

Setting the global research agenda for community-based HIV service delivery through the faith sector

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Research

Keywords: HIV, Health Systems, Agenda Setting, Faith, Religion, Healthcare, Research Priority Setting, Knowledge translation

Posted Date: November 12th, 2020

DOI: <https://doi.org/10.21203/rs.3.rs-104079/v1>

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Version of Record: A version of this preprint was published at Health Research Policy and Systems on May 17th, 2021. See the published version at <https://doi.org/10.1186/s12961-021-00718-w>.

Abstract

Background

While leading AIDS organisations expect faith and health collaborations to play a crucial role in organising and scaling up community-based HIV services, it is unclear how this can be realised. Little primary research has been conducted into which strategies for collaboration and service provision are most effective, efficient, scalable and sustainable. Seeking to align research with urgent needs, enhance coordination and increase the likelihood that results are used, this study aimed to set an inclusive global research agenda that reflects priority research questions from key stakeholders at the intersection of HIV healthcare and faith.

Methods

In order to develop this global research agenda, we drew from document analyses, focus group discussions, interviews with purposively selected key informants from all continents (policymakers, healthcare providers, faith leaders, academics and HIV activists), an online questionnaire, and expert meetings at several global conferences.

Results

Participants worked in 54 countries, with the majority having research experience (84%), experience with policy processes (73%) and/or experience as a healthcare provider (60%) and identifying as religious (79%). From interviews (N=53) and questionnaires (N=110), we identified ten research themes: addressing sexuality, stigma, supporting specific populations, counselling and disclosure, agenda setting, mobilising and organising funding, evaluating faith-health collaborations, advantage of faith initiatives, gender roles, and education. Respondents emphasized the need for more primary research and prioritised two themes: improving the engagement of faith communities in addressing sexuality and tackling stigma.

Conclusions

A wide range of respondents participated in developing the research agenda. To align research to the prioritised themes and ensure that results are used, it is essential to further engage key users, funders, researchers and other stakeholders, strengthen the capacity for locally embedded research and research uptake and contextualise priorities to diverse religious traditions, key populations and local circumstances.

Introduction

Worldwide, 36.9 million people live with human immunodeficiency virus (HIV).^{1,2} Services provided for people living with HIV include the provision of antiretroviral treatment, mental counselling, prevention, organisation of adherence groups, home-based care and other medical and social support. Currently, 95% of these services are provided by medical staff and medical facilities.³ In 2014, the United Nations (UN) launched fast-track goals to end AIDS, declaring that by 2030, 95% of the people living with HIV should know their status, 95% of those who know their status should be on antiretroviral treatment and 95% of those on treatment should be virally suppressed. According to UNAIDS, community-based services for people living with HIV need to increase from approximately 5% to 30% by 2030 in order to achieve these goals.⁴

One of the community structures expected to play an essential role in scaling up and sustaining community-based HIV services is the faith sector. Faith communities can be described as communities with a shared faith which can be characterised by beliefs in a higher power or order, a code or system that links values and actions and the idea that there is a reason and purpose to earthly existence.⁵ Faith communities have a long-standing involvement in service provision for people living with and affected by HIV. These initiatives are very diverse in terms of scale, organisation, populations reached and sustainability.⁶ Initiatives include large-scale programmes that have been integrated into the health system for decades, short-term programmes financed through temporary funding from an international donor and local initiatives organised by a specific faith leader. The role of faith communities in providing HIV services is not undisputed. Regarding stigma and care for specific populations in particular, both positive and negative influences of the faith sector are seen.⁷ Nevertheless, international organisations recognise the importance of involving the faith sector in providing services to people living with HIV and have developed and implemented a variety of approaches for collaboration.^{8,9,10}

While faith and health collaborations are expected to play a crucial role in organising and scaling up community-based HIV services, it is unclear how this can be realised successfully. Faith initiatives are often embedded in local and social structures, making it difficult to generalise these individual initiatives to a broader context.¹¹ More research is needed to efficiently use available resources, support

investments and make use of the community support that is needed for sustainable collaboration between the faith and healthcare sector.^{12,13}

Little primary research has been conducted into which strategies for collaboration and service provision are most effective, efficient, scalable and sustainable. Current scientific publications about faith and healthcare collaborations consists mostly of overviews and observational studies.¹⁴ Extensive grey literature on projects and programmes is available through organisations such as the Collaborative for HIV and AIDS, Religion and Theology (CHART). However, this literature does not provide insight into how current initiatives can be made more cost-effective, sustainable, integrated into systems, and successful on a larger scale.¹⁵ Moreover, different countries and populations have different research needs, and those which are most urgent for a specific setting are often unclear. Another unanswered question is how best to connect the various stakeholders working at the intersection of faith, healthcare and HIV. Research is thus needed that focuses on organising primary research, connects different stakeholders, and contributes to reproducing local successes on a larger scale and using the limited resources for research as efficiently as possible.^{16,17} As such, this study aims to set an inclusive global research agenda with a focus on cooperation between the faith and healthcare sector for organising services for people living with HIV or at risk for HIV infection.

