

Person-centred approaches to address the health needs of people living with HIV and co-infections and co-morbidities

Guest Editors: Jeffrey V. Lazarus, Georgina Caswell, Rena Janamnuaysook

Supplement Editor: Karoline Soerensen



Acknowledgements

The Guest Editors – Jeffrey V. Lazarus, Georgina Caswell, and Rena Janamnuaysook – wish to express their appreciation to all the authors who prepared, submitted and revised manuscripts in response to this supplement request, even those that were not included. They would also like to thank all the reviewers who invested their time to review and respond, providing feedback on each of the manuscripts. This work would have been impossible without the multitude of participants who were involved in the various studies in this supplement and we recognize their immense contributions. Ensuring the best possible quality of life for those living with and affected by HIV by reducing HIV acquisitions and related morbidity and mortality will only be possible through an integrated response to clients' health needs and preferences. We hope the research represented here demonstrates that getting care right for people living with and affected by HIV requires a flexible healthcare system that allows people to decide on their degree of self-management. Lastly, we acknowledge the consistent guidance, support and fortitude the editors and staff of the Journal of the International AIDS Society have accorded to us during the preparation of this supplement.

Support

This supplement was organized by IAS – the International AIDS Society. It was made possible with financial support from Gilead Sciences, as part of their sponsorship of the IAS Person-Centred Care programme. IAS has full control over the all activities and decisions relating to, and forming part of, the IAS Person-Centred Care programme. The content of this supplement is solely the responsibility of the authors and does not necessarily represent the official views of the International AIDS Society or Gilead Sciences. Gilead Sciences has not had any input into the content of the supplement.

Disclaimer

The authors alone are responsible for the views expressed in this supplement and they do not necessarily represent the views, decisions or policies of the institutions with which they are affiliated.

Person-centred approaches to address the health needs of people living with HIV and co-infections and co-morbidities

Guest Editors: Jeffrey V. Lazarus, Georgina Caswell, Rena Janamnuaysook

Supplement Editor: Karoline Soerensen

Contents

A people-centred health system must be the foundation for person-centred care in the HIV response <i>Jeffrey V. Lazarus, Rena Janamnuaysook and Georgina Caswell</i>	1
Lessons learned from community engagement regarding phylodynamic research with molecular HIV surveillance data <i>Diana M. Tordoff, Brian Minalga, Alfredo Trejo, Alic Shook, Roxanne P. Kerani and Joshua T. Herbeck</i>	4
Person-centred, integrated non-communicable disease and HIV decentralized drug distribution in Eswatini and South Africa: outcomes and challenges <i>Deborah Goldstein, Nathan Ford, Nicholas Kisyeri, Maggie Munsamy, Lirica Nishimoto, Kufor Osi, Herve Kambale, Thomas Minior and Moses Bateganya</i>	12
Facilitating person-centred care: integrating an electronic client feedback tool into continuous quality improvement processes to deliver client-responsive HIV services in the Democratic Republic of Congo <i>Cyprien Tendo-Bugondo, Osée Lieke, Pierre Kasongo, Baudouin Diur, Davina S. Canagasabey, Ibou Thior, Pascal K. Milenge and Jean-Claude Kiluba</i>	18
Uptake of a patient-centred dynamic choice model for HIV prevention in rural Kenya and Uganda: SEARCH SAPPHIRE study <i>Jane Kabami, Elijah Kakande, Gabriel Chamie, Laura B. Balzer, Maya L. Petersen, Carol S. Camlin, Marilyn Nyabuti, Catherine A. Koss, Elizabeth A. Bukusi, Moses R. Kamya, Diane V. Havlir and James Ayieko</i>	23
Clients in Uganda accessing preferred differentiated antiretroviral therapy models achieve higher viral suppression and are less likely to miss appointments: a cross-sectional analysis <i>Esther K. Karamagi Nkolo, Jessica Clinkscales Ejike, Simon Sensalire, Juliana Nabwire Ssali, Immaculate Ddumba, Jacqueline Calnan, Carolina Gonzalez, Nelly Maina, Melaku Dessie, Lauren Bailey, Ugochukwu Amanyeiwe, Thomas Minior, Karishma Srikanth, Herbert Kadama, Khushi Patel and Dina Patel</i>	31
Patterns of person-centred communications in public HIV clinics: a latent class analysis using the Roter interaction analysis system <i>Njekwa Mukamba, Chanda Mwamba, Salil Redkar, Marksman Foloko, Kasapo Lumbo, Herbert Nyirenda, Debra L. Roter, Musunge Mulabe, Anjali Sharma, Sandra Simbeza, Kombatende Sikombe, Laura K. Beres, Jake M. Pry, Katerina Christopoulos, Charles B. Holmes, Elvin H. Geng, Izukanji Sikazwe, Carolyn Bolton-Moore and Aaloke Mody</i>	39
Provider perspectives on patient-centredness: participatory formative research and rapid analysis methods to inform the design and implementation of a facility-based HIV care improvement intervention in Zambia <i>Chanda Mwamba, Laura K. Beres, Njekwa Mukamba, Lazarus Jere, Marksman Foloko, Kasapo Lumbo, Kombatende Sikombe, Sandra Simbeza, Aaloke Mody, Jake M. Pry, Charles B. Holmes, Izukanji Sikazwe, Carolyn Bolton Moore, Katerina Christopoulos, Anjali Sharma and Elvin H. Geng</i>	52
Person-centred care: shifting the power dynamic in the delivery of adolescent and youth-friendly health services <i>Lynn Phillips, Heleen Soeters, Maximina Jokonya, Allen Kyendikuwa and Luann Hatane</i>	62
A person-centred approach to enhance the long-term health and wellbeing of people living with HIV in Europe <i>Jeffrey V. Lazarus, Mario Cascio, Jane Anderson, Sini Pasanen and Richard Harding</i>	64
AUTHOR INDEX	67

EDITORIAL

A people-centred health system must be the foundation for person-centred care in the HIV response

Jeffrey V. Lazarus^{1,2,3,§} , Rena Janamnuaysook^{4,5} and Georgina Caswell⁶

§ **Corresponding author:** Jeffrey V. Lazarus, CUNY Graduate School of Public Health and Health Policy (CUNY SPH), New York, New York, USA. (jeffrey.lazarus@sph.cuny.edu)

Received 9 May 2023; **Accepted** 17 May 2023

Copyright © 2023 The Authors. *Journal of the International AIDS Society* published by John Wiley & Sons Ltd on behalf of the International AIDS Society. This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

The HIV field has been a champion in progressing global thought, action and capacity-building towards models of healthcare that centre the lived experience, needs and preferences of affected individuals and communities. In so doing, we have markedly transitioned to an understanding that it is people in their entirety that we are concerned with, not solely their physical health or viral disease. Advocacy and activism, led by people living with HIV and key populations most at risk of and affected by HIV (e.g. men who have sex with men, people who use drugs, transgender people, sex workers, migrants, people in prisons, adolescent girls and young women in settings where HIV is highly prevalent), have pushed for the meaningful involvement of people most at risk of and impacted by HIV in all areas and stages of the HIV response [1]. This has promoted the building and strengthening of trust and mutually beneficial relationships between people living with HIV and key populations with a range of stakeholders, including clinicians, researchers and policymakers.

However, despite areas of progress, it is undeniable that person-centred care models that serve people living with HIV and key populations remain scarce and haphazardly implemented globally. Moreover, elevating these models towards truly people-centred health systems (PCHS) will require additional effort.

PCHS are programmes of care that provide individuals, families and communities with humanistic, holistic and trusted healthcare [2]. Notably, in such systems, healthcare must be acceptable and responsive to the needs, rights and preferences of people living with HIV and key populations [3]. Some key elements and ideas delineating PCHS include: (1) ensuring that clients and communities have a say in and the authority to make decisions regarding their health; (2) that HIV-related services are designed according to the needs and preferences of individuals, are demand-driven and founded on quality, safety and long-term care engagement; (3) recognition that health systems are social institutions which thrive on mutual trust, dialogue and reciprocity; and (4) that values around justice, rights, respect and equity are at the forefront of care delivery. Furthermore, PCHS recognize that person-centred care delivery is not limited to clinical settings and

should be embraced across community settings through collaborative and coordinated approaches and partnerships [4].

Such a vision for care systems is not new. However, the need for such a vision to be systematically adopted, particularly to serve people living with HIV and key populations, has never been greater. With substantial advancements in prevention and treatment regimes, people living with HIV are living much longer. However, treatment requires a long-term commitment to adherence by clients [5], which remains exceptionally challenging given the numerous barriers which continue to exist for people living with HIV and key populations [6–8]. These barriers include psychosocial challenges, increased prevalence of comorbidities and multimorbidities, systems and policies built around systemic stigma and discrimination and the administrative burden of navigating health systems.

