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Navigating participation and evidence in emancipatory sexual and reproductive health care

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Significance:

Human health and well-being are central to social and economic justice. Therefore, interdisciplinary conversations about how health research is produced are significant, as they offer researchers and activists opportunities to consider knowledge from different research traditions. This Structured Conversation explores the perspectives of four experts working on aspects of health care, specifically sexual and reproductive health care.

Introduction

Mehita Iqani (M.I.) and Anna Feigenbaum (A.F.): This Structured Conversation is a summarised version of the fourth Evidence & Power roundtable in the webinar series co-hosted by the South African Research Chair in Science Communication (Stellenbosch University) and the Centre for Science, Health and Data Communication Research (Bournemouth University). The Evidence & Power series aims to foster an ongoing, critical dialogue about the role of evidence, data and research within broader scientific projects. Rooted in the ethic of science communication for social justice, the series critically engages with two key theoretical frameworks that inform science communication. First, we ask, what constitutes evidence, and how do its definitions vary across different disciplinary perspectives? Second, we explore how power shapes, influences or mobilises evidence within the scientific landscape, particularly in science communication. The full webinar recording is available on YouTube.

These questions are broad and cannot be definitively resolved one-off, hence our ongoing series of roundtables. Each session brings a set of diverse disciplinary perspectives to encourage reflection, debate and engagement on the dynamics of power and evidence in relation to science communication and the broader process of knowledge production. This essay reflects on our webinar organised around the theme of emancipatory health, with the intention of exploring the interplay of evidence and power in informing new research directions and critical theoretical frameworks in addressing this pressing issue. Our first talking point to the invited speakers, three of whom work in the area of sexuality and reproductive health, was to ask them to reflect on the current quantity and quality of evidence about healthcare research (in general, or in specific relation to their recent research on a specific domain of health care) that is available in the public domain.

The shapes of evidence in health research

Tamara Kredo (T.K.): As both a scientist and researcher in South Africa, I specialise in the discipline of methodology and clinical epidemiology, with a focus on health policy and health guidelines. My work spans both national and global contexts. Domestically, for example, there is significant interest in National Health Insurance, while globally, I focus on understanding the architecture of data and addressing issues such as duplication across countries. One of the key lessons from the COVID-19 pandemic has been the substantial wastage of resources directed toward data curation[1], raising critical questions about the quantity and quality of data. When it comes to quantity, the volume of available data is overwhelming. In my field of evidence-based health care, we often say that trying to find an answer to a research question online is akin to drinking from a fire hose: there is simply too much information to process. Data encompass a broad spectrum, including research evidence, expert opinions, and other forms of information. However, data become truly valuable when a specific research question is posed, particularly in health-related contexts, transforming it into research evidence.

For example, in South Africa, we are on the verge of rolling out electronic medical record systems as part of health system reforms.[1] However, a key question faced by many countries is: what do we do with all the data collected? Data remain just that – data – until someone asks a meaningful question that transforms data into actionable research. The sheer volume of information is staggering. According to Scopus, 3.3 million papers were published across all disciplines last year, with engineering leading in volume and China producing the most publications, followed by the USA.[2] In clinical medicine, the challenge is particularly acute. As a doctor, even within a narrow specialty such as paediatrics or paediatric surgery, staying updated with newly published papers takes more time than healthcare providers have. This underscores the importance of evidence synthesis and systematic reviews.

Systematic reviews aim to consolidate all available evidence on a specific topic, addressing the impracticality of reading all the individual studies available. Although creating systematic reviews is a labour-intensive and often difficult process, the results are invaluable. Once completed, a systematic review provides a comprehensive understanding of the topic. For example, during the COVID-19 pandemic, my team conducted over 70 systematic reviews with the national government, addressing critical questions such as effective treatments, vaccine recommendations, and even the role of supplements like vitamins C and D in preventing COVID-19.[3,4] A crucial aspect of systematic reviews is not just aggregating evidence but also assessing its quality. This ensures that findings are both credible and reliable. Quantity alone is insufficient; the quality of evidence is paramount. An analogy I find helpful is weather forecasting: when a weather app predicts an 80% chance of rain, that figure represents quantity. However, the credibility of that prediction, its quality, may be only 10%. Similarly, in research, we must balance the magnitude of the size of an effect with its credibility.

