Chapter 1

International Community-involved LGBTQ+ Health Research: Multidisciplinary Reflections and Strategies

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Abstract

This chapter examines the experiences, challenges, and strategies involved in conducting meaningful community-engaged research with Lesbian, Gay, Bisexual, Transgender, queer/questioning and other sexuality and gender

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4 Sujith Kumar Prankumar et al.

diverse identities (LGBTQ+) communities across three Asia-Pacific contexts: Australia, Hong Kong, and Singapore. It draws on the multidisciplinary expertise and lived experiences of collaborators working in health, social sciences, and community leadership. Addressing the complexities of multicultural LGBTQ+ health and migration research, the chapter explores structural, interpersonal, and conceptual challenges while critically interrogating Western-centric frameworks of gender, sexuality, and culture. Key strategies for fostering equitable, culturally safe research partnerships are presented, emphasising the importance of centring the voices and priorities of marginalised LGBTQ+ communities by actively involving them throughout the research process, from conception to dissemination. The chapter is grounded in insights from a participatory focus group facilitated by young, culturally diverse LGBTQ+ leaders. Through critical reflections, it identifies opportunities and barriers to advancing community-centred research that can support community well-being and shape inclusive policy and practice.

Keywords: LGBTQ+; Asia-Pacific; community engagement; health

research; cultural diversity

Introduction

Community engagement has become an essential feature of health and social care research and a core feature of community engagement is the inclusion of persons with 'lived experience' in the research. In the UK, National Institute for Health and Care Research (2021/2024) defines 'lived experience' research as research 'carried out "with" or "by" members of the public rather than "to", "about" or "for" them'. Such research disrupts subject-object binaries by, among other strategies, challenging the notion of 'researcher-as-expert' through centring and validating lived experience and community expertise (Sanjakdar, 2022, p. 3). Community engagement seeks to enhance research impact by ensuring that research concerning marginalised communities is ethically conducted, responsive to local needs, and contributes towards both advancing scientific knowledge and developing interventions that directly benefit these communities (Taffere et al., 2024).

The increasing application of community engagement in health research has brought attention to concerns with 'lived experience', including what types of 'lived experience' are prioritised, how and why certain community representatives are selected, and whose voices are conferred credibility (i.e., who is accorded epistemic authority and expertise). Quite often, sacrifices and trade-offs need to be managed and made to strike a balance between welcoming diverse perspectives and satisfying institutional timelines and bureaucratic demands (Mason, 2021). For example, a bias towards selecting individuals who are more confident, highly educated and experienced (in communicating in academic and sector-specific language), and who are community leaders, can streamline decision-making but can also 'easily exclude [less confident] voices [that come from more marginalised

positions]' (Pratt, 2021). A strategy to only include individuals with no engagement experience or professional expertise in the research topic can result in the exclusion of diverse voices and risk essentialising certain types of experiences as authentic (McIntosh & Wright, 2019). Decisions about who is included can create new hierarchies that fundamentally shape research, policy, and programme priorities in ways that may further alienate marginalised communities.

Trade-offs are often made when deciding when and how community members are engaged. Are they research participants, co-designers, advisors, authors, analysts, or investigators, and are they included in the early stages of project conceptualisation and grant review (Rittenbach et al., 2019)? What training and compensation are provided (e.g., Blair et al., 2022)? How are ethics committees engaged? While ethics committees ostensibly protect marginalised and vulnerable community members, they may instead often institutionalise practices that 'coopt research and ... impose or restrict research agendas' (Roffee & Waling, 2017, p. 14). Community members involved in research often risk being tokenised or are accorded epistemic deference, and, consequently, research based on subjective 'lived experience' has been dismissed as an illegitimate source of knowledge or held as unquestionable and infallible (Casey, 2023). Commenting on the dangers of deference for certain 'authentic' voices based on an uncritical investment in parochial notions of identity, Taíwò (2022, p. 82) noted, 'the same tactics of deference that insulate us from criticism and disagreement insulate us from connection and transformation. They prevent us from engaging empathetically and authentically with the struggles of other people – a prerequisite of coalitional politics'.

Over the past decade, LGBTQ+ communities internationally have been the subject of growing research and policy attention. Yet, despite the increasing focus on intersectionality (e.g., of race, class, sexuality, disability, and gender), research on sexuality and gender diverse communities often continue to treat LGBTQ+ communities as a monolithic group (Ferguson, 2021; Pilling et al., 2017; Sadika et al., 2020; Simpfenderfer et al., 2024). The homogenisation of LGBTQ+ communities centres a Western worldview of sexuality and gender that privileges binary notions of gender and race, which results in, among other things, an oversimplification of diverse experiences, a failure to understand the unique experiences and needs of specific groups, and the reinforcement of negative stereotypes (Vidal-Ortiz et al., 2018). Consequently, overlooking in-group differences can result in a misdirection of resources and further marginalise underrepresented groups (see Adley's chapter in this collection).