Putting people at the centre of care provides an opportunity to address the multifaceted and intersectional challenges that people living with HIV and key populations encounter in a context-adapted, sustainable and meaningful way [9]. In so doing, we create the potential to empower clients and communities and establish models of care built around shared decision making and HIV self-management—all of which are essential facilitators to long-term treatment and care adherence [10, 11]. Additionally, while decades of work have ensured that people living with HIV are living *longer*, PCHS can transition our practices to ensure that people living with HIV are living *well* [12].

In this supplement of *JIAS*, we asked nine research groups to share developments around implementing the components of PCHS in their unique settings, in countries from across Africa (including the Democratic Republic of Congo, Eswatini, Kenya, South Africa, Uganda and Zambia), North America and Europe. In this Editorial, we summarize four key themes that emerge from this supplement and share how they add to our understanding and capacity to design and implement PCHS for people living with and at risk of HIV:

(1) PCHS require meaningful and sustained engagement between stakeholders, co-designed approaches and feedback mechanisms: at the very least, any successful effort towards the development or implementation of a PCHS

requires engagement among stakeholders. When healthcare professionals listen to the voices of clients and communities, they are introduced to a perspective they may not have been aware of. Notably, engaging people and listening to their recommendations is among the first steps towards truly empowering people and facilitating the development of PCHS.

Tordoff et al. [13], for example, shed light on just how powerful and transformative a collaborative experience can be. Through community engagement activities held in the United States, they realized that the potential harm of publishing their work (e.g. increasing stigma and distrust, alongside increasing barriers to HIV prevention and treatment access) outweighed the potential benefits and, as such, decided to stop the publication of their work.

To note, stakeholders are not just clients and healthcare professionals working within a particular organization. To establish a strong and successful PCHS, partnerships between health ministers and governmental agencies, non-governmental organizations, international donors and for-profit private organizations are all important. This was noted by Goldstein et al. [14] in their experience in Eswatini and South Africa, where through these public–private partnerships, they were able to develop scalable programmes for HIV and non-communicable diseases integration without requiring out-of-pocket costs to clients.

Importantly, to know if you are on the right track, monitoring people's experience of health systems and the care they received is essential, as was the case with Tendo-Bugondo et al.'s [15] experience in the Democratic Republic of Congo, where they co-designed an electronic client feedback tool. In this way they were able to pinpoint key challenges that their clients were facing, including wait times, stigma, service confidentiality and viral load turn-around time. Such co-designed and collaborative monitoring systems allow for the identification of gaps in quality of care and facilitate the development of realistic opportunities for system improvement.

(2) PCHS result in higher retention in care and better HIV outcomes for clients: PCHS principles require that client and community needs, rights and preferences are put first. As such, rather than choosing prevention and treatment regimens based on what is convenient or acceptable for health systems, choices and decisions should be given to clients and communities. This would serve as a way to support active and long-term engagement.

To demonstrate the importance of this, Kabami et al. [16] developed and implemented a patient-centred model which offered a dynamic choice in HIV biomedical prevention across distinct settings in rural Kenya and Uganda. They found that prevention products, product delivery and HIV testing modality varied between locations and over time. Notably, they report that their approach was both responsive to client preferences and resulted in higher retention in prevention services than previously reported. Nkolo et al. [17] furthered this evidence by demonstrating the importance of responding to client preferences in Uganda. They were able to determine that those who were on their preferred differentiated antiretroviral therapy model were less likely to miss appointments and achieved higher viral suppression. With these quantitative findings in sight, and recognizing that retention

in care is the key to HIV prevention and treatment success in our current era of HIV care, it becomes challenging to deny the paramount importance of providing person-centred care.

(3) Health providers encounter barriers to implementing person-centred care: as we have seen, work towards developing and integrating person-centred care models has been done across all aspects of the HIV response (i.e. prevention to long-term adherence). However, the move towards integrated PCHS requires a systemic shift which addresses inequity in all its forms and for all stakeholders involved.

Mukamba et al. [18] provide interesting insight into client-provider encounters through quantitatively parsing and characterizing patterns of person-centred communication behaviours across Ministry of Health facilities in Zambia. They found that the majority of medical encounters (69%) were considered to have minimal to low person-centred interactions, whereas only 8% of all medical encounters were identified as highly person-centred. Clearly, something is amiss. Mwamba et al. [19] built on this investigation within the Zambia context by conducting focus groups with healthcare workers. Their findings suggested that while healthcare workers identify with and support principles of person-centred care, barriers to deliver such an approach to care exist, including a work culture characterized by differential power dynamics, restricted healthcare worker autonomy, high client volume and limited human resources, laboratory capacity, infrastructure and skills to translate clients' perspectives into practice.

To transition to PHCS, we must challenge the status quo, reflect on what it means to provide quality care and actively go against decades of ingrained policies and practices to develop new ways of working well in health systems. To facilitate this shift from traditional models to PCHS, Phillips et al. [20] provide several recommendations that resonate across global contexts. These include changes at the level of principal, policy and practice, alongside investment in and capacity-building of healthcare providers to strengthen their engagement and enable them to build trusting relationships with clients.

(4) PCHS must go beyond focusing on acuity and instead champion wellbeing: HIV has successfully transitioned from a life-limiting condition to a manageable chronic disease and this is largely due to major international efforts to focus on ensuring that people living with HIV everywhere, in all their diversity, can achieve viral suppression. Now, we must shift our thinking, frameworks and policies to reflect the new challenges we are met with in this current era of HIV care and management. These include: barriers to treatment adherence and retention in care, particularly for the most marginalized individuals living with HIV; increased prevalence of comorbidities and multimorbidity in people living with HIV; ageing with HIV; measuring and monitoring health-related quality-of-life through the integration of client reported outcome measures; and continued efforts to eliminate HIV-related stigma, discrimination and other human rights violations. In line with this thinking, Lazarus et al. [21] present a consensus piece developed with over 60 HIV organizations and experts from

the HIV Outcomes Initiative, in which they present policy asks and recommendations for European health systems and authorities. Most notably, it is recognized that the integration of these policy innovations can support the grounds for transitioning to PCHS.

In summary, the articles in this supplement contribute to a growing evidence base demonstrating the need to adopt PCHS globally, while also sharing challenges to and strategies for implementing such models. Though it is recognized that each country is unique, and has distinct contexts and health systems in place, it is undisputed that PCHS is the foundation to addressing the challenges that exist in our current era of HIV care and management. Furthermore, the articles in this supplement serve to highlight our demonstrated capacity to incorporate human rights principles in health systems as part of the HIV response. PCHS is, therefore, not an ideal and impractical utopian concept—it is the embodiment of the right to health. Furthermore, despite the plethora of institutionalized barriers that have markedly halted global progress for years, this work shows that we *can and are* working towards more equal, just and trusted health systems, centred around people, their families and communities. With these learnings in mind, it is time for the HIV field to, once again, raise its banners as a champion towards equity in healthcare and strive for the accelerated and universal shift towards PCHS globally.

AUTHORS' AFFILIATIONS

¹CUNY Graduate School of Public Health and Health Policy (CUNY SPH), New York, New York, USA; ²Barcelona Institute of Global Health (ISGlobal), Hospital Clinic, University of Barcelona, Barcelona, Spain; ³Faculty of Medicine and Health Sciences, University of Barcelona, Barcelona, Spain; ⁴Institute of HIV Research and Innovation, Bangkok, Thailand; ⁵Center of Excellence in Transgender Health, Chulalongkorn University, Bangkok, Thailand; ⁶Global Network of People Living with HIV, Cape Town, South Africa

COMPETING INTERESTS

No funding was received for this work. JVL reports grants and speaker fees from AbbVie, Gilead Sciences, MSD and Roche Diagnostics to his institution, speaker fees from Intercept, Janssen, Novo Nordisk and ViiV and consulting fees from Novavax, outside of the submitted work. RJ reports speaker fees from Gilead Sciences and ViiV, outside of the submitted work. GC has no competing interests to report.

AUTHORS' CONTRIBUTIONS

JVL drafted the editorial with input from GC and RJ. All authors further revised the editorial and approved the final, submitted version.

ACKNOWLEDGEMENTS

JVL acknowledges support to ISGlobal from the grant CEX2018-000806-S funded by MCIN/AEI/10.13039/501100011033 and the 'Generalitat de Catalunya' through the CERCA Programme, outside of the submitted work. JVL also acknowledges the contribution of Anish Arora to this editorial. GC acknowledges the inputs, experiences and ideas of colleagues at the Global Network of People Living with HIV.