In health policymaking, evidence is often categorised in specific ways. For example, there is the type of evidence that determines whether something works or is safe, an obvious and necessary focus. However, in guideline development and decision-making contexts, other forms of evidence are increasingly recognised, though not yet as equal. These include contextual factors such as acceptability, feasibility, equity implications, and the values and preferences of the people affected. For instance, do the outcomes selected by researchers align with the values of the affected populations? These contextual considerations are becoming more prominent, particularly through work on qualitative evidence synthesis. This approach brings together rich data sets and assesses their credibility and reliability. Interestingly, during the COVID-19 pandemic, when we encountered poorly conducted trials with small sample sizes, it was often the contextual and equity-focused evidence that drove decisions. While there is still work to do, I am encouraged by the growing acknowledgement of these factors in health policy decisions. Ignoring these contextual elements in major health decisions often leads to significant mistakes.

Suntosh R. Pillay (S.R.P.): While I am a clinical psychologist by profession, I also completed courses in journalism during my undergraduate degree in Media and Communication at the University of KwaZulu-Natal (South Africa). For a time, I identified more as a student journalist than as a health professional, although I eventually trained and registered as a psychologist. This dual background informs my interest in the intersection of science communication and mental health. Over the past two decades, I have maintained a strong connection and presence in both mainstream media and social media, striving to communicate evidence-based mental health insights to the public. Discourse around mental health is becoming more common in popular culture, making the conversation about balancing the quantity and quality of information especially relevant. The analogy of drinking from a fire hose resonates deeply with me; I recall one of my university professors suggesting that academics could benefit from a year-long pause in writing – just to focus on reading – thus emphasising the overwhelming nature of academic information even then. Today, in the hyperdigital era, this challenge has intensified. There is a deluge of information on Google, in academic databases and through artificial intelligence (AI). Systematic reviews, scoping reviews and meta-analyses have become essential tools for navigating this complexity.

However, even with review tools or AI, there are challenges. A key critique is whether these reviews are read or integrated into mainstream practice, and how long it takes for this synthesised knowledge to effect tangible change. Quality remains another significant issue, as editorial standards vary widely across journals and platforms. It is often said that there is no such thing as a rejected paper, only journals where it has yet to be accepted. This underscores the difficulty for the average person trying to make sense of the vast amount of information available. One consequence of this information overload is confirmation bias, whereby individuals gravitate toward data that align with their existing beliefs, avoiding evidence that challenges their views.[5] This resistance to changing beliefs presents a significant challenge for evidence communication.

To illustrate this, my colleagues and I conducted a scoping review of LGBTQIA+ mental health research in Africa, analysing reviews published between 2011 and 2021. We found nine reviews on this topic over the decade. While there is a proliferation of research on queer mental health globally, the reviews synthesising data in the African context are much fewer, and their quality is often poor. For instance, many reviews fail to specify the databases searched, whether they are systematic or scoping reviews, or the countries represented in the included studies.

Systematic reviews are invaluable in identifying such gaps. Our review highlighted significant omissions, such as the absence of studies on intersex individuals or asexual people from a psychosocial perspective, and less data on sexual and gender diversity among women. Instead, there is an overrepresentation of data on men. This demonstrates the need not only for greater quantity in these areas but also for higher quality research.

Carolina Matos (C.M.): I will briefly outline how I came to focus on reproductive health. For the past 20 years, I have collaborated with journalists, centring my research on the role of communication for social change. My scholarly contributions include books and research on communication for development, with a particular emphasis on journalism's role in democratisation processes in Latin America and Europe and some work on the BBC.[6] More recently, my work has shifted toward examining communication for social change within the broader framework of international development, particularly regarding women's rights. This focus developed through my experience as Programme Director for International Relations and Development (City St George's, University of London, UK) and my engagement with students.