This chapter draws on our multidisciplinary lived, professional, and academic experiences working with LGBTQ+ communities on health research across three Asia-Pacific contexts: Australia, Hong Kong, and Singapore. We offer critical reflections on the experiences, challenges, and strategies involved in conducting meaningful community-engaged research across these unique contexts. We first briefly outline the context of our work, and then offer two challenges that present opportunities or barriers with regard to community engagement (i.e., the politics of neutrality and identity; and power dynamics and ethical considerations with research), before discussing strategies that we have implemented in our work that have supported effective community engagement.

LGBTQ+ Research in Australia, Singapore, and Hong Kong

While the three contexts share similarities – they are developed economies with highly educated populations and increasingly visible LGBTQ+ communities, and are former British colonies that have been subject to anti-gay laws – there are important distinctions that materially affect the conduct of LGBTQ+ research.

Australia is a multicultural society with full legal recognition of same-sex marriage since 2017, strong anti-discrimination legislation, a vibrant LGBTQ+ social infrastructure in urban areas, an open media environment, and a generally accepting social climate. In Hong Kong, homosexuality is not explicitly criminalised, and there is some recognition of same-sex partnerships. Significant court cases have incrementally advanced LGBTQ+ rights. This includes a 2023 High Court ruling in favour of same-sex marriage recognition (Leung, 2023), which reflects glowing popular support for marriage equality – now at 60% (Lau et al., 2023). In Singapore, male same-sex sexual activity was decriminalised in 2022 with the repeal of Section 377A of the penal code. However, media restrictions on LGBTQ+ content remain. A constitutional ban on same-sex marriage was introduced with the repeal of 377A, and support for marriage equality, while growing, remains low at 32% (Ipsos, 2024).

These social and political sensitivities have had material impacts on the research environment pertaining to LGBTQ+ topics. LGBTQ+ research in Australia is supported by initiatives and funding from government and academic institutions, resulting in extensive conceptual and empirical research being conducted across a wide variety of topics across the life course, using myriad methods. In the Australian context, community co-design is increasingly mandated in state-funded research. In contrast, LGBTQ+ research in Singapore and Hong Kong remains considerably more constrained, and is often dependent on partnerships with international institutions, philanthropic organisations, and nongovernmental organisations. Scholarship in these latter contexts appears predominantly positivist and empirical, which might reflect national research policy expectations about what constitutes 'good' research, i.e., research with a quantitatively measurable impact.

We are a group of research collaborators with significant experience working with LGBTQ+ and other socially marginalised populations in Australia, Hong Kong, and Singapore. Some of us are full-time social researchers employed at universities, while others are nurses, social workers, health promotion officers, policy officers, programme managers, community advocates, and students, with a few of us fulfilling multiple roles. Within our group, we have engaged in several community-engaged quantitative and qualitative projects at the intersection of race, sexual and mental health, and sexual citizenship. In much of our work, we work closely with community members and organisations, although the sociopolitical realities in our respective contexts shape the design and scope of our studies.

Method

The content of this chapter was informed by our international collaborative research activity and then developed from an online focus group discussion. The discussion, which lasted 85 minutes, was facilitated in English by two authors with the support of the senior authors (SKP and HW). The facilitators, both sexuality and gender diverse young community leaders of migrant backgrounds, iteratively and collaboratively developed the interview guide from a list of collaborator-contributed questions. The shortlisted questions were grouped in five domains: Safe and Ethical Research Practices; Language and Terminology; Intersectionality, Bias, and Cultural Humility; Conceptualisations of Gender, Sexuality, and Cultural Diversity; and Community Engagement and Representation. The discussion was recorded and transcribed verbatim, with the chat logs and transcripts analysed thematically by the first author (SKP). The study did not undergo an institutional ethics procedure, as all of the focus group members are also authors who gave their permission to participate.

