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Pantelic, Marija, Steinert, Janina I, Ayala, George, Sprague, Laurel, Chang, Judy, Thomas, Ruth Morgan, Nininahazwe, Cedric, Caswell, Georgina, Bach-Mortensen, Anders M and Bourne, Adam (2022) Addressing epistemic injustice in HIV research: a call for reporting guidelines on meaningful community engagement. Journal of the International AIDS Society, 25 (1). a25880 1-5. ISSN 1758-2652

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Addressing epistemic injustice in HIV research: a call for reporting guidelines on meaningful community engagement

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Abstract
Introduction: Despite the widely recognized ethical and practical benefits of community engagement in HIV research, epistemic injustice persists within the field. Namely, the knowledge held by communities disproportionately affected by HIV is systemically afforded less credibility than that of more privileged academic researchers. In order to illustrate what this looks like in practice, we synthesized the extent of reporting on community engagement within recent high-impact HIV intervention research papers. However, we also posit that the HIV research sector has the potential to devise and showcase world-leading examples of equitable research-community partnerships and suggest actionable key steps to achieving this goal.

Discussion: In the absence of reporting requirements within the publishing process, it is difficult to infer whether and how the community have been consulted in the design, implementation, analysis and/or interpretation of findings. As an illustrative exercise, we offer a rapid synthesis of the extent of reporting on community engagement in HIV research from 2017 to 2019, which highlighted sporadic and very low rates of reporting of community engagement in recent high-impact HIV intervention studies. Of note is that none of the included studies reported on community engagement through all stages of the research process. There were also discrepancies in how community involvement was reported. We provide three actionable recommendations to enhance reporting on community engagement in HIV research: (1) community-led organizations, researchers and scientific journals should band together to develop, publish and require adherence to standardized guidelines for reporting on community involvement in HIV research; (2) research funders should (continue to) require details about how relevant communities have been engaged prior to the submission of funding requests; and (3) researchers should take proactive measures to describe their engagement with community organizations in a clear and transparent manner.

Conclusions: There is a clear and urgent need for guidelines that facilitate transparent and consistent reporting on community engagement in HIV intervention research. Without standardized reporting requirements and accountability mechanisms within the research sector, the extent of meaningful community engagement cannot be established and may remain a catchphrase rather than reality.

Keywords: community; HIV trials; key populations; engagement; reporting guidelines; GIPA

Additional information may be found under the Supporting Information tab of this article.

Received 26 April 2021; Accepted 11 January 2022

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1 | INTRODUCTION

For the past four decades, people living with and affected by HIV have advocated for being meaningfully involved in the knowledge production that informs understanding of, and responses to, their health, wellbeing and survival. The HIV response has benefited from a wide range of organizations that are led by and for communities affected by HIV, including people living with HIV, sex workers, people who inject drugs, transgender people and men who have sex with men. In 1983, the Denver Principles were drafted by activists living with HIV, stating: “We condemn attempts to label us as ‘victims’, a term that implies defeat, and we are only occasionally ‘patients’, a term that implies passivity, helplessness, and dependence upon the care of others. We are ‘People With AIDS’” [1]. A decade later at the 1994 Paris AIDS Summit, heads and representatives of 42 governments agreed to “support a greater involvement of people living with HIV at all […] levels […] and to […] stimulate the creation of supportive political, legal and social environments.” This set of principles...
is commonly referred to as "Greater Involvement of People living with HIV/AIDS" (GIPA) and was endorsed by 189 UN member states in 2001 [2].

Today, GIPA is widely recognized as an imperative for ethical HIV research [3–5]. Principles around meaningful engagement in research have been extended to communities who are not necessarily living with but are affected by HIV [6], including sex workers, transgender people, people who use drugs, people in confined settings and men who have sex with men. These principles require that communities are meaningfully engaged throughout every phase of the research process, from defining the research questions and designing the study to analysing the data and disseminating the results. As such, meaningful engagement requires "a sustained effort which ensures that the capacity of communities involved in research is strengthened, that community members and researchers work collaboratively, and that research results benefit the community and support efforts to influence positive change" [6]. Community engagement in HIV research also ensures that findings are relevant to the end users of the resulting testing, prevention and treatment delivery mechanisms. A growing body of evidence suggests that community engagement in research is associated with improved study outcomes, intervention uptake, applicability of findings to real-world implementation and improved dissemination of findings [7].