REFERENCES

1. Joint United Nations Programme on HIV/AIDS. The greater involvement of people living with HIV and/or AIDS. Policy Brief. https://data.unaids.org/pub/briefingnote/2007/jc1299_policy_brief_gipa.pdf (Accessed 14 Apr, 2023).
2. Papanicolaou I, Rajan D, Karanikolos M, Soucat A, Figueras J. Health system performance assessment: a framework for policy analysis. World Health Organization; 2022.
3. World Health Organization. People-centered health care: a policy framework 2007. Geneva; 2014.
4. Sheikh K, Ranson MK, Gilson L. Explorations on people centredness in health systems. *Health Policy Plan*. 2014;29(suppl 2):ii1–5.
5. Johnston MI, Scarlatti G, Pitisuttithum P, Bekker LG. HIV vaccines: progress and promise. *J Int AIDS Soc*. 2021;24(Suppl 7):e25828.
6. Lazarus JV, Van Hout MC, Fuster-Ruiz de Apodaca MJ, Brown G, Guaraldi G. A call for health systems to monitor the health-related quality of life of people living with HIV. *HIV Med*. 2023;24(2):107–10.
7. Arora AK, Ortiz-Paredes D, Engler K, Lessard D, Mate KK, Rodriguez-Cruz A, et al. Barriers and facilitators affecting the HIV care cascade for migrant people living with HIV in organization for economic co-operation and development countries: a systematic mixed studies review. *AIDS Patient Care STDs*. 2021;35(8):288–307.
8. Poteat T, Phanuphak N, Grinsztejn B, Reisner SL. Improving the HIV response for transgender populations: evidence to inform action. *J Int AIDS Soc*. 2022;25(Suppl 5):e25993.
9. Miles A, Asbridge J. Person-centered healthcare—moving from rhetoric to methods, through implementation to outcomes. *Eur J Pers Cent Healthc*. 2017;5(1):1–9.
10. Hickmann E, Richter P, Schlieter H. All together now—patient engagement, patient empowerment, and associated terms in personal healthcare. *BMC Health Serv Res*. 2022;22(1):1116.
11. Adams N, Grieder DM. Treatment planning for person-centered care: shared decision making for whole health. Academic Press; 2013.
12. Arora AK, Lessard D, Dubé K, Lebouché B. Brief report: it's time to embed health-related quality of life across all steps of the HIV care cascade. *J Acquir Immune Defc Syndr*. 2022;91(3):251–4.
13. Tordoff DM et al. Lessons learned from community engagement regarding phylogenetic research with molecular HIV surveillance data. *J Int AIDS Soc*. 2023;26(S1):e26111. <https://doi.org/10.1002/jia2.26111>
14. Goldstein D et al. Person-centred, integrated non-communicable disease and HIV decentralized drug distribution in Eswatini and South Africa: outcomes and challenges. *J Int AIDS Soc*. 2023;26(S1):e26113. <https://doi.org/10.1002/jia2.26113>
15. Tendo-Bugondo C et al. Facilitating person-centred care: integrating an electronic client feedback tool into continuous quality improvement processes to deliver client-responsive HIV services in the Democratic Republic of Congo. *J Int AIDS Soc*. 2023;26(S1):e26112. <https://doi.org/10.1002/jia2.26112>
16. Kabami J et al. Uptake of a patient-centred dynamic choice model for HIV prevention in rural Kenya and Uganda: SEARCH SAPHIRE study. *J Int AIDS Soc*. 2023;26(S1):e26121. <https://doi.org/10.1002/jia2.26121>
17. Karamagi Nkolo EK et al. Clients in Uganda accessing preferred differentiated antiretroviral therapy models achieve higher viral suppression and are less likely to miss appointments: a cross-sectional analysis. *J Int AIDS Soc*. 2023;26(S1):e26122. <https://doi.org/10.1002/jia2.26122>
18. Mukamba N et al. Patterns of person-centred communications in public HIV clinics: a latent class analysis using the Roter interaction analysis system. *J Int AIDS Soc*. 2023;26(S1):e26119. <https://doi.org/10.1002/jia2.26119>
19. Mwamba C et al. Provider perspectives on patient-centredness: participatory formative research and rapid analysis methods to inform the design and implementation of a facility-based HIV care improvement intervention in Zambia. *J Int AIDS Soc*. 2023;26(S1):e26114. <https://doi.org/10.1002/jia2.26114>
20. Phillips L et al. Person-centred care: shifting the power dynamic in the delivery of adolescent and youth-friendly health services. *J Int AIDS Soc*. 2023;26(S1):e26116. <https://doi.org/10.1002/jia2.26116>
21. Lazarus JV et al. A person-centred approach to enhance the long-term health and wellbeing of people living with HIV in Europe. *J Int AIDS Soc*. 2023;26(S1):e26117. <https://doi.org/10.1002/jia2.26117>

RESEARCH ARTICLE

Lessons learned from community engagement regarding phylodynamic research with molecular HIV surveillance data

Diana M. Tordoff^{1,§} , Brian Minalga², Alfredo Trejo³, Alic Shook^{4,5}, Roxanne P. Kerani^{1,6,7}  and Joshua T. Herbeck⁸

[§]Corresponding author: Diana M. Tordoff, Department of Epidemiology, University of Washington, Seattle, WA, 98195, USA. (dtordoff@stanford.edu)

Abstract

Introduction: The widespread implementation of molecular HIV surveillance (MHS) has resulted in an increased discussion about the ethical, human rights and public health implications of MHS. We narrate our process of pausing our research that uses data collected through MHS in response to these growing concerns and summarize the key lessons we learned through conversations with community members.

Methods: The original study aimed to describe HIV transmission patterns by age and race/ethnicity among men who have sex with men in King County, Washington, by applying probabilistic phylodynamic modelling methods to HIV-1 *pol* gene sequences collected through MHS. In September 2020, we paused the publication of this research to conduct community engagement: we held two public-facing online presentations, met with a national community coalition that included representatives of networks of people living with HIV, and invited two members of this coalition to provide feedback on our manuscript. During each of these meetings, we shared a brief presentation of our methods and findings and explicitly solicited feedback on the perceived public health benefit and potential harm of our analyses and results.

Results: Some community concerns about MHS in public health practice also apply to research using MHS data, namely those related to informed consent, inference of transmission directionality and criminalization. Other critiques were specific to our research study and included feedback about the use of phylogenetic analyses to study assortativity by race/ethnicity and the importance of considering the broader context of stigma and structural racism. We ultimately decided the potential harms of publishing our study—perpetuating racialized stigma about men who have sex with men and eroding the trust between phylogenetics researchers and communities of people living with HIV—outweighed the potential benefits.

Conclusions: HIV phylogenetics research using data collected through MHS data is a powerful scientific technology with the potential to benefit and harm communities of people living with HIV. Addressing criminalization and including people living with HIV in decision-making processes have the potential to meaningfully address community concerns and strengthen the ethical justification for using MHS data in both research and public health practice. We close with specific opportunities for action and advocacy by researchers.

Keywords: community engagement; HIV; informed consent; molecular HIV surveillance; phylogenetics; public health ethics

Received 6 October 2022; Accepted 9 May 2023

Copyright © 2023 The Authors. *Journal of the International AIDS Society* published by John Wiley & Sons Ltd on behalf of the International AIDS Society.

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

1 | INTRODUCTION

HIV surveillance systems are critical for monitoring HIV epidemics, understanding disparities along the HIV care continuum and directing services to communities most impacted by HIV. In the United States, the National HIV Surveillance System includes the collection of partial HIV gene sequences obtained from people living with HIV through routine clinical care for the purposes of drug resistance genotyping. Public health agencies use these sequences to monitor and respond to HIV drug resistance and transmission patterns, a practice called “molecular HIV surveillance” (MHS). As with traditional HIV surveillance data, de-identified HIV gene sequence data

collected through MHS are used in academic research. Phylogenetic analyses of data collected through MHS are a powerful scientific tool due to the high sampling coverage and longitudinally available data made possible through HIV surveillance. MHS data have been used to identify the transmission of multiclass highly drug-resistant HIV and to characterize the increasing non-B HIV-1 subtype diversity within the United States [1, 2]. These types of analyses have important implications for the clinical management of HIV, pre-exposure prophylaxis efficacy, vaccine development and HIV prevention efforts in local jurisdictions.

Beginning in 2018, the United States Centers for Disease Control and Prevention (CDC) mandated that health

departments use HIV gene sequences collected through MHS to identify emerging HIV transmission clusters (defined as people whose HIV sequences have a high degree of genetic similarity) for targeted HIV prevention and linkage-to-care efforts. Then, in 2019, cluster detection and response utilizing MHS data were announced as the “fourth pillar” of the Ending the HIV Epidemic initiative [3]. The widespread implementation of MHS for cluster detection and response has resulted in increased discussion about the ethical and human rights implications as well as the public health utility of MHS.