Reproductive health is an extensively researched area that draws on social sciences, medicine and public health. Issues around access to reproductive health have garnered renewed attention, as seen in the USA's reversal of Roe v. Wade. Within health communication, my recent work, which culminated in a book supported by a four-year Global Challenges Research Fund project (2018–2022), has explored the discourse on reproductive health in the public sphere. Despite extensive data collection and analysis, the quality of public discourse remains weak. My research involved partnerships with 52 non-governmental organisations (NGOs) from various regions, including Latin America, India, Europe and North America. This mixed-methods study combined surveys with experts, in-depth interviews with gender specialists, and critical discourse analysis of organisational communication materials and social media engagement. Collaborating with organisations like Care International UK and Amnesty International, the study interrogated the complexities of reproductive health communication and its implications for NGOs navigating a broader democratic crisis and the rise of populist rhetoric targeting women's rights.[7] Findings revealed that reproductive health discourse often remains confined to echo chambers, engaging predominantly with public health professionals and narrowly framed feminist perspectives. This observation was particularly pronounced in Latin America, with case studies in Brazil illustrating how ideological manipulation impacts NGOs' ability to communicate effectively. For instance, Brazilian NGOs often operate defensively, relying on public health arguments to counteract myths, while organisations in India demonstrate greater emphasis on creative storytelling and entertainment education through digital media.

Digital media emerged as a pivotal tool, particularly for organisations like India's Population Foundation of India, which employs innovative strategies such as chatbots and educational campaigns. However, resource disparities mean some organisations must rely on creativity rather than extensive funding. Despite these efforts, the quality of communication about reproductive health continues to fall short, raising concerns about its effectiveness in fostering progressive policies and public understanding. Currently, I am conducting focus groups with communities in collaboration with NGOs from the USA, India and Brazil. These discussions aim to understand how target audiences perceive reproductive health communication and to explore how these messages can be more inclusive and dialogical, empowering communities who often feel excluded from the discourse.

Kevin Guyan (K.G.): My research focuses on how data about lesbian, gay, bisexual, transgender and queer (LGBTQ+) communities are collected, analysed and used. Although my work spans diverse areas – such as education, housing, and health care – it applies a critical queer lens to examine philosophical and conceptual challenges surrounding evidence and data. My approach centres the lives and experiences behind the data, questioning how such evidence is defined, constructed and deployed. A central question in my work is, 'What counts as evidence?' This inquiry examines how definitions of evidence are shaped by historical, political and institutional contexts, especially regarding marginalised communities. For example, data about gay men in the UK have historically been shaped by systems introduced to document deviance and criminality, and to 'prove' that these communities are a 'problem'.[8] These biased data sets continue to influence contemporary evidence systems, including AI and generative technologies. Understanding this historical context reveals how data collection often reinforces systemic inequalities, particularly for marginalised groups.

Data quality is therefore deeply political and subjective. It is crucial to interrogate who defines quality and how historical biases shape contemporary perceptions of evidence. In my research, poor quality data about marginalised communities often reflects the oppressive contexts in which these data sets were originally constructed. This highlights the need for a critical examination of what evidence is deemed sufficient or necessary to address structural inequities. A related challenge involves determining when additional data collection is necessary versus when existing evidence suffices to address systemic problems. For instance, within UK higher education, there is often a wealth of data on staff and students from underrepresented groups.[9] However, calls for "more data" frequently serve as stalling tactics, delaying meaningful action to address structural issues. This underscores the need to critically evaluate when collecting new data genuinely contributes to solving problems and when it merely postpones action.

Enacting change by way of evidence?

M.I. and A.F.: It is particularly striking how the discussion so far has focused on the importance of synthesis and scoping at the outset. It is particularly insightful to gain awareness of both ends of the spectrum in terms of the quality and quantity of the synthesis process, and to pause to consider foundational questions about data gathering itself. There are important issues to consider regarding the existence and reliability of data at the point of collection. Further complicating matters, at the other end of the chain, public knowledge informing policy and decision-making, flaws in synthesis, or political challenges in data collection can lead to suboptimal outcomes.

Considering these challenges in assessing both the quantity and quality of data generated through research, particularly when viewed from multiple disciplinary perspectives in relation to health and well-being, we posed the following question for the next round of reflections: from the context of your research, experience and disciplinary expertise, what is required for data to be considered compelling by those in positions of power, individuals who are able to effect improvements in health, well-being, medicine and health care? Specifically, who holds the power to enact change? What types of data do they typically find actionable or indeed overlook? And what obstacles hinder the delivery of equitable health care? In essence, we are asking: what kinds of data, and what conditions, are necessary for those in power to bring about meaningful and positive change?

T.K.: This is a complex question with many layers to unpack. The first issue I grappled with is: who is in power? This question brought me back to the framework I typically work within. Although I am not a communication specialist, my field is knowledge translation or research translation, within which communication is a key component. It focuses on bridging the gap between what we know and what people do, whether in policy or practice. Within this framework, we often analyse the various role players involved. Who holds power? How much power do they have? Who are the champions and brokers? The goal is to understand how to engage these stakeholders in evidence-based decision-making. My work primarily involves policymakers, particularly within government ministries such as the Ministry of Health, as well as multilateral organisations like the World Health Organization (WHO).