Politics of Neutrality and Identity

Understanding positionality is important for health and social care research, and a common feature of research conducted across the various contexts was the necessity to maintain an appearance of neutrality. Participants working in Singapore attributed this to state policies that emphasise neutrality in relation to social issues to 'keep the peace' within society, in acknowledgement of a vocal community of conservative religious activists and in view of the state's endorsement of the heterosexual family unit as the basis of society, with the result that LGBTQ+ populations are barely mentioned in sex education, the media and health promotion (see Ramdas, 2021; Yulius et al., 2018, p. 187). Beyond maintaining silence, neutrality was also associated with the expected and calculated inclusion of voices hostile to LGBTQ+ equality for the sake of 'balance'. The emphasis on neutrality continues to maintain and even exacerbate health inequities in Singapore, as a participant noted:

One of the Singapore government's reasons for keeping 377A on the books for a long time was to be 'neutral' to 'both sides'... even if one side causes harm. This push for 'respectful neutrality', to give legitimacy to homophobic views alongside LGBTQ+ perspectives... hinders progress. Real change often requires challenging power structures, even at personal cost. True neutrality can reinforce systemic violence, benefiting those in power while harming marginalised communities. For example, LGBTQ+ lives are barely mentioned in sex education or public sexual health communication because of this need to be 'neutral' and 'keep the peace', because of the fear of coming across as supporting a certain marginalised community...

These dynamics – of maintaining neutrality in an effort to not attract criticism, unwanted attention or social stigma - also feature in the Australian and Hong Kong contexts (e.g., Barrow, 2020; Kin & Denise, 2019; Riseman, 2019). In these settings, participants' focus on appearing neutral was reflected in their decisions about which aspects of their identities they disclosed publicly. Their decision as to whether to publicly identify as sexuality or gender diverse, or to keep such information private, was a careful balance between a desire for transparency with community members and concerns about potential political, occupational and funding repercussions. They were anxious that such disclosures could lead to criticism, stigma and discrimination from their respective institutions, the state and the public, and that their research would be deemed 'biased' or 'one-sided', and therefore untrustworthy. Their hesitation to disclose their positionalities was recognised as a barrier to establishing community trust, particularly in studies exploring personal topics such as sexuality and sexual behaviour. As a result, these participants expressed needing to spend more time in building effective and trusting relationships with study populations. Some participants, however, noted that being able to identify themselves as 'insider researchers' – particularly in the Australian context – enabled them to embody a transformative praxis (Thambinathan & Kinsella, 2021) that bolstered rather than challenged their credibility.

The management of neutrality also affected the language used in research. Participants contrasted the diverse and rapidly evolving ways that communities described themselves against the 'elite' language used in research studies that privileged Western binary ways of understanding identity. They grappled with the challenge of navigating between Western and local language regimes, not solely to ensure cultural and context-specific relevance, but more fundamentally to reconcile the tension between critiquing and aspiring to decolonise dominant discourses, and needing to comply with institutional norms necessary for securing funding, advancing careers and achieving research goals that align with both participant well-being and institutional expectations. For example, deciding on the terminology to be used during the recruitment stages of their studies was experienced as challenging and time-consuming. The use of the terms 'queer' or 'LGBTQ+' among multicultural populations, the growing pressure to declare one's pronouns (itself premised on Western epistemologies of gender), and assumptions around culture and ethnicity – such as the use of the term culturally and linguistically diverse (CALD) in Australian recruitment material to describe anyone not Anglo Australian; the instruction to identify as either Chinese, Indian, Malay and 'other' in surveys in Singapore; and the presumption of ethnic homogeneity in Hong Kong – were all acknowledged as privileging dominant ways of understanding ethnicity (i.e., equating ethnic Chineseness with being Singaporean and whiteness with being Australian). The imposition of Western frameworks of sexuality and gender diversity were seen as both actively and implicitly functioning to erase community diversity.

Further, participants reflected on how the reliance on broad terms informed by Western epistemologies of identity shaped the research focus and data, and then led to the over-recruitment of cisgender gay men from dominant cultural backgrounds to participate in research studies. This, in turn, privileged certain ways of understanding gender and sexuality while marginalising the perspectives of ethnic minorities and gender diverse individuals. These minoritised voices often felt pressured to articulate themselves in ways that did not fully align with their own experiences and languages, making it difficult for them to see themselves reflected in the research. For instance, although participants appreciated the inclusive intent behind the demand for pronouns, they noted that the prescriptive ways such questions were presented often pressured them to 'out' themselves or provide false information. For several participants, the pressure on respondents to be transparent in particular ways, alien to their cultural heritage, often felt unsafe for those whose heritage languages did not orally differentiate between pronouns and which had therefore afforded them the capacity to express themselves neutrally, without lying. One participant said:

I did some research exploring terms like 'Queer' with Chinese communities, and many people did not relate with the terms and had different understandings of them compared to the Western understandings. Many [of them also] felt that they had to come out when speaking in English because English uses pronouns, but in Chinese, all pronouns sound the same. ("ta": 他 - he/him, 她 - she/her, '它 - it)

Power Dynamics and Research Ethics

In addition to navigating identity concerns/constructs and demands for neutrality, participants reflected on the power dynamics that are often present in community-engaged research. These included balancing academic and career goals with community engagement, navigating dynamics within LGBTQ+ communities, and managing demands from institutional ethics committees who might not appreciate diversity and difference within marginalised communities.