Methods

This research priority setting process consisted of three phases and nine steps inspired by the priority setting guidelines developed by the Council on Health Research for Development (COHRED) and other globally used priority setting procedures (figure 1).^{18,19}

Phase 1 Setting the scene and designing the process

Step 1

To assess the situation in which the priority setting takes place and clarify the need for a priority setting exercise at the intersection of healthcare and religion, we purposively sampled a core group of experts with extensive global work experience. In addition, data was used from document analyses and five focus group discussions with faith leaders and healthcare workers (N=170) in South Africa. We interviewed selected experts and used these preparatory interviews to establish a larger group of stakeholders, which was important for the priority setting.

Step 2

To specify the scope, map and engage potential key informants and users and help set the scene for the priority setting, we organised an expert meeting in Geneva with representatives from World Council of Churches, UNAIDS, IAS members and academia.

Step 3

Following the COHRED guidelines, we developed a tailored research priority setting approach, for which we combined the Delphi²⁰ method with elements from the CHNRI method.²¹ We defined our expected output as an inclusive global agenda, citing research priorities at the intersection of healthcare, HIV and religion. We aimed to bring together the expertise of scholars with in-depth knowledge of the existing research reservoir and the needs and experience-based knowledge of other stakeholders.

Phase 2 Constructing and conducting Research Priority Setting

Step 4

In this next phase, we identified key stakeholders (policymakers, healthcare providers, faith leaders, academics and HIV activists) from around the world, through purposive sampling and snowball sampling. Two researchers (MN, HS) interviewed the selected stakeholders about the need for research (N=53). Interviews lasted between 45 and 90 minutes, took place either in person (N=30) or via skype (N=23) and were audio recorded and transcribed verbatim.

Step 5

A preliminary list of research questions and themes was identified by four researchers (MN, MK, SLvE, HS) after analysing and coding all interviews. Interviews were analysed using MAXQDA and constant comparative method of analyses.²²

Step 6

The list of research questions and themes was sent out by email as part of a digital questionnaire to purposively sampled key informants representing high-burden countries. Themes and questions were ranked and potentially missing topics were identified (N=110). The process did not yield any new themes.

Step 7

Based on the questionnaire outcomes, a specified list of questions and themes was compiled by three researchers (MN, MK, SLvE). These questions and themes were presented and discussed at two expert working groups at the IAS conference in Paris (N=7) and a workshop organised by the University of Kwazulu-Natal, Collaborative for HIV and AIDS, Religion and Theology (CHART) (N=14). Experts were from different high burden countries and represented international organisations such as the World Council of Churches, IAS, UNAIDS and several universities.

Step 8

Based upon the discussions in the experts working groups, a final research priority agenda was constructed by three researchers (MN, MK, SLvE). This agenda was member checked and approved by five experts from the two working groups in step 7.

Phase 3 Making the research priority agenda work

Step 9

As a final step, we closely collaborated with key funders, researchers, HIV activists and other key stakeholders to promote the use of the research priority setting agenda. The agenda was presented at several national and international conferences, discussed with key stakeholders in planning meetings and in workshops and both a soft copy and printed booklet has been made available. In addition, collaborations with global partners such as the World Council of Churches, Christian AIDS Bureau for Southern Africa (CABSA) and others will ensure that the agenda is known and used in an international context.

Descriptive data from the questionnaires was analysed using SPSS statistics package version 25.0, USA. This study was approved by University of Cape Town Health Research Ethics Committee (Reference number: 123/2015). Written informed consent was obtained from all participants prior to the interviews, focus groups and questionnaires.

Results

Participants

Initial research priorities and themes were identified in phase 2, step 4 (N=53, data saturation after 47 expert interviews). The response rate to the questionnaire sent out in step 6 to rank the identified themes and priorities was 34.2% (N=110 of N=322 questionnaires sent out). The majority of the participants worked in Africa (70%) or on multiple continents (20%). Most participants worked in high-burden countries. The respondents worked in 27 of the 30 countries representing 89% of global HIV infection.²³ Figure 2 shows an overview of the countries in which respondents worked. The majority considered themselves religious (79%). Almost all respondents (92.1%) had experience working with specific populations (the top three of which were children and adolescents, women and girls, and sex workers).

