*Effective Prevention and Inclusive Responses: The Healthcare Needs of LGBTI People in the Great Lakes Region of Africa*

*About this Strategic Network*

Funded by the UK Economic and Social Research Council (ESRC) Global Challenges Research Fund, one of the key aims of strategic networks is to break down the boundaries between traditional academic disciplines and thereby facilitate the forging of ambitious cross-disciplinary research collaborations. A second aim is to fully engage partner organizations in the Global South in efforts to address development challenges. A third aim is to bring together researchers with a track record of research in developing countries with scholars who have not previously worked on global development challenges. This strategic network brings together cross-disciplinary academic expertise and practitioners with extensive knowledge and experience in the fields of: gender and sexuality studies; human rights; global health governance; sexual and gender-based violence; and HIV/AIDS.

The network responds to the need forfoundational research on health needs and barriers to healthcare for lesbian, gay, bi-sexual, transgender and intersex (LGBTI) people. The empirical focus of the work is the Great Lakes Region of Africa (GLR), concentrating on two specific areas: sexual and gender-based violence (SGBV) and HIV/AIDS. Across the social sciences, there is substantial literature on: the conceptualisation and theorisation of sexual orientation and gender identity; human security and human rights; sexual and gender-based violence; global health, global health governance and the delivery of healthcare. However, there are significant gaps in knowledge on HIV/AIDS among LGBTI persons, particularly lesbians and transwomen. Further, there is little substantive research on SGBV and health with respect to LGBTI people. This strategic network aims to lay the foundations for research projects that will fill gaps in existing knowledge by interrogating the political, socio-legal, methodological and ethical challenges in conducting research on LGBTI persons in challenging environments. The network further aims to strengthen the interface between research, policy, and advocacy by ensuring that NGOs and other research users are included in a series of workshops funded by the grant and, subsequently, in the research design and execution of future research projects that arise out of these activities.

Why the Great Lakes Region?

The GLR has been selected as the empirical focus of the work because the region poses substantial challenges in researching marginalized, often hidden or hiding, communities. Further, it is a highly challenging location for thinking through and developing policy responses to SGBV and HIV infection and the possible direction and distribution of resources. In many countries across the region homosexuality is illegal. This is not always the case and it is important to acknowledge differences in the way the law operates in practice in specific countries. Nonetheless, in countries across the region, LGBTI persons are subjected to widespread stigmatization and discrimination, whether or homosexuality is criminalized or not. Hence, there are substantial challenges in conducting research on -or better with- people for whom expose entails significant risks and who, consequently, often prefer to remain covert. In some contexts, these challenges are compounded by the interrelated effects of living in conflict and post-conflict societies and/or in emergency situations. The net result is that LGBTI people are at considerable risk of violence, but are often excluded from health services, social protection and have little or no recourse to legal redress of harms suffered. Very few countries in the regions have HIV/AIDS programs directed to LGBTI communities. However, despite-or perhaps because- LGBTI people and communities must negotiate such difficult circumstances in their everyday lives, the region is a site of significant political organizing and activism, by individuals and groups who use the global health agenda as an entry point to promote LGBTI rights as human rights. In turn, the region has also been- and continues to be- the site of myriad, often contentious, ‘interventions’ by international and regional organisations and agencies and donors. Such interventions are bolstered by the growth in political advocacy and activism on LGBTI issues.

Why sexual and gender-based violence?

In current usage by major international organizations, the acronym SGBV refers to**; ‘**any act that is perpetrated against a person’s will and is based on gender norms and unequal power relationships. It encompasses threats of violence and coercion. It can be physical, emotional, psychological, or sexual in nature, and can take the form of a denial of resources or access to services. It inflicts harm on women and girls and men and boys’ (UNHCR).’ It is well-known that there are high rates of sexual and gender-based violence in conflict situations and during humanitarian crises. However, while there have been reported cases of LGBTI persons being targets of gender-based violence and sexual violence in conflict zones, it is wrong to assume that instances of SGBV are always or necessarily ‘conflict related’, since this over-shadows violence that is not directly related to conflicts in the region. LGBTI persons are, however, at risk of gender-based violence perpetrated as a form of social control, used to police sexed and gendered bodies and enforce Cis (heteronormative) gender norms. There is pushback against all transgressions of gender norms, but violence is acknowledged to be widespread against transwomen particularly.