Firstly, with growing expectations to meet challenging institutional key performance indicators (KPIs) for career advancement and to attract research funding, participants felt pressured to collect data and publish as efficiently as possible to continue attracting more funding to benefit marginalised communities. For example, one participant described a situation in which their colleague's attempt to share research findings with LGBTQ+ communities in Singapore was blocked by the study's principal investigator. The principal investigator insisted on prioritising publication in academic journals, fearing that others might use their findings if they were released publicly prior to publication. The participant considered this an example of a power imbalance, whereby 'the principal investigator or the senior investigator controls when and how such information is given back to the relevant communities to help the communities in various ways'.

Secondly, participants observed power differentials within LGBTQ+ communities. These differentials were noted along various dimensions, including gender, class, ethnicity, nationality, and educational status.

Power differentials are also apparent in political dynamics within LGBTQ+communities, whereby some established groups control access and therefore community discourse, making it difficult for alternative voices to influence more inclusive and culturally relevant research and advocacy. Participants discussed how power struggles between LGBTQ+ leaders and groups complicated community engagement. They recounted having experienced debates about who – and whose experiences – should be included on the study team. The conflation of 'co-design' with 'equal' was challenged, as those with most power often controlled the process, as one participant said:

There are some queer groups who have longstanding relationships with people in power (the media and government), and therefore they want to protect that. It can be quite difficult to negotiate relationships if... you don't follow that particular way that this power broker wants you to do it ... There's quite a bit of infighting, and everybody has a different way of doing things, so it's difficult to figure out the most appropriate way of engaging the community when we're doing research.

Thirdly, participants recalled having frustrating interactions with review committees that often insisted that researchers include problematic terminology (such as outdated or culturally insensitive wording, deficit-based language, and binary notions of gender) that can reinforce stereotypes and retraumatise participants, and who frequently imposed a positivist paradigm and quantitative expectations of evidence on qualitative projects (e.g., generalisability and validity). They felt that health and social research ethics committees, as gatekeepers who were often unfamiliar with qualitative methods since they usually worked within positivist and biomedical frameworks, prioritised compliance and the mitigation of institutional risk over the expressed needs and expectations of community members. In order to receive ethics approval, the participants felt researchers may be compelled to frame the notion of 'risk' to align with the ethics review committees' expectations. As a result, ethics applications encourage the consideration of 'risk' at the individual level (e.g., psychological risk, which is mitigated superficially through the provision of information regarding support services) rather than at the community level (e.g., through engaging in meaningful, trauma-informed co-design).

Beyond noting ethics committees' influence on study design, participants discussed how the use of specific terms (e.g., categories of gender, sexuality, ethnicity, mental health, discrimination, and deficit-based language), as recommended by ethics committees, complicated recruitment efforts. They expressed concern that prospective participants sometimes felt they did not qualify for studies that were, in fact, intended to include them. Essentially, the ethics committees' recommendations often restricted participation to individuals who could easily identify with these terms, which were typically aligned with Western, mainstream conceptions of gender, sexuality, and ethnicity.

Participants working in the Australian context also commented on increasing expectations from funders regarding community engagement. While they

appreciated the intent, they felt that the requirement was often met in superficial or 'tokenistic' ways. Participants felt that government agencies and funders cared more about the extent to which KPIs were met, rather than meaningful community engagement. An Australia-based participant with a background in public health expressed concern about the colonial and extractive behaviour regarding knowledge production and sponsorship:

Health policy (in LGBTQ+ research) is dominated by white, cisgender gay men who are often very vocal. It's almost like they feel like they speak on behalf of the community and feel like they've done the work, but often it's quite tokenistic. When I sit in meetings and hear about the way they do community consultations, I feel quite concerned that they would take credit for that piece of work to build their profile. They might not necessarily understand what they're talking about, but they will always claim that they've done the consultation and engagement, to meet their KPI. I'm like, wow, these people don't really know their work, but they can talk the talk. Sometimes, 'co-design' is box ticking, or used to confirm what the researchers wanted to do anyway, so they ignore the ideas that challenge their initial plans.

Despite their concerns about the lack of meaningful minority ethnic and gender diverse representation at the project management and commissioning levels, participants were encouraged by the slowly increasing number of LGBTQ+ people from culturally diverse backgrounds who are beginning to lead research projects, and by efforts of ethics committees to become more familiar with qualitative, community-engaged research.