Table 1 describes the key professional role(s) and work experience of participants. Respondents could report several professional roles at the same time. The primary professional role represents the role(s) with which participants currently identified. Many participants also had other relevant experience, such as experience as HIV activist, researcher, policy maker/advisor, health service provider or as faith leader.

Table 1 Respondents' roles (respondents could choose multiple professional roles)

Respondents N=163	Primary professional role(s)	Experience with other relevant (professional) role	Mean years of experience (min – max years)
Researcher N=107	43%	84%	11 (1-41)
Policymaker/Advisor N=96	28%	72%	9 (1-25)
Faith Leader N=63	35%	35%	18 (1-42)
Healthcare Professional N=70	23%	60%	15 (1-45)
HIV activist N=70	36%	50%	12 (1-32)

Key themes

Ten themes with specific research questions were identified and ranked and are presented in table 2 according to ranking, starting with most prioritised themes.

Table 2 Research themes and questions presented in ranking order.. (Here the table should be placed, table sent as extra file)

Priority themes: addressing sexuality and stigma

Participants consistently prioritised two research themes: addressing sexuality and addressing stigma. Participants acknowledged that while a lot of research has focused on stigma and sexuality, these themes remain a clear priority for the future. Research questions focusing on how specific elements of faith traditions enable or hamper health service delivery (including addressing sexuality and key populations) were identified as important and specifically highlighted during expert meetings. Researcher: *"If you can find theological ways of speaking about sexuality, you can speak about sexuality in the church. So, religion is a doorway. It is a gatekeeper, but it is also a doorway."*

Should prevention be a separate theme?

During several interviews and expert meetings, participants discussed the role of the faith sector in prevention and the need for research on prevention. Some argued that prevention should be a separate theme, whereas others considered prevention as part of the remaining themes identified. Participants linked this discussion to the debate about the role of the faith sector in prevention. Several faith leaders and policymakers did not consider prevention to be something that should be addressed by faith and health collaborations. Policymaker:

"What they the church did was, they thought 'What can we do?', instead of 'What can't we do?' What they can do is they can support the inclusion of people living with HIV. They can provide religious support [...] They can support and promote treatment, so they can do that. [...] they can promote testing. What they cannot do is prevention. So they ignored it. They basically said, 'Okay, we are not touching that. We are not going to say it is good or bad [...] we are going to the areas that we can go.' And that has been very interesting."

Improving the use of research

Many participants pointed out that there is not just a need for more primary research, but also a need for better dissemination and use of available research and more cooperation between different stakeholder groups. Participants pointed out that while some themes have been studied for years, many findings remain unused because they do not reach those who could benefit from them. Participants argued that future efforts should therefore not just focus on conducting more and better research, but also on strengthening local research capacities, engaging key stakeholders in research formulation, interpretation and use, strengthening infrastructures for sharing results and best practices and collaboration between international and local stakeholders.

Discussion

The research agenda provides an overview of the research priority themes and questions for faith involvement in service delivery for people living with HIV. It is a combined agenda representing the views of different stakeholders from various parts of the world. While the themes and questions presented reflect a wide variety of responses, some of the themes and questions will fit certain regions better than others.

Participants consistently prioritised tackling stigma and addressing sexuality. While useful research has been conducted into these themes, new locally led and locally specific research and better dissemination of results is clearly needed to better address sexuality and stigma-related research questions.²⁴ Faith initiatives concerning HIV and messaging about sexuality remain controversial and under-researched. Specific populations and faith initiatives have a very ambiguous history, with some initiatives increasing stigma and some diminishing it.²⁵ In addition, experts questioned whether a tailored approach to diminish stigma for specific populations is needed, or that an all-inclusive approach will help diminish overall stigma, including for specific populations. There is a debate as to whether faith leaders themselves can or should play a role in addressing sexuality, or whether they should collaborate with others who can address these issues more effectively. Research should focus on clarifying and evaluating these roles and the possibilities for faith communities in addressing stigma and sexuality.