The international community’s response to the problem has been inadequate in key respects. In practice, the dominant framing of SGBV still tends to represent women and girls as the principal victims and survivors. While it is now acknowledged that men and boys can also be victims and survivors, LGBTI persons remain largely invisible. The lack of recognition and legal protection afforded to LGBTI people in many countries in the region creates a climate of impunity which exposes individuals and communities to a further risk. Moreover, forms of legal redress-where available in principle-do not address the relationship between homophobia and transphobia, prevalent across the region. Non-governmental organizations (NGOs) have played important roles in raising awareness and running programmes to tackle SGBV, working to challenge dominant cultural and gender norms in specific countries across the GLR. However, such organizations have limited capacity and resources and, further, face a difficult task in including LGBTI people without exposing them to further risk. There is a need, therefore, for Western based researchers to work with civil society organizations doing vital, community focused work to challenge dominant gender norms and promote social and cultural change. There is also a need for Western based researchers, institutions and donors to help build capacity among NGOs across the region.

Why HIV/AIDS?

In relation to marginalized or convert groups, current research on HIV tend to employ the term ‘key populations.’ In relation to LGBTI people, in practice this usually means men who have sex with men (MSM). As such, current research neglects people who fall into the categories of non-heteronormative sexualities or who embody and perform diverse gender identities. There are both gaps in research on key populations and a dearth of data on the health needs and barriers to health among lesbians, bi-sexual women and transmen specifically. However, LGBTI people and communities at risk are difficult to access. This poses considerable methodological and ethical challenges to researchers, endeavouring to generate reliable quantitative data on the incidence of HIV among LGBTI populations and, indeed, on any link between SGBV and HIV.

Moreover, there are myriad power relations at work in ‘meaning making.’ While ‘evidence-based policy’ is championed as the ideal among many research funders, the generation of evidence is coloured by the framing of issues, agenda setting and the setting of key objectives. Coalition building between academics, advocacy groups and practitioners requires a shared frame of reference, yet coalition building is also a political process. With respect to research on HIV specifically, in consequence of activism around HIV/ AIDS, LGBTI rights as human rights is now built into the architecture of global health, notwithstanding significant political contestation around Agenda 63 (‘leave no one behind) and the contentious nature of LGBTI rights claims at the World Health Organization. The UN Global Fund recognizes the need to include marginalized groups, including LGBTI persons and sex workers, in combatting HIV and has devoted considerable resource to this effort. There is a growing trend towards directly funding LGBTI organizations to carry out surveys and other data generating exercises. Potentially, this presents fruitful opportunities for collaboration between activists and academics in the co-production of knowledge, but it also raises questions about what the proper relationship between advocacy and academia should be, which must be confronted.

A note on terminology

In this project, the term LGBTI is used to denote non-gender conforming people. We have adopted the term LGBTI (sometimes, LGBT, LGBTIQ or LGBT+) because it has now passed into the lexicon of researchers, policy-makers and activists across the world. However, we recognized that the acronym is a construct (of Western origin) that does not necessarily capture diverse sexualities and dynamic gender identifications in varied cultural contexts. Rather, it is a category that reflects the need for people with diverse sexual orientations, gender identities and expression and sex characteristics (SOGIEC) to be administratively recognized. The category LGBTI is also compatible with contemporary human rights discourse and with current rights-based approach to sexual minorities in development. When deployed in discussions on of the legitimacy of interventions and in aid policy, LGBTI rights claims can be contentious, problematically bolstering homo-nationalist discourses that characterizing the world as beset by ‘Queer wars’ or ‘cultural wars’ between Western and (many) non-Western states, in ways that belie more nuanced, complex realities. As such, we employ the term in a reflective and not uncritical vein. Researchers, activists and practitioners employ different acronyms. Generally, the term LGBTI has been retained in reports on workshop activities, except in cases where participants have been paraphrased or directly quoted and the acronym employed in the original usage has been retained.

*Project aims*

Politics, socio-legal and cultural contexts

* To better understand cultural norms and attitudes to LGBTI persons in specific countries across the region.
* To confront socio- legal factors that act as barriers to accessing healthcare.
* To identify ways of accessing marginal and/or covert populations in specific socio-economic, political and cultural contexts.

Making visible people and communities that are marginalized and/or covert can serve to politicize sexual and gender-based violence and HIV health issues in ways that are unhelpful or worse that expose LGBTI people and communities to greater harm or danger. As such, researchers must interrogate both the nature of marginality and/or covertness and how this varies in socio-economic, political, economic and cultural contexts.

The politics of LGBTI in global health

* To further the development of a research process that is cognizant of substantive, complex problems of taxonomy, measurement and access.
* To better understand how specific groups (i.e. ‘LGBTI’) are constituted in relations to modes of organisation, engagement with international bodies and modes of alliance formation in the global institutional political economy.
* To further understanding of how the politics and economics of financing and donor funding shape or impact on the construction of taxonomies and categorisations (i.e. LGBTI).
* To further understanding of how NGO and international organizations frame and operationalize responses and the likely impacts in specific locations.
* To better understand how dominant framings of gender, sexuality and health include and exclude specific groups.