The next part of the question, about the obstacles facing those in power, recalls the process of decision-making itself. Decision-making, even when supported by evidence, is inherently non-linear and circular. One of my roles at WHO involves working with diverse panels of policymakers, implementers, ethicists, patients and the public to develop consensus on complex issues, often related to clinical care and treatment for diseases like malaria, TB and HIV. This highlights how multifaceted decision-making processes can be. An example from my experience is a project called Policy Buddies, which aimed to bridge the gap between researchers and policymakers.[10] In this initiative, researchers were paired with policymakers from provincial governments in South Africa. The idea was not simply to answer the policymakers' questions but to collaborate with them, helping them navigate databases, develop reasonable search strategies, locate systematic reviews and evaluate their quality. Through this, we encountered common barriers faced by policymakers globally. These barriers include limited access to relevant information, lack of time, difficulties interpreting scientific literature, competing priorities and skill gaps. Cost and contextual factors, such as whether colleagues are also prioritising evidence-based approaches, further complicate the landscape.

Reflecting on how to plug gaps and absences, my experience is that decision-makers are often too focused on 'putting out fires' to consider evidence proactively. Instead, they react to past errors or immediate crises, which underscores a broader issue in evidence translation and policymaking. A very useful foundation for our work is integrated knowledge translation, which involves building relationships between researchers and decision-makers to enable the mutually beneficial use of evidence.[11] This requires trust, relationship-building and credible synthesis of evidence. As a self-described 'knowledge broker', fostering these relationships and ensuring evidence-informed decision-making are central to my practice.

S.R.P.: The key question here is: who do we consider to be in power? Often, the assumption is that 'people in power' refers to official policymakers or lawmakers. While that may be true in some cases, it is not always the case. Power also resides with individuals within the systems we work in. For example, I worked in a public hospital for over a decade as a clinical psychologist. At the coalface of service delivery, I would have considered myself to be in a position of substantial power. I was not writing national or provincial policies, but I was making departmental decisions that directly impacted patient care. For instance, consider the policy implementation of managing a suicidal patient who walks into a public hospital's psychology department. The everyday decisions in such situations are often guided by pragmatics, staff availability, patient load and competing clinical priorities, rather than systematic reviews or evidence-based guidelines. This highlights the complexity of power hierarchies and how they influence decision-making.

Recently, I moved into a higher-level role in the healthcare system, where I engage with policymaking and evaluation more directly. However, evidence-based decision-making remains challenging, particularly in a context like South Africa, and specifically in my province, KwaZulu-Natal. Much of our healthcare system operates reactively, 'putting out fires' rather than proactively planning services based on evidence. A tragic example of this is the Life Esidimeni incident in South Africa.[12] Nine years ago, the Gauteng Department of Health decided to transfer psychiatric patients from private healthcare facilities to non-profit organisations as a cost-saving measure. This decision, made without proper evidence-based planning, resulted in the deaths of 144 patients. Although there were numerous warnings from civil society organisations, these concerns were ignored. The tragedy serves as a cautionary tale about the consequences of sidelining evidence in policymaking. Unfortunately, it often takes such tragedies to prompt serious consideration of evidence in creating policies and managing services. Ideally, a proactive approach prioritises careful evidence-based planning to prevent such outcomes, but this remains a significant challenge within reactive healthcare systems like ours.

C.M.: On the topic of research evidence and its application to reproductive health within health communication, one growing area of concern is the challenge faced by medical providers, doctors and healthcare institutions in communicating information to the public. Due to the rise of social media and the dissemination of health-related disinformation, there is significant anxiety within the field.

Recently, I was invited by healthcare providers in the USA to share insights from my work in this area, on the contrasts within findings from my research on NGOs worldwide.[13] Many NGOs reported severe constraints, particularly a lack of funding, amidst numerous challenges. These challenges included difficulties in improving communication about reproductive health with their target audiences, especially in countering manipulative narratives that frame feminist debates as promoting a "culture of death". Simultaneously, more studies are examining, for instance, contraceptive-related content on platforms like TikTok.[14] One focus group in Miami revealed that participants frequently encountered misinformation about reproductive health across various online sources. This highlights a discrepancy between the capabilities of established medical institutions, which often wield significant power, and the limited resources available to smaller, grassroots NGOs working in this field.