Community concerns highlight issues around consent, stigma, privacy and HIV criminalization that disproportionately impact vulnerable populations of racial and ethnic minorities, people experiencing homelessness, transgender communities, people who inject drugs and sex workers. Although at least eight states have recently modernized their HIV criminalization laws, most of which were written before the availability of antiretroviral therapy and scientific evidence in support of treatment as prevention, 35 states have laws that criminalize the behaviour of people living with HIV [4]. In September 2019, HIV advocates called for a moratorium on all MHS activities until the CDC standardizes data protections, develops partnerships with networks of people living with HIV to facilitate ongoing community engagement and ensures human rights protection [5, 6].

Early discussions of community concerns focused on the use of MHS by health departments with less attention to the use of MHS data for research. In September 2020, the *American Journal of Bioethics* published an issue highlighting the ethics of MHS (Volume 20, Issue 10). In this issue, Moll-drem and Smith summarized key bioethical challenges associated with using MHS for public health *as well as* research [7]. These include the criminalization implications of methods that determine the direction of transmission, HIV genotype results obtained without informed consent and the increased stigmatization of communities that disproportionately experience marginalization and oppression.

This rapidly evolving discourse underscores how current MHS practices challenge person-centred HIV prevention services and research. Person-centred approaches require that institutions and providers promote individual agency and also recognize how personal, contextual and structural factors—including stigma, racism, and criminalization—impact engagement in HIV prevention and treatment [8, 9]. As argued by Moll-drem and Smith, “HIV-related marginalization means that extra care must be taken by practitioners to ensure not only that HIV data are properly managed, but also that individual and collective rights, personhood, and autonomy are respected during every stage of program implementation” [7].

In this article, we narrate our process of pausing our phylogenetic research that used HIV gene sequences collected through MHS to understand community perspectives about our specific research study. We briefly summarize the original study aims, methods, findings, the key lessons we learned through conversations with community members and advocates, and factors guiding our decision to pause the publication of our study. The authors of this article include the academic research team that conducted phylogenetic analyses, academic researchers conducting concurrent qualitative

studies of community concerns related to MHS and community advocates.

2 | METHODS

2.1 | Original study

The original study aimed to describe HIV transmission patterns among gay, bisexual and other men who have sex with men in King County, Washington by age, race, and ethnicity. We applied a probabilistic phylodynamic method developed by Volz and Frost [10, 11]. This method uses: (i) a phylogenetic tree reconstructed from HIV-1 *pol* gene sequences collected through MHS; (ii) person-level data on CD4 counts and demographics (i.e. age, race/ethnicity); and (iii) a mathematical model of HIV transmission. These inputs were used to estimate the probability of transmission for all pairs in a phylogenetic tree. The resulting pair-level probabilities cannot reliably determine direct HIV transmission events from one person to another. Rather, when the probabilities are aggregated over a larger population, inferences can be made about population-level transmission patterns. This method was previously used to understand transmission patterns among men who have sex with men in the United Kingdom [12]. Our analysis estimated: (i) the conditional probabilities associated with one (demographic) group acquiring/transmitting HIV to another group (e.g. younger men had an X% probability of acquiring HIV from older men); (ii) the percentage of excess transmission relative to what was expected under random mixing (e.g. X% excess HIV transmission among Black men); and (iii) Newman’s assortativity coefficient.

The original scientific motivations for this analysis were to provide inputs and/or calibration targets to improve the predictive accuracy and specificity of mathematical models that evaluate the impact of interventions on HIV incidence, as well as to inform HIV-related public health activities in King County. Unlike egocentric surveys, which are time- and cost-intensive and indirectly estimate transmission probabilities via estimates of sexual mixing and dyad-level behaviours, phylodynamic methods can directly estimate the assortativity parameters.

This research study was part of a set of related HIV molecular epidemiological studies funded by the National Institutes of Allergy and Infectious Diseases. Ethical approval was received from the Washington State and University of Washington (UW) Institutional Review Boards. We employed recommended methods for data security, confidentiality and legal protections [13]: (i) we used de-identified data and did not have access to identifiable information; (ii) we had formal data and confidentiality agreements with Public Health—Seattle & King County and Washington Department of Health to only use the data for the intended public health-related research purposes; and (iii) we had a Certificate of Confidentiality (CoC) from the National Institute of Health that allows researchers to refuse to disclose information for civil, criminal, administrative, legislative or other proceedings at the federal, state or local level.

2.2 | Community engagement

Members of the original study team first became aware of community concerns related to MHS in 2016 [14, 15] and

again in early 2019 through a four-part lecture series facilitated by *The Legacy Project*. Afterwards, we followed the increasing visibility of community concerns related to MHS in the published literature [13, 16], media and conferences. In September 2020, our team read and discussed articles in the *American Journal of Bioethics* [7, 17–23]. The authors of the original study team (DMT, RPK and JTH) decided to pause the research study to conduct community engagement, specifically due to emerging discussions related to inferring transmission directionality. Due to the analytical method we were applying to MHS data, we anticipated that there would be concerns about the specific phylodynamic method we utilized.

Although there is no single best method for conducting community engagement, it ideally occurs at all stages of the research process, to centre and uplift the experiences of people living with HIV in research that affects their lives. Since we began our community engagement process after analyses were completed, we first consulted with the UW/Fred Hutch Center for AIDS Research Community Engagement Office. We then organized two public-facing online presentations. The target audience of one presentation was researchers and clinicians (approximately 50 attendees), while the second presentation included local community-based organizations and HIV advocates (approximately 15 attendees). After we integrated feedback from these sessions into a manuscript draft, we invited two members of a national community coalition on MHS to review and provide feedback on the manuscript. This process included both written and oral feedback given during an hour-long meeting. Lastly, we held a meeting with eight members of the national community coalition on MHS, which included representatives of networks of people living with HIV across the United States. These activities occurred between October 2020 and June 2021. During each presentation and community consultation meeting, we shared a 10- to 15-minute presentation of our methods and findings that incorporated the feedback we had received to date and explicitly solicited feedback on the perceived public health benefit and potential harm of our analyses and results. The first and senior authors (DMT and JTH) took detailed notes during each meeting, practised reflexive writing and journaling, and met weekly to discuss the issues and topics that arose. The recommendation to share our community engagement process and decision-making framework for whether to publish the original study was suggested by members of the national community coalition on MHS and was the impetus for this article.

3 | RESULTS

To provide context for the community feedback we received, we first briefly summarize our original study findings. Our analysis found phylodynamic evidence of assortative transmission by age, race, and ethnicity; that is our modelling indicated that Black, Hispanic/Latino and Asian men were more likely to acquire HIV from men of the same race or ethnicity than would be expected under random mixing. In addition, contrary to prior hypotheses about age-discrepant HIV transmission, we estimated that younger men acquired HIV from older men less frequently than expected under random mixing.

In the following sections, we summarize the key takeaways from our community engagement exercise. Some community concerns about MHS in public health practice extend to research using MHS data, namely those related to informed consent, inferring directionality and criminalization. We also received critical feedback specific to our research application related to the use of phylogenetic analyses to study assortativity by race and ethnicity, and the importance of considering the broader context of stigma and structural racism.

3.1 | Informed consent

The lack of informed consent for the future use of HIV biospecimens collected through routine clinical care is central to community concerns about MHS, both in public health practice and its use in research. Historically, public health surveillance programmes have had legal mandates to collect data without informed consent in order to facilitate the collection of complete, timely and reliable data with which to monitor and improve the health and wellbeing of the public [24]. This practice is considered ethically justified in contexts in which public health departments engage impacted communities and the data include the minimum necessary information, are stored securely and used for public health *action* [25]. Some scientists have expressed concern that the collection of informed consent in standard public health surveillance practices may lead to higher rates of refusal for genotypic testing and negatively impact engagement in care [22].

The lack of informed consent in surveillance has also raised ethical issues related to privacy, autonomy and risks/harms posed to vulnerable populations [24, 26]. Importantly, concerns about the lack of informed consent for public health and research reuses of HIV genotype results differ from other forms of public health surveillance due to: (i) the increased risks posed to people living with HIV due to HIV criminalization; and (ii) the unique potential for MHS data, when taken alongside additional epidemiological and clinical data, to infer (and be misinterpreted to prove) specific transmission events. These unique contexts, as well as the influences of stigma and structural racism, are central to understanding why informed consent is a primary community concern about MHS.

A lack of meaningful dialogue around the issue of informed consent has the potential to erode trust in MHS and health systems overall. Throughout our community engagement process, the lack of informed consent for the research use of HIV sequences collected through MHS was described by some individuals as analogous to the harm and distrust created by the Tuskegee Syphilis Study and the HeLa cell line of Henrietta Lacks. Therefore, we believe that progress towards building trust and bridging understanding between researchers, public health agencies and community members will need to meaningfully address concerns related to informed consent and community consultation over the applications of MHS data.