This commentary argues that despite the widely recognized ethical and practical benefits of community engagement in HIV research, epistemic injustice persists within the field. Epistemology is the science of knowledge, and epistemic injustice occurs when the knowledge held by communities disproportionately affected by HIV is "systematically afforded less credibility" than that of more privileged academic researchers [8]. Examples of this include research where community input is solicited but not acknowledged, where community input is only partially solicited without meaningful involvement in all stages of the research process; or where input is not solicited at all. As such, epistemic injustice can perpetuate the marginalization of communities affected by HIV and lead to poorer quality research.

To illustrate what this looks like in practice, we synthesized the extent of reporting on community engagement within recent high-impact HIV intervention research papers. We suggest actionable steps to achieving equitable research-community partnerships in the HIV sector.

1.1 | Co-production of this commentary

This commentary was conceptualized and written in a collaborative effort between community experts, activists and academic researchers. The team consisted of experts from the Global Network of People Living with HIV (GNP+), the Global Network of Young People Living with HIV (Y+) and the International Network of People Who Use Drugs (INPUD), the Global Network of Sex Work Projects (NSWP), MPact Global Action for Gay Men’s Health and Rights (formerly the Global Forum on MSM and HIV) and UNAIDS, as well as HIV researchers working on community engagement in the HIV response.

2 | DISCUSSION

As a basic premise, we contend that all research working on issues relating to HIV among key populations should engage with affected communities and their representatives at all stages of the research process. While researchers are expected to meaningfully engage with communities affected by HIV, there are currently no reporting requirements within the publishing process. The lack of accountability on community engagement makes it difficult to infer whether and how the community have been consulted in the design, implementation, analysis and/or interpretation of findings.

We make no claim that those authors who do not report on community engagement did not do so but instead seek to emphasize the lack of transparency on this, as a first step to overcome epistemic injustice.

The last decade of the HIV pandemic has seen the development of guidelines, resources and action plans by national and parastatal organizations that aim to facilitate community engagement in HIV-related research, especially among those populations most affected. While varying in tone and detail, all emphasize the need for research to inform HIV prevention, testing and treatment interventions so as to ensure they sufficiently address the issues of critical importance in an ethical and pragmatic manner. As outlined in the 2011 UNAIDS guidelines on good participatory practice for biomedical HIV prevention trials, such engagement should span the entirety of the research process, from formative research activities through to protocol development, data collection, analysis, publication and dissemination [9]. The same document emphasizes how meaningful community engagement can help ensure that research questions and procedures are culturally sensitive and appropriate, thus improving recruitment, retention, adherence and other trial outcomes. More recent guidelines on community engagement with gay men and other men who have sex with men also acknowledge how meaningful engagement with those most affected can improve the quality of research, its uptake and implementation [6]. This may be particularly salient in contexts where key populations are criminalized and where strong, clear advocacy is required to help effect change.

2.1 | Epistemic injustice: extent of reporting on community engagement in high-impact HIV research

Without standardized reporting requirements and accountability mechanisms within the research sector, meaningful community engagement is likely to remain a catchphrase rather than reality. In order to illustrate the need for greater transparency on the level of community engagement in HIV intervention research, we reviewed studies published between 2017 and 2019 that evaluated the effectiveness of interventions aiming to improve uptake, use and/or adherence to efficacious HIV prevention, testing and treatment tools among key populations. We chose this period because of the high number of trials conducted in various parts of the world to determine what works to improve uptake of and adherence to antiretroviral medications for both prevention and treatment [10,11]. These trials informed World Health...
Call to action: key tasks for researchers, scientific journals and research funders

There is an urgent need for clearly articulated guidelines that could facilitate transparent and consistent reporting on community engagement in HIV intervention research. Here, we provide three actionable recommendations to enhance reporting on community engagement in HIV research:

1. **Community-led organizations, researchers and scientific journals should collectively develop, publish and require adherence to standardized guidelines for reporting on community involvement in HIV research**. This recommendation is in line with previous calls for metrics to help track community engagement in global health research [17,18]. There is precedent for this; in 2017, Staniszewska and colleagues published the first international Guidance for Reporting Involvement of Patients and the Public (GRIPP2) [19], which prompted the British Medical Journal (BMJ) to “request that [submitting] authors provide a Patient and Public Involvement statement in the methods section of their papers” [20]. However, standardized reporting guidelines for trials, which are meant to improve the quality and transparency of the research process, currently do not include any requirements to explain whether and how communities were involved in the study [21].