These NGOs, particularly those operating in regions such as Latin America, India and parts of Europe, have reported that systemic constraints, primarily financial, hinder their ability to communicate effectively and achieve their objectives. While larger organisations may face fewer limitations, smaller groups often find themselves unable to advance initiatives that could promote gender equality due to these challenges. An additional complication is the prevalence of self-censorship practices within these organisations. This issue arose repeatedly in my research and was expressed differently depending on the local context.[15] Ultimately, this raises a pressing question: how can these organisations enact meaningful change in the face of such persistent challenges, including resource constraints and systemic censorship?

K.G.: Another fundamental question we must address is the role of data and evidence in changing the world around us. This is a complex and often thorny issue, and one that I have grappled with extensively in my work on LGBTQ+ political and policy issues in Scotland and the UK. In my book *Queer Data*[16], I explore the premise that even if a society had the most comprehensive evidence and extensive data sets on LGBTQ+ communities, whether quantitative, qualitative, disaggregated or intersectional, this may not necessarily translate into a society that provides positive material conditions or lived experiences for these communities.

This disconnect between the availability of evidence and the lived realities of marginalised communities became particularly clear during my work on Scotland's Gender Recognition Reform Bill. This legislation, which sought to simplify the process for trans individuals to change the sex marker on their birth certificates, underwent extensive evidence gathering. Experts, policymakers and community groups contributed substantial and high-quality evidence, yet the legislation was ultimately defeated due to political contentions between the Scottish and UK governments.[17] This experience highlights a broader systemic issue: the final stages of evidence-driven policymaking, changing the hearts and minds of those in power, are often fraught with obstacles. While we might assume that identifying a problem, collecting evidence and presenting it to decision-makers *should* result in change, this idealised model frequently fails in practice. Policymakers (and politicians) often remain resistant, regardless of the quality of the evidence.

I am increasingly sceptical of the belief that accumulating more and better data will inevitably lead to change. My recent work has shifted towards understanding how to communicate evidence in ways that influence decision-makers. This requires considering the strategic uses of evidence in political contexts, even when this may mean presenting data in ways that do not fully capture the complexity of the issue but are more likely to compel action. However, this approach comes with its own risks. For example, if we prioritise data that appeal to decision-makers at the expense of accuracy or inclusivity, we risk misrepresenting the diversity *within* marginalised communities. In the context of LGBTQ+ advocacy, this might mean focusing only on the experiences of white, non-disabled lesbian and gay individuals, which could lead to the exclusion of more intersectional narratives. This raises ethical concerns about tailoring evidence to fit the expectations of those in power. By doing so, we risk perpetuating exclusionary practices and compromising the integrity of our advocacy efforts. Ultimately, we must consider not only how to use data to influence decision-making but also how to do so without distorting the lived experiences of the communities we aim to represent.

Participation as power?

M.I. and A.F.: The discussion so far offers a pivotal realisation that critique directed towards those traditionally perceived as holding power is inherently limited. This observation in turn raises critical questions. What is power, and who truly possess it? The assumption that policymakers or individuals in political positions inherently hold and exercise power may, in fact, be a red herring. Key themes that have emerged so far include consensus building, trust and the credibility of information. Moreover, the complex interplay of diverse actors in decision-making processes. These actors range from governmental institutions to individual researchers, each of whom engages with evidence differently in terms of production, interpretation or application. As such, it is fitting that the discussion then turned to an explicit consideration of whether, and if so, how evidence about health might be used as an instrument of empowerment or resistance by ordinary people?

T.K.: Evidence, as we have established, is both powerful and contested, particularly when it comes to making sense of research evidence and its application. One of my favourite interviews during a project examining the development and implementation of health policy in South Africa, particularly, during the discussions surrounding the National Health Insurance Bill, provided an insightful comment: "You can bamboozle people with evidence." This metaphor captures the complexity of evidence use, likened to the agile footwork of a skilled boxer who can outmanoeuvre opponents. In the domain of evidence-informed decision-making and evidence-based health care, there exists a formalised process for utilising evidence. However, in practice, multiple forms of 'evidence' emerge, such as 'eminence-based health care' (where seniority prevails), 'vehemence-based health care' (dominated by the loudest voice) and 'eloquence-based health care' (where rhetoric and numbers wield undue influence).[18]

Reflecting on my clinical experiences, the individuals I most respected were those who relied on systematic reviews rather than those who cherry-picked studies to support preconceived positions. This underscores a significant gap in our current approaches to evidence use, particularly concerning the decision-making processes around National Health Insurance. Issues such as determining the benefits package, defining accessible health care, and strategising delivery methods are informed by evidence, yet there is a glaring lack of public participation.