3.2 | Inferring directionality and criminalization

Community-based advocacy and scientific publications have increasingly highlighted concerns about the use of HIV sequences to infer the direction of transmission and

implications for HIV criminalization cases [7, 27]. As we had anticipated, the phylodynamic method applied in our original study directly touched on these concerns. Although these methods are unable to robustly infer transmission from one individual to another [10], they can be misinterpreted by scientists and community members not familiar with the limitations of phylogenetic methods.

Community members also had concerns that the results of our analysis could be used in HIV criminalization cases. We believe this is not true for our specific study, as our study team would not be required to respond to a subpoena request for the de-identified MHS data or our phylodynamic results because of the NIH CoC, nor are these data actionable if subpoenaed (as we cannot identify specific individuals). However, these data protections are perhaps not universal or consistent across localities, and not all researchers who possess access to MHS data may be aware of these legal protections. Importantly, this is also not made transparent to the community by researchers and public health agencies. These concerns highlight the different uses of MHS data by research groups compared to public health organizations that *do* have the ability to identify individuals in their cluster detection and response work. Increasing transparency and community engagement around specific uses of MHS data and their implications for criminalization is a key step towards addressing community concerns.

3.3 | Assortativity, stigma and structural racism

Assortativity, or the increased likelihood of choosing partners from one's own identified subgroup, has been hypothesized to contribute to disparities in HIV incidence [28–32]. Our original study used data collected through MHS to quantify assortativity by age, race, and ethnicity among men who have sex with men to better understand the role of assortativity in producing disparities. Through our community engagement, we repeatedly heard from people living with HIV and community-based service providers that these types of analyses felt “voyeuristic,” like “racial profiling,” and that they perpetuated harmful stereotypes. They emphasized that assortative mixing by race and ethnicity occurs in the context of systemic oppression, and in many cases, arises out of the need for in-group love and support. Therefore, because assortative mixing is not a directly intervenable network-level characteristic, overemphasizing its role in sustaining disparities has the potential to stigmatize love, sex, healthy coping and partnerships within communities of people of colour.

Although assortative transmission in combination with high community viral load likely contributes to racial and ethnic disparities in HIV, numerous structural and social determinants of health also influence infectious disease transmission dynamics and have been hypothesized to explain these sustained disparities [32–36]. Structural factors related to racism and stigma play a more fundamental role in producing and sustaining these disparities (and are likely the root structural causes of the sexual network characteristics, like assortativity). For example, HIV criminalization laws, as well as laws that criminalize behaviours (including LGBTQ identities, breastfeeding, sex work, and drug use/possession) dispro-

portionately impact racial minorities and are associated with reduced access to HIV services [37–40].

Residential segregation is also highly correlated with higher HIV incidence rates among Black populations [33, 41]. There are several pathways through which residential segregation contributes to disparities in HIV. It is an indicator of a concentrated disadvantage as Black families disproportionately live in neighbourhoods with fewer resources and more frequent interactions with a criminal justice system that disproportionately incarcerates people of colour [35, 41]. Residential segregation impacts access to high-quality healthcare through a lack of local clinics and poor transportation infrastructure [34]. Lastly, higher levels of segregation and socio-economic inequalities that were present at the onset of the HIV/AIDS crisis of the 1980s contributed to a higher background prevalence of HIV within Black and Latinx communities.

Similarly, stigma likely plays a central role in sustaining racial disparities in HIV. In Earnshaw et al.'s stigma and HIV disparities model, structural racism enacted through residential segregation, historical traumatic assaults and medical distrust can be conceptualized as structural-level manifestations of stigma. These produce differences in social status and resources that serve to reinforce individual-level stigma, including prejudice, stereotypes, discrimination and internalized stigma [42].

The role of sexual network characteristics—such as assortativity—as mediators between structural and individual-level factors has largely been unstudied. Therefore, we recommend that future phylogenetic research aims to better understand how assortativity and transmission patterns are a consequence of structural causes of HIV disparities, including structural racism and stigma.

3.4 | Deciding to pause publication

Our decision to pause the publication of our original study was guided by the Belmont Report, the Denver Principles, recommendations of the NIH Working Group on Ethical Issues in HIV Phylogenetic Research, and our community consultation process. The 1979 Belmont Report declared three basic ethical principles for research: respect for persons (autonomy), maximize possible benefits and minimize possible harms (beneficence/non-maleficence) and equitable access to the benefits and burdens of research (justice). The Denver Principles were written by an advisory committee of people with AIDS in 1983. As they relate to people living with HIV's interactions with biomedical institutions, this historic document states the right to “be involved at every level of decision-making” and “to full explanations of all medical procedures and risks [and] to refuse to participate in research without jeopardizing their treatment” [43]. Lastly, the NIH Working Group discussed the use of public health surveillance data in research, and underscored that due to public health agencies' “ethical and legal mandate to collect communicable disease data,” research that uses MHS data “must be ethically justified on the basis of potential benefits to public health” [13]. Our community consultation process led us to interpret and apply these principles and recommendations within a new cultural context.

Given that HIV sequences collected through MHS are obtained without informed consent for their future use in research, we felt this raised important questions about the public health utility of our research findings as well as the application of the ethical principles of beneficence/non-maleficence and justice in this research. Those questions included:

1. Does this research translate into public health action and efforts to end the HIV epidemic? (Public Health Utility)
2. Does this research benefit—or at minimum not harm—communities of people living with HIV who are included in this research without their consent? (Beneficence/non-maleficence)
3. Does this research equitably distribute benefits and risks to people living with HIV *and* people susceptible to acquiring HIV? (Justice)

Ultimately, guided by the above-described concerns as well as the lack of *directly* intervenable factors (e.g. assortativity) or public health interventions in the original study, we determined that our original study has insufficiently addressed all three of these questions. Although our community engagement process revealed that some individuals thought our findings could be beneficial for prioritizing the distribution of public health resources and dispelled harmful stereotypes about young men frequently acquiring HIV from older partners, we concluded that these benefits did not balance the potential harms of publishing our study. The two most significant potential harms included (1) perpetuating racialized stigma about/among gay, bisexual and other men who have sex with men and (2) eroding the trust between phylogenetics researchers and communities of people living with HIV by choosing to publish despite their clearly and consistently articulated concerns. Although criminalization was a major theme in community discussions, we believe that our data protections, the inability of our analytical methods to reliably infer transmission directionality and the recent decriminalization of HIV in Washington significantly minimized the potential for harmful outcomes. While we believe research use of MHS data to identify transmission dynamics is an important tool that can inform public health action (even if not directly), we concluded that moving forward with publication requires deeper community engagement and transparency.

4 | DISCUSSION

The use of MHS data for research—data which are originally collected for routine clinical care and HIV surveillance purposes—raises complex considerations about the role of informed consent and the relationship between public health research and practice. In this article, we described lessons learned from incorporating community engagement at the final stages of a research study in response to growing ethical concerns about MHS and new guidance on conducting ethical HIV phylogenetics research, as well as our decision to not publish our findings [13]. We found that some community concerns about MHS in public health practice also

impact research using MHS data, while other critiques were more specific to our research. This was a challenging yet transformative process that required us to practice cultural humility and reflexivity, including ongoing self-reflection to unpack how our personal experiences, identities and positions as researchers contributed to our lack of awareness regarding community perspectives. While it is uncommon for researchers to publish on their experiences of pausing a study, understanding these types of decision-making processes may aid other scientists in ethically designing and conducting future research.

Community engagement has long been the cornerstone of ethical HIV research and public health policy. Recent publications have provided guidance for conducting ethical HIV phylogenetics research, highlighting the importance of meaningful community engagement at all stages of the research process and careful consideration of the risks/benefits posed to both individuals and groups of people living with HIV [13, 44]. However, there is also a demonstrable need to directly address ongoing community concerns around the use of MHS data. Structural factors that curtail the human rights of people living with HIV, namely laws and policies that criminalize HIV, are a key barrier to community acceptance of MHS and HIV phylogenetic research more broadly. In line with the CDC and the *Ending the HIV Epidemic* Initiative, which explicitly names HIV criminalization as a structural barrier to HIV prevention, we advocate for states to repeal laws that criminalize HIV [45, 46]. In addition, some researchers may be well-positioned to facilitate increased dialogue about MHS that meaningfully includes people living with HIV and conduct research examining these issues. Table 1 describes opportunities for researchers to promote autonomy, transparency, and partnerships between communities of people living with HIV, public health agencies and research institutions.

4.1 | Limitations

Our approach had several limitations. Contrary to best practices, our community consultation process occurred after our study analyses were completed. It is possible, had we engaged with the community from the beginning of our study, we would have been able to develop a research question or approach that was acceptable and minimized harm to communities of people living with HIV. In addition, we did not conduct a formal qualitative study, and at the onset of our community engagement process did not anticipate publishing about our process or the key takeaways that emerged from our conversations. The community engagement exercise undertaken by our team represents an initial and ongoing effort to better understand how community concerns about MHS extended to our research. Despite being relatively limited in its scope, our community consultation process was sufficient to aid us in our decision to not publish our original study, and revealed concerns that were consistent with published concerns about MHS. In addition, many of our key takeaways related to informed consent, language, directionality, assortativity, stigma and structural racism may be useful for other researchers.