Future enhanced guidelines for quantitative research reporting should draw on existing best practices, including those from qualitative research, which has traditionally...
emphasized community engagement at a greater extent. To remove ambiguity, reporting guidelines should include explicit statements pertaining to the level of community involvement in study conceptualization, recruitment (such as making explicit efforts to attract and empower people living with and at high risk for HIV in hiring processes), analysis and write-up. To accommodate the need for more detailed reporting, journals may consider increasing word count allowances and integrating reporting requirements for community involvement in their author guidelines.

2. Given that conceptualization of research occurs at or before the grant writing stage, research funders should (continue to) require details about how relevant communities have been engaged prior to the submission of funding requests and how their participation in the proposed research will be resourced. We found few intervention studies reported on community engagement in the conceptualization stage of studies. Community engagement in research is not cost neutral and few community organizations are core funded to engage with researchers. Research funders can address this by actively making provisions for meaningful community involvement in their funding structures, including as grants or consultancies to community organizations to ensure their involvement. Research funders could also require open science practices during the grant writing process itself, which would encourage open exchanges of research ideas between scholars and civil society organizations at an early stage.

3. In the absence of reporting standards or accountability mechanisms among the funders and publishers of research, researchers should take proactive measures to describe their engagement with community organizations in a clear and transparent manner – within conceptualization, design, delivery, analysis and interpretation phases, in line with existing guidance [5,6,22–24]. Such an approach helps to ensure the value of the research and further facilitates the translation of research findings into advocacy and action. Based on what is currently being reported in research papers, community involvement in research is likely to be occurring within power-imbalanced scenarios, which is not unique to the HIV sector [8]. This could be overcome in the medium- and longer-term through engaging community partners as co-principal investigators or co-investigators from the outset; naming community-based organizations as partners in grant proposals, with clarity on whether these organizations are community-led; agreeing to principles of engagement that are project specific and are negotiated ahead of time; setting up memorandums of understanding; building capacity strengthening plans that are bidirectional; and building equitable budgets and plans for division of labour.

3 | CONCLUSIONS

We make no claim that the authors of the 66 papers reviewed as part of this commentary did not engage communities in their research but rather note the absence of clear and consistent reporting as to whether and how this is occurring. The lack of reporting guidelines on community engagement HIV intervention research brings to question the validity, suitability and relevance of the very interventions that are considered cutting edge and evidence based by the HIV scientific community. Without enhanced accountability mechanisms, epistemic injustice persists despite substantial progress towards community engagement in the HIV response. This is because the lack of reporting on community engagement often makes it impossible to infer whether and how the community have been consulted in the design, implementation, analysis and/or interpretation of findings, further fuelling power imbalances in the knowledge production process.

Many academic researchers, including those co-authoring this commentary, have failed to report on community engagement when it did occur due to a lack of accountability mechanisms and requirements to report on other aspects of the study methodology within tight word limits. Reporting guidelines and accountability mechanisms enforced by journals have the potential to make us all do better, which we must.

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COMPEting INTERests

The authors have no competing of interests.

AUTHORS’ CONTRIBUTIONS

All authors contributed to the conceptualization of the paper, interpretation of findings and resultant recommendations, as well as the manuscript write up. MP led on the paper and analysed the data with feedback from all authors. JIS and AMBM ran the searches, screened articles and extracted the data, with contributions from MP. All authors have read and approved the final manuscript.

DATA AVAILABILITY STATEMENT

This commentary did not involve collection or analysis of primary data. Data extracted from primary studies as part of the rapid review are available upon request.

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ACKNOWLEDGEMENTS

We would like to thank the communities of people living with and affected by HIV who have generously shared their time, experiences and bodies for the purposes of primary research that was reviewed in this paper. Much of the fight against HIV and AIDS relies upon people living with and affected by HIV continuing to put themselves forward. HIV research and our fight against HIV and AIDS is indebted to those past and present.

FUNDING

Funding for preliminary searches and article screening was provided by Frontline AIDS. No other parts of this review were funded.

DISCLAIMER

The views expressed are solely those of the authors and do not represent those of UNAIDS.

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