Responding to Power and Identity Politics in Health Research

Participants' responses highlighted three linked strategies that can enhance community-engaged research: developing genuine community partnerships, investing in community-driven marketing and communications efforts, and adapting research tools to reflect the ways local communities understand themselves. These will be discussed in turn.

Develop Genuine Community Partnerships

Engaging communities early and throughout the research process, incorporating diverse manifestations of lived experience and expertise, co-developing the study's design – including research questions, methods, instruments, and dissemination plans – before finalisation, and prioritising training and knowledge transfer are essential to building reciprocal trust.

The development of genuine and effective partnerships is associated with greater transparency and accountability and mitigates feelings of exploitation. For example, on the question of data justice: to what extent can community

groups give feedback on the study's findings, and to what degree do they own the data they collect or provide? To achieve this, researchers should actively involve community groups in the dissemination of findings, ensuring they have opportunities to provide feedback and feel validated in their contributions. It is also critical for researchers to honour commitments made during the research process by maintaining communication with participants, sharing outcomes, and creating pathways for ongoing collaboration. This includes ensuring community members know where their data are going, how it will be used, and leaving the door open for future engagement or research opportunities. By doing so, researchers can foster trust, mitigate feelings of exploitation and promote data justice, thereby ensuring communities feel ownership and agency over the stories they share. To further foster transparency, accountability, and equitable partnerships, researchers could think about how they disclose their own positionalities, offering clarity to stakeholders about how their personal backgrounds, biases, and social positions influence the research process.

Invest in Community-driven Marketing and Communications Efforts

Efforts to address the underrepresentation of marginalised populations in research should include targeted marketing, recruitment, and engagement strategies. These may involve using imagery that reflects diverse communities to ensure participants feel represented, contracting with community organisations to manage recruitment, and hiring facilitators with relevant lived experience to build trust between participants and research teams. There are four key benefits of this outsourcing approach: firstly, partnering with community organisations enhances the political and public credibility of both the research team and the community organisation. Secondly, it improves participant recruitment efforts by aligning them with scientific and programme needs and priorities. Thirdly, it provides the organisation with a steady income stream that can be applied towards supporting community initiatives. Fourthly, it creates opportunities for skills development within the community organisation.

However, while targeted strategies can be effective, they need to be implemented carefully to avoid stigma. For example, overly narrow approaches in health education can inadvertently signal that certain groups are inherently at higher risk, creating discomfort or resistance. The value of using inclusive, non-stigmatising language to encourage open engagement must be stressed. Fostering trust and dialogue, rather than immediately and solely focussing on sensitive topics like race, sexuality, or Human Immunodeficiency Virus (HIV), can lead to more meaningful and productive relationships.

Adapt Research Tools to Reflect the Ways Local Communities Understand Themselves

The language and structure of research tools can either foster inclusion or alienate marginalised populations. Ensuring flexibility in methods (e.g., art-based approaches, interviews, and surveys), terminology (e.g., using gender-affirming

language and avoiding assumptions about pronouns), and delivery (e.g., offering online or in-person options) is essential to respectfully engaging diverse communities. For example, researchers could consider organising paid community focus groups to review and refine research tools, ensuring they are trauma-informed, inclusive, clear, and reflective of lived experiences. Feedback from these focus groups can guide adjustments to language and content, such as adding qualitative questions that invite participants to share personal experiences. The inclusion of a qualitative question about community belonging and access to services could provide unexpected and valuable insights into themes like inclusion, exclusion, trauma, race, and lateral violence, deepening the understanding of participants' lived realities, individually and collectively.

Conclusion

Research into and with LGBTQ+ communities often requires heightened sensitivities due to social and legal marginalisation. Community-engaged research, built on mutual respect and trust, is essential for producing respectful, accurate, rigorous, and actionable research that can directly benefit such populations. Our chapter here has been informed by our empirical work and a sympathetic critical appraisal of it across Australia, Hong Kong, and Singapore. While community engagement can often be a long and challenging process, such research, which is culturally sensitive and positions community members as active collaborators and co-creators of knowledge, can more effectively reflect the community's complex realities and needs, protect their safety and dignity, promote their health and well-being, and strengthen communities. Those who wish to follow our work and learn from our experiences need to consider the context of our work, positionality and the constant need to be reflexive and reflective at every point in their own research journey. Taking steps to adapt research tools to reflect the ways local communities understand themselves, while investing in community-driven recruitment and dissemination efforts, is key to driving more authentic and genuine forms of community engagement.

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