Table 1. Areas for advocacy for researchers

Advocate for structural interventions:

- Advocate for state-level decriminalization of HIV and sex work.
- Advocate for policies that prohibit the use of MHS data in criminal, civil or immigration investigations or prosecutions.
- Commit to providing expert testimony in HIV criminal cases and educate courts, judges and lawyers about the limitations of HIV sequence analyses and their inability to reliably infer direct transmission.

Promote autonomy:

- Apply implementation science and community-based participatory research methods to understand the feasibility of, and barriers to, collecting informed consent as well as the acceptability of alternative methods that promote data justice (e.g. opt-out systems, data ownership, etc.).
- Develop partnerships, community advisory boards and other power-sharing mechanisms with networks of people living with HIV to facilitate ongoing community engagement around the use of MHS data.

Promote transparency:

- Support local, state and national public health agencies to increase transparency. For example, by publicly sharing information about how often HIV gene sequences collected through MHS are analysed, what types of analyses are conducted, what data and confidentiality protections are in place and what potential interventions or contact with people living with HIV may or may not result from these analyses.
- Assist local, state and national public health departments to evaluate the effectiveness of cluster detection and response (i.e. if this intervention is successful at averting HIV transmission, linking individuals to care, increased HIV testing, etc.).
- Assist local, state and national public health departments to quantify the cost and financial benefits of MHS systems in response to advocates' requests to understand the economics of MHS and cluster detection and response.

Bridge understanding:

- Pause research to conduct in-depth community-based participatory research and community engagement to determine how to conduct research using data collected through MHS in a way that is acceptable.
- Facilitate community engagement and restorative justice between community members and public health departments to bridge understanding and build trust around the use of MHS data.
- Conduct community engagement and rigorous qualitative studies to understand the experiences and perspectives of people living with HIV who have been contacted as a result of cluster detection and response investigations.

5 | CONCLUSIONS

HIV phylogenetics research using data collected through MHS is a powerful scientific technology with the potential to benefit and harm communities of people living with HIV. MHS data can improve our knowledge about HIV and reduce onward transmission of HIV if applied appropriately. It can also increase stigma, distrust and create barriers to HIV prevention and treatment. Due to significant concerns rooted in consent, criminalization and stigma, the benefits of such research need to be clearly outlined and communities should be empowered to set priorities for why, how and when to do such analysis. Addressing criminalization, including people living with HIV in decision-making processes related to MHS, and increasing transparency have the potential to meaningfully address community concerns and strengthen the ethical justification for the use of MHS data in both research and public health practice.

AUTHORS' AFFILIATIONS

¹Department of Epidemiology, University of Washington, Seattle, Washington, USA; ²Fred Hutch, Office of HIV/AIDS Network Coordination, Seattle, Washington, USA; ³Department of Political Science, University of California Los Angeles, Los Angeles, California, USA; ⁴Seattle University, College of Nursing, Seattle, Washington, USA; ⁵Seattle Children's Center for Pediatric Nursing Research, Seattle, Washington, USA; ⁶Public Health – Seattle & King County, HIV/STD Program, Seattle, Washington, USA; ⁷Department of Medicine, University of Washington, Seattle, Washington, USA; ⁸Department of Global Health, University of Washington, Seattle, Washington, USA

COMPETING INTERESTS

DMT received support unrelated to this work from NIH NIAID (grant F31AI152542). BM's role in this work was supported separately with funds from the United States Government Department of Health and Human Services, NIH NIAID, under: (a) Grant 2 UM1 AI068614-15, "Leadership Group for a Global HIV Vaccine Clinical Trials Network" (Office of HIV/AIDS Network Coordination) to the Fred Hutchinson Cancer Research Center. The authors have no competing interests.

AUTHORS' CONTRIBUTIONS

DMT, AS, RPK and JTH conceived of and conducted original studies and analyses. DMT, BM, AT, RPK and JTH participated in the community engagement process as researchers and/or community advocates. DMT drafted the original manuscript, and all authors reviewed, edited and approved the final manuscript.

ACKNOWLEDGEMENTS

The authors gratefully acknowledge the Community Coalition on Molecular HIV Surveillance for participating in our community consultation process, including Alexander McClelland, Andrew Spieldecker, Ronald Johnson, Marco Castro-Bojorquez, Edwin Bernard, Naina Khanna and the Positive Women's Network USA. We thank Stephann Wallace and University of Washington/Fred Hutch Center for AIDS Research Office of Community Engagement for their guidance in beginning our community engagement process, as well as Susan Buskin and Richard Lechtenberg for reviewing and providing feedback on this manuscript.

FUNDING

This work was supported by the National Institutes of Health (NIH), National Institute of Allergy and Infectious Diseases (NIAID) grant R01AI127232 awarded to JTH and RPK.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

REFERENCES



1. Buskin SE, Ellis GM, Pepper GG, Frenkel LM, Pergam SA, Gottlieb GS, et al. Transmission cluster of multiclass highly drug-resistant HIV-1 among 9 men who have sex with men in Seattle/King County, WA, 2005–2007. *J Acquir Immune Defic Syndr*. 2008;49:205–11. <https://doi.org/10.1097/QAI.0b013e318185727e>
2. Kline RL, Saduvala N, Zhang T, Oster AM. Diversity and characterization of HIV-1 subtypes in the United States, 2008–2016. *Ann Epidemiol*. 2019;33:84–8. <https://doi.org/10.1016/J.ANNEPIDEM.2019.02.010>
3. Fauci AS, Redfield RR, Sigounas G, Weahkee MD, Giroir BP. Ending the HIV epidemic. *JAMA*. 2019;321:844. <https://doi.org/10.1001/jama.2019.1343>
4. The Center for HIV Law & Policy. HIV criminalization in the United States: an overview of the variety and prevalence of laws used to prosecute and punish people living with HIV (PLHIV) in the US. 2020.
5. U.S. People Living with HIV Caucus. Open Letter to the CDC: Networks of People Living with HIV Demand a Moratorium on Molecular HIV Surveillance 2021. (Cited 2021 Jun 17) <https://actionnetwork.org/forms/open-letter-to-the-cdc-we-demand-a-moratorium-on-molecular-hiv-surveillance?&source=twitter>.
6. Artavia D. Watch activists storm the stage at USCA, protesting neglect from CDC. *HIV Plus Magazine*. 2019 (cited 2021 Jul 23) <https://www.hivplussmag.com/treatment/2019/9/05/activists-storm-stage-hiv-conference-citing-neglect-cdc>.
7. Molldrem S, Smith AKJ. Reassessing the ethics of molecular HIV surveillance in the era of cluster detection and response: toward HIV data justice. *Am J Bioeth*. 2020;20:10–23. <https://doi.org/10.1080/15265161.2020.1806373>
8. Pantelic M, Stegling C, Shackleton S, Restoy E. Power to participants: a call for person-centred HIV prevention services and research. *J Int AIDS Soc*. 2018;21:e25167. <https://doi.org/10.1002/JIA2.25167>
9. Spieldecker A, French M, Ray V, Minalga B, Sardina C, Suttle R, et al. The meaningful involvement of people with HIV/AIDS (MIPA): the participatory praxis approach to community engagement on HIV surveillance. *J Commun Engage Scholarsh*. 2022;14. <https://doi.org/10.54656/jces.v14i2.26>
10. Volz EM, Frost SDW. Inferring the source of transmission with phylogenetic data. *PLoS Comput Biol*. 2013;9:e1003397. <https://doi.org/10.1371/journal.pcbi.1003397>
11. Le Vu S, Ratmann O, Delpech V, Brown AE, Gill ON, Tostevin A, et al. Comparison of cluster-based and source-attribution methods for estimating transmission risk using large HIV sequence databases. *Epidemics*. 2018;23:1–10. <https://doi.org/10.1016/J.EPIDEM.2017.10.001>
12. Le Vu S, Ratmann O, Delpech V, Brown AE, Gill ON, Tostevin A, et al. HIV-1 transmission patterns in men who have sex with men: insights from genetic source attribution analysis. *AIDS Res Hum Retroviruses*. 2019;35:805–13. <https://doi.org/10.1089/AID.2018.0236>