Currently, public involvement in these processes is nearly absent, and this represents a critical area for further exploration. How do people wish to participate? Would they prefer direct engagement on guideline or policy panels, or would participatory methods such as workshops or webinars be more effective? Understanding these preferences is essential. Beyond how evidence is packaged for different stakeholders, the most urgent gap lies in fostering meaningful public participation in health care decision-making.

S.R.P.: I want to highlight an example that aligns with earlier discussions about how calls for additional data can often act as a red herring, diverting attention from substantive issues of social justice and health equity. A striking case is the *Anti-Homosexuality Act* in Uganda, a deeply regressive piece of legislation enacted in 2023 (and unfortunately not the only example from the continent). As part of my work with the African LGBTQIA+ Human Rights Project, housed within the Psychological Society of South Africa (PsySSA), I have observed how evidence can be manipulated, or outright ignored in these contexts.[19]

This issue has a long history. In 2009, Ugandan President Yoweri Museveni introduced the Anti-Homosexuality Bill and invited "evidence" to "change his mind" about the so-called harmful effects of homosexuality on families and children. Despite the submission of extensive credible evidence, the Bill lingered for 15 years, culminating in its enactment in 2023. This law is now among the harshest globally, criminalising mere identification as gay, lesbian or transgender. In response, resistance emerged on multiple fronts. The Ugandan scientific community, the Association of South African Scientists, and other global authorities, including figures like Glenda Gray and Linda-Gail Bekker, issued open letters and calls for evidence-based policies. Within South Africa, the PsySSA developed the continent's first guidelines for working with queer individuals, yet these efforts were largely ignored by Ugandan policymakers.[20]

Ironically, the lack of evidence-based policymaking triggered a groundswell of resistance, both from Ugandans affected by the legislation and from the global scientific community. This mirrors tragedies like Life Esidimeni, which became a pivotal moment for reflection and reform. These events remind us of the urgent need to transition from reactive responses to proactive strategies that anticipate and address issues before they escalate. While such tragedies provide reference points for improvement, they also highlight the critical importance of embedding evidence and equity into legislative processes from the outset.

C.M.: I will build on the conversation about participation and how communities should be engaged. A key insight from our work is that many communities affected by health communication campaigns on reproductive health have felt excluded, noting a lack of meaningful engagement. Despite some efforts at community involvement, much of the communication remains predominantly top-down, with information flowing one way. To address this, we are collaborating with partners I mentioned earlier, as well as researchers in the UK and the USA, to submit a grant application for additional funding to expand our work. This aims to address these gaps and ensure broader community engagement. Through prior resources, we have already begun this process, particularly in the USA and Brazil via Reprolatina, and in Guatemala through the US-based organisation Saving Mothers. For example, in Guatemala, we worked with midwives who shared valuable insights into how they wished to participate in these discussions.[21]

Findings from focus groups have highlighted several key themes. Communities want safe spaces for engagement, further training and advocacy communications that respect their languages, cultures and local contexts – areas they feel are currently neglected. In response, I am developing an advocacy communications plan with one of the organisations involved and creating an NGO toolkit to disseminate our findings. This work also ties to the broader issue of social justice within emancipatory health. As noted by the lead of SheDecides UK, discussions on reproductive health remain entangled in historical debates dating back to the 1980s, particularly concerning women's agency and bodily autonomy. These issues continue to be marginalised. Thus, our research aims to advance this discourse and explore how participatory methods in health communication can contribute to genuine social justice.