While the acronym LGBTI is widely used and deployed by researchers and in international institutions, among national and local religious leaders, politicians, local government officials and NGOs, the term is not necessarily embraced by all ‘non-heteronormative’ people and indeed might be an unfamiliar concept among populations at large in specific countries.

It is important to recognise that existing taxonomies are complex and reflect the politics and economics/financing of such groupings, their inter-relationships, modes of organisation, engagement with international bodies and modes of alliance formation in the global institutional political economy. Therefore, we need to better understand the factors that shape the international response to discrimination against LGBTI people, how NGO and international organizations frame and operationalize responses and the likely impacts in specific locales.

Develop best practice on ethical research

* Confront the ethical dilemmas that arise when conducting research on marginal and covert groups.
* Develop ways to access research subjects and conduct research with LGBTI people and communities that minimize risks to vulnerable people.
* Contribute to the development of a protocol on the ethics of research on LGBTI people and communities that ensure that their dignity and rights are respected.

Develop appropriate methodological tools

* To develop appropriate, reflexive methodological tools to interrogate SGBV in relation to LGBTI people and communities, which pay due regard to the need to respect their dignity and rights and safeguard their well-being.
* To develop appropriate methodological tools to identify and access LGBTI people and communities at risk of HIV infection, which pay due regard to the need to respect their dignity and human rights and which are sensitive to risks arising in exposure for such people and groups.
* Identify appropriate, effective methodologies to generate reliable quantitative data on the incidence and risk of HIV infection among LGBTI persons.
* To develop qualitative methods better suited to the task of uncovering and recording personal experiences, often of an intimate and highly sensitive nature.

A useful starting point is to review methodological tools and epidemiological techniques that have been employed in studies of marginalized or other convert communities (for example, sex-work, criminal gangs, drug users and LGBTI persons in other contexts). However, ultimately the research must be contextualized within the context of the concrete conditions and circumstances that exist in countries across the region. As such, it is necessary to call upon and work with NGOs and other civil society groups to identify the most effective ways of gathering both quantitative and qualitative data. Further, researchers and the research must be located in relation to research subjects. The need for reflexivity in the research process, and in developing methods and methodological tools, is central to this project.

Produce research agendas with concrete policy relevance

* To develop and disseminate workable and effective strategies to promote social and cultural change which will have a positive impact on diminishing stigmatization and other forms of discrimination that act as barriers to accessing health provision.
* Build upon existing research, to further develop best practice with a focus on the ‘coal-face’ of implementation and operational delivery of health services.
* To recommend concrete measures and strategies to extend health services to such people, within the boundaries imposed by the practical observance of relevant laws and according to the demands of social justice and human rights.
* To develop and disseminate strategies that target and reach legislators, policy-makers and influential opinion formers and other change drivers, at local and national levels in specific countries, and in relevant international institutions.

Contribution to academic knowledge

* Generate research that fills a gap in knowledge at the nexus of gender and sexuality studies, human rights scholarship, development studies, global governance and global health.

*Output*

A final report that:

* Summarises the activities of the network over the lifetime of the project.
* Notes possible policy implications identified by this initial programme of foundational work.
* Produces a draft protocol of research ethics for research on populations subject to stigmatization and discrimination.
* Identify priorities for future research.
* Identifies effective ways of engaging with groups to take forward research of policy relevance.

*Network team*

Principal Investigator: Dr Jill Steans (University of Birmingham, UK). Expertise: SGBV; human rights; theorizing gender and sexuality.

Co-Investigators: Professor Poku (University of Kwa-Zulu Natal, SA). Expertise: HIV/AIDS; global health; human security; political economy.

Professor Jane Freedman (University Paris 8). Expertise: refugee and asylum; SGBV.

Dr Claire Somerville (Graduate Institute, Geneva). Expertise: methodologies; gender issues in global governance; global health; knowledge transfer.

Professor Tony Barnett. Expertise: infectious diseases; HIV/AIDS; global health.

Partner Organization: UNAIDS

Partner Organization: UNDP Africa.

Partner Organization: Positive Vibes (Namibia based): Extensive practical expertise in networking with consultants and NGOs working on LGBTI rights and health (HIV) across Southern Africa.

Partner Organization: ISIS-WICCE (Uganda based): Extensive practical expertise in women’s human rights, armed conflict, violence against women, SGBV.

*Project start date*

January 2017

*Duration of the project*

18 months

(Document compiled by Dr Jill Steans, April 2016, revised June 2018)