13. Dawson L, Benbow N, Fletcher FE, Kassaye S, Killelea A, Latham SR, et al. Addressing ethical challenges in US-based HIV phylogenetic research. *J Infect Dis*. 2020;222(12):1997–2006. <https://doi.org/10.1093/infdis/jiaa107>
14. Evans D, Benbow N. Ethical considerations for a public health response using molecular HIV surveillance data: a multistakeholder approach. *Project Inform and Northwestern University*; 2018. <https://doi.org/10.18131/G3MT7B>
15. Gilbert M, Swenson L, Unger D, Scheim A, Grace D. Need for robust and inclusive public health ethics review of the monitoring of HIV phylogenetic clusters for HIV prevention. *Lancet HIV*. 2016;3:e461. [https://doi.org/10.1016/S2352-3018\(16\)30156-4](https://doi.org/10.1016/S2352-3018(16)30156-4)
16. Chung C, Khanna N, Cardell B, Spieldecker A, Strub S, McClelland A, et al. Consent and criminalisation concerns over phylogenetic analysis of surveillance data. *Lancet HIV*. 2019;6:e420. [https://doi.org/10.1016/S2352-3018\(19\)30138-9](https://doi.org/10.1016/S2352-3018(19)30138-9)
17. Bernard EJ, McClelland A, Cardell B, Chung C, Castro-Bojorquez M, French M, et al. We are people, not clusters! Vol. 20. Routledge; 2020. <https://doi.org/10.1080/15265161.2020.1809550>
18. Smith JC. Fourth pillar or "third rail?": towards a community-centered understanding of the role of molecular HIV surveillance in ending the HIV epidemic in the United States. *Am J Bioeth*. 2020;20:5–6. <https://doi.org/10.1080/15265161.2020.1812266>
19. Watson M, Sweeney P. Furthering discussion of ethical implementation of HIV cluster detection and response. *Am J Bioeth*. 2020;20:24–6. <https://doi.org/10.1080/15265161.2020.1806398>
20. Mutenherwa F, Wassenaar D, de Oliveira T. Adding a voice to the unique ethical considerations in molecular HIV surveillance. *Am J Bioeth*. 2020;20:34–6. <https://doi.org/10.1080/15265161.2020.1806399>
21. Dawson L, Latham SR. Molecular HIV surveillance and public health ethics: old wine in new bottles. *Am J Bioeth*. 2020;20:39–41. <https://doi.org/10.1080/15265161.2020.1806393>
22. Rennie S, Sullivan K, Dennis A. HIV molecular epidemiology: tool of oppression or empowerment? *Am J Bioeth*. 2020;20:44–7. <https://doi.org/10.1080/15265161.2020.1806392>
23. Haire B. Benefit of HIV molecular surveillance is unclear, but risks to prevention norms are clear. *Am J Bioeth*. 2020;20:47–9. <https://doi.org/10.1080/15265161.2020.1806388>
24. Klingler C, Silva DS, Schuermann C, Reis AA, Saxena A, Strech D. Ethical issues in public health surveillance: a systematic qualitative review. *BMC Public Health*. 2017;17:1–13. <https://doi.org/10.1186/s12889-017-4200-4>
25. Lee LM, Heilig CM, White A. Ethical justification for conducting public health surveillance without patient consent. *Am J Public Health*. 2012;102:38–44. <https://doi.org/10.2105/AJPH.2011.300297>
26. Kehr J. Blind spots and adverse conditions of care: screening migrants for tuberculosis in France and Germany. *Sociol Health Illness*. 2012;34:251–65. <https://doi.org/10.1111/j.1467-9566.2011.01415.x>
27. Taylor BS, Sapién H. Determining the direction of human immunodeficiency virus transmission: benefits and potential harms of taking phylogenetic analysis one step further. *Clin Infect Dis*. 2021;72:38–40. <https://doi.org/10.1093/cid/ciz1248>
28. Coburn BJ, Blower S. A major HIV risk factor for young men who have sex with men is sex with older partners. *J Acquir Immune Defic Syndr*. 2010;54:113–4. <https://doi.org/10.1097/QAI.0b013e3181d43999>
29. Joseph HA, Marks G, Belcher L, Millett GA, Stueve A, Bingham TA, et al. Older partner selection, sexual risk behaviour and unrecognised HIV infection among Black and Latino men who have sex with men. *Sex Transm Infect*. 2011;87:442–7. <https://doi.org/10.1136/sextrans-2011-050010>
30. Hurt CB, Matthews DD, Calabria MS, Green KA, Adimora AA, Golin CE, et al. Sex with older partners is associated with primary HIV infection among men who have sex with men in North Carolina. *J Acquir Immune Defic Syndr*. 2010;54:185–90. <https://doi.org/10.1097/QAI.0b013e3181c99114>
31. Jin F, Grulich AE, Mao L, Zablotska I, O'Dwyer M, Poynten M, et al. Sexual partner's age as a risk factor for HIV seroconversion in a cohort of HIV-negative homosexual men in Sydney. *AIDS Behav*. 2013;17:2426–9. <https://doi.org/10.1007/s10461-012-0350-7>
32. Bonett S, Meanley S, Stevens R, Brawner B, Bauermeister J. The role of networks in racial disparities in HIV incidence among men who have sex with men in the United States. *AIDS Behav*. 2020;24:2781–96. <https://doi.org/10.1007/s10461-020-02798-1>
33. Buot M-LG, Docena JP, Ratemo BK, Bittner MJ, Burlew JT, Nuritdinov AR, et al. Beyond race and place: distal sociological determinants of HIV disparities. *PLoS One*. 2014;9:e91711. <https://doi.org/10.1371/journal.pone.0091711>
34. Freeman R, Gwadz MV, Silverman E, Kutnick A, Leonard NR, Ritchie AS, et al. Critical race theory as a tool for understanding poor engagement along the HIV

- care continuum among African American/Black and Hispanic persons living with HIV in the United States: a qualitative exploration. *Int J Equity Health*. 2017;16:54. <https://doi.org/10.1186/s12939-017-0549-3>
35. Henderson L. Mass incarceration, residential segregation and racial disparities in HIV. *J AIDS HIV Res*. 2016;8:150–62. <https://doi.org/10.5897/jahr2016.0387>
36. Millett GA. New pathogen, same disparities: why COVID-19 and HIV remain prevalent in U.S. communities of colour and implications for ending the HIV epidemic. *J Int AIDS Soc*. 2020;23:e25639. <https://doi.org/10.1002/jia2.25639>
37. Hoppe T, McClelland A, Pass K. Beyond criminalization: reconsidering HIV criminalization in an era of reform. *Curr Opin HIV AIDS*. 2022;17:100. <https://doi.org/10.1097/COH.0000000000000715>
38. Bernard EJ, Symington A, Beaumont S. Punishing vulnerability through HIV criminalization. *Am J Public Health*. 2022;112:S395–7. <https://doi.org/10.2105/AJPH.2022.306713>
39. Shannon K, Strathdee SA, Goldenberg SM, Duff P, Mwangi P, Rusakova M, et al. Global epidemiology of HIV among female sex workers: influence of structural determinants. *Lancet*. 2015;385:55–71. [https://doi.org/10.1016/S0140-6736\(14\)60931-4](https://doi.org/10.1016/S0140-6736(14)60931-4)
40. Arreola S, Santos G-M, Beck J, Sundararaj M, Wilson PA, Hebert P, et al. Sexual stigma, criminalization, investment, and access to HIV services among men who have sex with men worldwide. *AIDS Behav*. 2015;19:227–34. <https://doi.org/10.1007/s10461-014-0869-x>
41. Ibragimov U, Beane S, Adimora AA, Friedman SR, Williams L, Tempalski B, et al. Relationship of racial residential segregation to newly diagnosed cases of HIV among black heterosexuals in US metropolitan areas, 2008–2015. *J Urban Health*. 2019;96:856–67. <https://doi.org/10.1007/s11524-018-0303-1>
42. Earnshaw VA, Bogart LM, Dovidio JF, Williams DR. Stigma and racial/ethnic HIV disparities: moving toward resilience. *Am Psychol*. 2013;68:225–36. <https://doi.org/10.1037/a0032705>
43. The Denver Principles: statement from the people with AIDS advisory committee. 1983.
44. Coltart CEM, Hoppe A, Parker M, Dawson L, Amon JJ, Simwinga M, et al. Ethical considerations in global HIV phylogenetic research. *Lancet HIV*. 2018;5:e656. [https://doi.org/10.1016/S2352-3018\(18\)30134-6](https://doi.org/10.1016/S2352-3018(18)30134-6)
45. Centers for Disease Control and Prevention. HIV criminalization and ending the HIV epidemic. (Cited 2021 Aug 25) <https://www.cdc.gov/hiv/policies/law/criminalization-ehe.html>.
46. Mermin J, Valentine SS, McCray E. HIV criminalisation laws and ending the US HIV epidemic. *Lancet HIV*. 2021;8:e4–6. [https://doi.org/10.1016/S2352-3018\(20\)30333-7](https://doi.org/10.1016/S2352-3018(20)30333-7).

