out about HIV prevention without using judgemental language or spreading conflicting messages about faith healing.

What can Faith Leaders do to reduce stigma and discrimination?

■ Host awareness meetings, dialogue, support group meetings or voluntary counselling and testing in places of worship

■ Hold forums with congregation members to talk about HIV.

■ Establish new support groups for PLHIV and raising resources to fund them.

■ Entrust PLHIV with tasks and leadership roles in the faith community.

■ Conduct proper funeral rites for PLHIV.

Some Faith leaders are unable to disclose their status to their congregations. Faith leaders will have competing priorities and overwhelming community needs. Consider developing motivational plans including certificates.

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15 INERELA+ is an international, interfaith network of religious leaders – both lay and ordained, women and men – who are living with or personally affected by HIV. For more info, visit http://inerela.org/
Conclusion

As a result of the SRI, HIV-related knowledge, attitudes and practices of the faith leaders in the initiative significantly improved across all three project sites which in turn has reduced HIV related stigma. The SRI also contributed towards improving the social wellbeing of people living with and affected by HIV and also increased access to HIV testing services for the wider community.

We recognise further work needs to be done if the SRI is to have a significant impact on improving economic opportunities such as employment and education for people living with HIV. We seek to continue to work with faith leaders through meaningful engagement with PLHIV in the three projects sites and aim to scale this up in these countries and across other countries where CAFOD works. This will be done in partnership with PLHIV Networks, and faith leaders.

Appendix and further links

- Example of a Memorandum of Understanding between CAFOD partner and the National PLHIV Network
- Example of a Contract between CAFOD and an external consultant
- Narrative summary template (condensed, user-friendly version)
- Full comprehensive report template (technical, full graphs and tables)
- Resources for Faith Leaders Responding to HIV-related Stigma and Discrimination

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Faith leaders meet to develop stigma reduction action plans in Adigrat, Ethiopia
(Photo credit: CAFOD Partner)