K.G.: Building further on this theme of participation, I want to focus on the intersection of resistance and empowerment. A critical question in my work is how we engage individuals who are unwilling to participate, those who are ambivalent or outright resistant to data collection and evidence-gathering exercises. This has been particularly evident in my work with LGBTQ+ communities, many of whom have lost all faith in government agencies, healthcare providers and other institutions. These communities often resist or subvert efforts by systems to collect data about them, rejecting what they perceive as intrusive or exploitative processes. How do we create spaces that acknowledge their existence and agency without forcing participation according to terms dictated by those in power? Currently, such individuals are often perceived as difficult, awkward, or, to borrow Sara Ahmed's term, "killjoys" – people who disrupt the established order.[22]

I am particularly interested in how demands for participation can create a superficial sense of inclusion. These processes often impose rigid structures, requiring individuals to jump through hoops to be included. Such inclusion is piecemeal, partial and typically serves the interests of those in positions of power rather than addressing the needs of marginalised groups. It is vital to rethink how we approach evidence collection for marginalised communities, particularly those who have lost faith in the systems that claim to serve them. We must avoid doubling their exclusion by casting them as 'killjoys' when the institutions have historically failed them. Instead, we need to design inclusive practices that respect people's decision to resist, subvert or reject traditional modes of engagement.

Concluding thoughts: Rethinking evidence

M.I. and A.F.: Community-driven participation methods in health projects often produce evidence that is excluded because it does not meet clinical or traditional validity standards. For example, evidence rooted in social science is frequently dismissed in medical syntheses because it fails to meet the methodological criteria favoured in more 'hard science' disciplines. These processes can belittle qualitative research. This raises an important question: are we making progress toward greater recognition of alternative forms of evidence, or are we still far from achieving that?

S.R.P.: As researchers, clinicians, policymakers and policy implementers, I believe we need to move toward more innovative forms of knowledge translation and science communication, and its relationship to funding. In particular, I see an opportunity to leverage visual media in our communication strategies. This approach could be especially impactful for engaging politicians, policymakers and funders. In an increasingly visual world, there seems to be a diminishing culture of reading. I wonder if evidence presented on social media platforms like TikTok or Twitter (X) – via infographics – actually has more influence than that from traditional academic formats, such as journal articles, despite its dangers.[23] Translating evidence into diverse spheres for different publics is a critical task we must prioritise.

Additionally, I want to highlight the issue of competing demands for limited resources, which is especially pressing in the field of mental health. Government budgets often face numerous competing priorities, despite good evidence supporting the funding of mental health care and its return on investment. Evidence must guide meaningful conversations about resource allocation for mental health so that it moves beyond an either/or debate and toward holistic, impactful solutions.

C.M.: There has been considerable discussion about the collaboration between sociologists, social scientists and the medical field, which I see as essential. My work strongly emphasises interdisciplinarity, engaging with public health professionals, medical staff and sociologists. The interdisciplinary approach is vital but remains a challenge. Many of us are striving to bridge these gaps and ensure our perspectives are heard. The ongoing debates about what constitutes scientific evidence, who defines it and how it is valued, highlight the role of power structures in shaping knowledge.

K.G.: My focus is on the looping effects between the evidence collected about marginalised communities and how those communities come to understand and define themselves. In my research with LGBTQ+ communities, I have observed how data, both quantitative and qualitative, does not merely reflect pre-existing realities. Instead, it actively shapes how communities conceptualise their identities and experiences. This reciprocal relationship between evidence and self-perception is a fascinating and critical area of study. The history of this work in science and technology studies provides valuable insights, but we must now apply those lessons to contemporary experiences of minoritised groups. Evidence does not operate unilaterally; it reflects and redefines the communities it represents, influencing how we live and understand our lives in today's world.

T.K.: For those of us in research and academia, I believe it is crucial to engage directly with the end users of our work, whether they are policymakers, practitioners or members of the public. Before finalising a research question, we should ask these stakeholders if it aligns with their needs and refine it accordingly. Ideally, we should work alongside them throughout the research process and maintain communication so that, when the findings emerge years later, they are relevant and usable. This collaboration offers an exciting opportunity to build relationships that enhance the impact of our work, ensuring it serves the people who can benefit most from it.

M.I. and A.F.: Researchers across disciplines should embrace the call to action to devise and implement new participatory methods for gathering evidence that involve both the people affected and policymakers. If we claim that our work should contribute to building a better and more just world, as is so clearly the case in the health sciences aimed at achieving a better quality of life across populations, then both science and communication must actively seek new, inclusive ways to achieve this goal.

Declarations

We have no competing interests to declare. We have no AI or LLM use to declare. All authors read and approved the final manuscript.

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