Several themes of the research agenda focus on issues that are considered part of health systems research, such as mobilising and allocating funding for HIV collaboration and organising the role of faith organisations in HIV initiatives. Shifting HIV services from healthcare, to community structures, requires a shift in funding for these activities. In addition, funding for HIV programmes is shifting from vertical to integrated funding for health systems. More health systems research is needed to explore which strategies for mobilising and allocating funding work best. The new financing possibilities also raise the important question of which structure has to take ownership for specific parts of HIV service provision – a question that needs to be answered to make future programmes successful and sustainable.

HIV prevention was not identified as a separate theme in this research priority setting, despite being described in the literature as an important focus for future faith involvement.²⁶ Some respondents consider faith involvement in HIV prevention as controversial and feel that it should therefore not be a current focus of research. Even in countries such as Brazil, where faith-based organisations are highly integrated into service delivery for people living with HIV, prevention services are generally not carried out by these organisations. Prevention in the context of faith and HIV initiatives is closely linked to stigma and often prevention remains a difficult topic to address in faith and healthcare collaborations. In order to achieve the fast-track goals, however, it is vital that prevention services are scaled up, and the faith sector has huge potential for contributing in this regard.^{27,28}

An important outcome of this agenda is the need for more stakeholder collaboration and improved governance and uptake of research. The faith sector, healthcare sector and academic world have their own goals and systems of communicating and disseminating knowledge. The diverse goals and systems make it a challenge to connect research with needs from the field and support the use of results.^{29,30}

There is a clear need for more demand-driven and locally led research in high burden countries, and further development of a communication infrastructure for sharing best practices and lessons learned. To develop and support such demand-driven and locally led research and increase the likelihood that results are used, a systemic approach is required.^{31,32,33}

While foreign donors can support such research, it is essential to also build a local 'sponsorship constellation' that mobilises local funding for research and legitimates the role of research in society.^{33,34} But also monitor to what extent results are used, and ensure from local practices to those who interpret findings and offer technical guidance.^{35,36}

Available research on faith and health initiatives has mostly been conducted in Christian, English-speaking countries in Sub-Saharan Africa.^{13,37} While this agenda emerged from a wide variety of interviews and questionnaires, the research priorities might tend towards needs that are specific to this region and its corresponding traditions. With 19.6 million of the 36.9 million people worldwide living with HIV in 2017 (53.1%), Eastern and Southern Africa represent an important focus area for future HIV research.¹

Conclusion

The research priority agenda presented here aims to provide an overview of the research most needed at the intersection of healthcare and religion globally. The great diversity in both religious traditions and healthcare involvement should be considered when interpreting this agenda. In addition, given that the HIV epidemic impacts different populations in different countries and regions, it is vital that the priorities are contextualised.

While some priority areas might concern research topics which there is existing research, our data showed that there is an urgent need for new primary research that focuses on core questions from the field. This agenda allows researchers and their funders to align research with

current needs. People living with HIV and their representatives, policymakers and civil society organisations can help attune research to these priorities, inform actual studies and support the translation of results into action.

Declarations

- Ethics approval and consent to participate

This study was approved by University of Cape Town Health Research Ethics Committee (Reference number: 123/2015). Written informed consent was obtained from all participants prior to the interviews, focus groups and questionnaires.

- Consent for publication

Not applicable

- Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request. Due to the specific terms of the ethical clearance for this study, data is not publicly available.

- Competing interests

The authors declare that they have no competing interests

- Funding

This study was funded by the Dutch Nationale Postcode Loterij. The funders of the study had no role in study design, data collection, data analysis and interpretation, or writing of the article.

- Authors' contributions

The idea of conducting a research priority setting emerged collectively from the group of authors. All authors developed the design for this study collectively. MN, MK, SLvE and HS conducted data collection and analyses. MN wrote the first draft of the article on which all authors commented and added for the final manuscript. All authors contributed, read and approved the final manuscript.

- Acknowledgements

The authors are grateful to everyone who participated in this study. In particular we like to thank Mpho Tutu, Francesca Merico, Aneleh Fourie Le Roux, Beverley Haddad, and Jill Olivier for their contribution to this agenda. Furthermore, we are grateful for the opportunities given at the University of KwaZulu Natal to discuss and further develop this research agenda. Without the help and connections from the Christian AIDS Bureau of Southern Africa, this agenda would not have been the same, thank you.

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Tables

Due to technical limitations, table 2 is only available as a download in the Supplemental Files section.

Figures

Phase 1 Setting the scene and designing the process

- Step 1: Assessing the situation through document analyses, preparatory interviews and focus group discussions with stakeholders that have global work experience.
- Step 2: Convening experts to formulate the scope of the priority setting process, ensure engagement of potential key users, and help set the scene for the research priority setting
- Step 3 Developing a tailored research priority approach combining the COHRED guidelines with elements of the Delphi method

Phase 2 Constructing and conducting research priority setting

- Step 4 Identifying key stakeholder groups and conducting interviews (N=53)
- Step 5 Formulating first list of research themes and questions based on analyses of the interviews
- Step 6 Sending out a questionnaire with the research themes and questions to a wide variety of global stakeholders to rank and add on to the identified themes and questions (N=110)
- Step 7 Reviewing and adjusting themes and questions by researchers and working groups (N=21)
- Step 8 Formulating a draft research agenda which is member checked by experts (N=5)

Phase 3 Making the research priority agenda work

- Step 9 The agenda with research priorities at the intersection of HIV, healthcare and religion is presented at several national and international conferences, discussed with key funders and other stakeholders and both a soft and hard copy version is made available

Figure 1

Phases and steps of research priority setting process

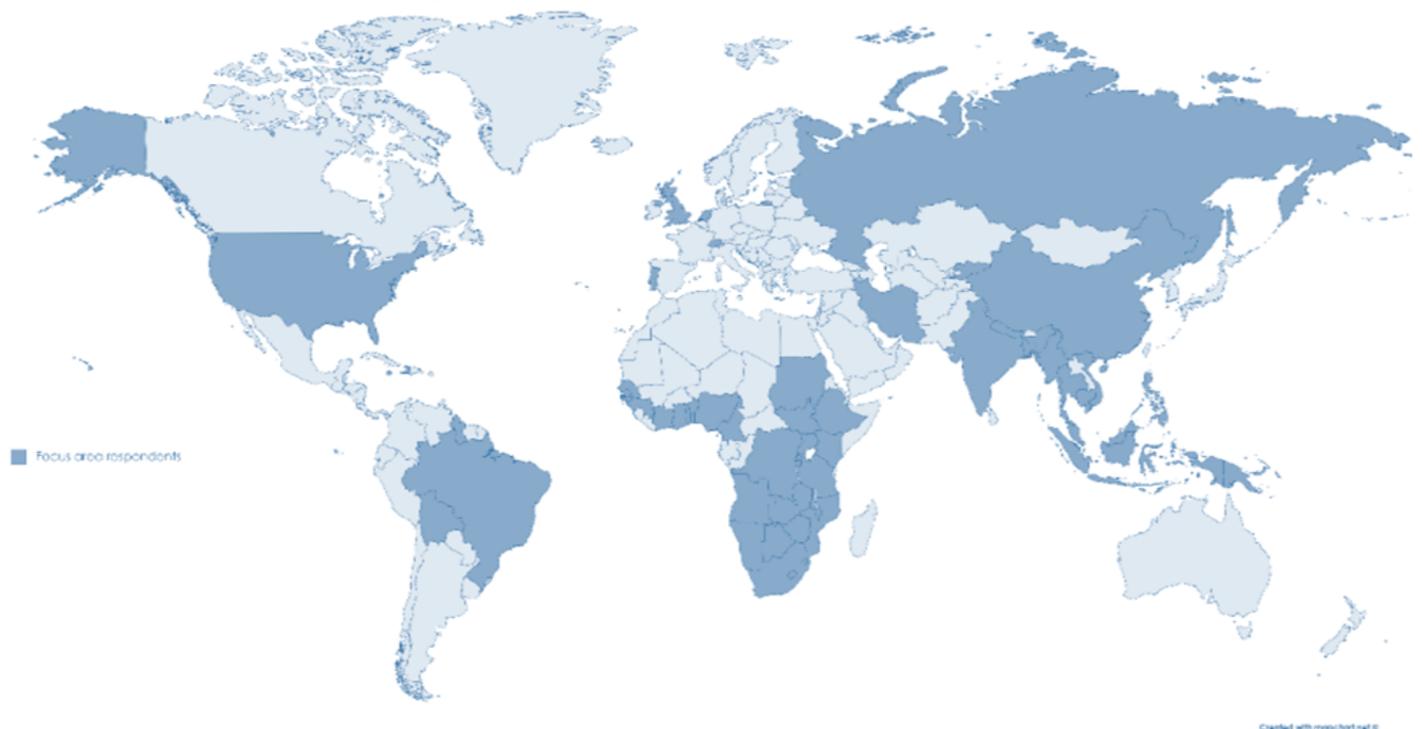


Figure 2

The 54 countries in which participants of the research priority setting process worked

Supplementary Files

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- [Table2RPS.docx](#)