COMMENTARY

Person-centred, integrated non-communicable disease and HIV decentralized drug distribution in Eswatini and South Africa: outcomes and challenges

Deborah Goldstein^{1,§} , Nathan Ford², Nicholas Kisyeri^{3,4}, Maggie Munsamy⁵, Lirica Nishimoto⁶, Kufor Osi⁷, Herve Kambale⁸, Thomas Minior¹ and Moses Bateganya⁶ 

[§]**Corresponding author:** Deborah Goldstein, Office of HIV/AIDS, USAID, 500 D St SW, Washington, DC 20547, USA. (degoldstein@usaid.gov)

Abstract

Introduction: Non-communicable diseases (NCDs) are highly prevalent in people living with HIV above 50 years of age and account for increasing mortality. There is little published evidence supporting person-centred, integrated models of HIV care, hypertension and diabetes treatment in southern Africa, and no data demonstrating mortality reduction. Where clinical visits for NCDs and HIV cannot be combined, integrated medication delivery presents an opportunity to streamline care and reduce patient costs. We present experiences of integrated HIV and NCD medication delivery in Eswatini and South Africa, focusing on programme successes and implementation challenges. Programmatic data from Eswatini's Community Health Commodities Distribution (CHCD) from April 2020 to December 2021 and South Africa's Central Chronic Medicines Dispensing and Distribution (CCMDD) from January 2016 to December 2021 were provided by programme managers and are summarized here.

Discussion: Launched in 2020, Eswatini's CHCD provides over 28,000 people with and without HIV with integrated services, including HIV testing, CD4 cell count testing, antiretroviral therapy refills, viral load monitoring and pre-exposure prophylaxis alongside NCD services, including blood pressure and glucose monitoring and hypertension and diabetes medication refills. Communities designate neighbourhood care points and central gathering places for person-centred medication dispensing. This programme reported fewer missed medication refill appointments among clients in community settings compared to facility-based settings. South Africa's CCMDD utilizes decentralized drug distribution to provide medications for over 2.9 million people, including those living with HIV, hypertension and diabetes. CCMDD incorporates community-based pickup points, facility "fast lanes" and adherence clubs with public sector health facilities and private sector medication collection units. There are no out-of-pocket payments for medications or testing commodities. Wait-times for medication refills are lower at CCMDD sites than facility-based sites. Innovations to reduce stigma include uniformly labelled medication packages for NCD and HIV medications.

Conclusions: Eswatini and South Africa demonstrate person-centred models for HIV and NCD integration through decentralized drug distribution. This approach adapts medication delivery to serve individual needs and decongest centralized health facilities while efficiently delivering NCD care. To bolster programme uptake, additional reporting of integrated decentralized drug distribution models should include HIV and NCD outcomes and mortality trends.

Keywords: non-communicable disease; integration; person-centred care; decentralized drug distribution; HIV; hypertension; diabetes

Received 28 November 2022; **Accepted** 9 May 2023

Copyright © 2023 The Authors. *Journal of the International AIDS Society* published by John Wiley & Sons Ltd on behalf of the International AIDS Society.

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

1 | INTRODUCTION

In low- and middle-income countries, 15% of people living with HIV are aged 50 years and older [1]. Non-communicable diseases (NCDs) have increased in prevalence among older people living with HIV [2] with a significant impact on health and increasing contributions to mortality [3]. NCD prevalence among people living with HIV in low- and middle-income

countries includes 21% hypertension, 22% hypercholesterolemia and 1.3%–26% diabetes [4]. A multicentre cohort study of U.S. President's Emergency Plan for AIDS Relief (PEPFAR)-supported clinical sites in Kenya, Uganda, Tanzania and Nigeria from 2011 to 2021 found up to 30.5% had elevated blood pressure and up to 15.8% had dysglycaemia; additionally, the prevalence of NCDs increased among people older than age 50 years living with and without HIV [5].

Despite increasing NCD prevalence, there is a lack of high-quality published evidence to support person-centred NCD/HIV integration models in southern Africa [6–8]. A World Health Organization guideline process in 2021 identified implementation studies of the integration of hypertension and diabetes care with differentiated models of HIV service delivery as a specific research gap [9]. Integration may increase access to hypertension and diabetes care among people living with HIV with limited access to primary preventive services [10, 11] and may potentially improve health outcomes and reduce mortality [3, 12].

Person-centred programming places individuals' values and preferences at the centre of all aspects of programme design and implementation. To promote awareness of successful large-scale NCD/HIV integration projects, we present experiences with person-centred models for HIV and NCD integration through decentralized drug distribution from Eswatini and South Africa, focusing on programmatic successes and implementation challenges. Programmatic data from Community Health Commodities Distribution (CHCD) in Eswatini and Central Chronic Medicines Dispensing and Distribution (CCMDD) in South Africa were provided by programme managers and are summarized for Eswatini, from April 2020 to December 2021, and for South Africa, from January 2016 to December 2021.

2 | DISCUSSION

2.1 | Eswatini: Community Health Commodities Distribution

2.1.1 | Programme design

In April 2020, the Eswatini Ministry of Health responded to the COVID-19 pandemic by creating CHCD, building upon differentiated service delivery (DSD) models within their national Community Commodity Distribution framework, to ensure ongoing access to medications while minimizing client risk [13]. With 11 implementing partners supported by the Government of Eswatini, PEPFAR, the Global Fund and Médecins Sans Frontières, CHCD provides medication distribution, community engagement and supply chain management for community-based DSD models, including community antiretroviral therapy (ART) groups [14].

CHCD initially used HIV medication distribution as the entry point due to the existing foundation of the HIV programme. As a response to client perceptions of HIV stigma, however, NCDs, family planning and other services were later added at some facilities, allowing people living with HIV to access these medications, and allowing those without HIV to also participate in CHCD.

CHCD services currently include HIV testing, ART, CD4 cell count, viral load monitoring, adherence support services and pre-exposure prophylaxis alongside NCD services, including blood pressure and weight monitoring, glucose testing, hypertension and diabetes medication refills, sexually transmitted infection screening, family planning and treatment of minor ailments. Participants living with HIV must be 18 years or older, on ART for at least 12 months with two undetectable viral loads, on a first-line antiretroviral (ARV) regimen, not

pregnant, and agree and consent to participate. There are no out-of-pocket costs for CHCD participation and transportation subsidies are not offered.

Eligible clients receive decentralized services either at small, convenient public health facilities or at decentralized pickup points (PUPs). At both facility and community levels, Expert Clients and community leaders identify secure locations of community distribution points within catchment areas; clients then select the most convenient site for ART pickup. Neighbourhood PUPs are at central gathering places, including under a tree, schools, churches, bus stops, community halls, football pitches, shops and local government offices.

Expert Clients at the community level also coordinate with client support groups to recruit clients established on ART. Client information is first recorded in a paper CHCD register, then transferred into electronic client management software. Eswatini's Ministry of Health adapted the national electronic Client Management Information System to enable tracking of data relevant to DSD and conducted annual assessments to evaluate coverage, quality and impact of DSD models [15].

Nurses and Expert Clients at CHCD facilities pre-pack ART and NCD medications and carry them to community distribution points. Multi-month dispensing of 3–6 months of ART is aligned with up to 3 months for NCD medications, depending on stock availability. After their vital signs are taken, clients are screened for COVID-19, tuberculosis and other illnesses. Viral load specimens are obtained where possible, or ART clients are referred to a health facility.

The proportion of health facilities implementing DSD models grew from 13% in 2016 to 96% in 2020, and the diversity of these models increased over time, currently with five facility-based and two other community-based models in addition to CHCD; there are also tailored models for adults and adolescents living with HIV, individuals with comorbidities and advanced HIV disease, men, pregnant and breastfeeding women, high viraemic, and key and vulnerable populations. The proportion of people on ART enrolled in less-intensive DSD models increased from 7.9% in 2017 to 80.4% in 2020. Viral load suppression increased from 90% in males and 91% in females in 2017 to 96% and 97%, respectively in 2020 [15].

The Ministry of Health medication-dispensing locker pilot has started in high-volume sites in two regions and will evaluate viral suppression among HIV/NCD clients and the extent of hypertension and diabetes control. These findings will inform future directions, including potentially involving private pharmacies.

2.1.2 | Programme outcomes

Eighty-three PEPFAR-supported facilities and 721 functional community distribution points implemented CHCD during the study period. The 26,776 clients enrolled represent people living with and without HIV; 63% female and 4% below 15 years of age. Accounting for additional clients who spontaneously present to care, a total of 28,851 clients received medicines through CHCD in Eswatini during the study period. Less than 10% of all clients receiving ART from facilities that conduct CHCD collected medications from PUPs. Only 1% of CHCD

clients missed appointments in this programme compared to 7% who missed appointments for facility-based refills.

2.1.3 | Programme challenges

The low percentage of clients collecting ART from PUPs is thought due to perceived HIV-related stigma as CHCD was initially designated only for people living with HIV. While client preference for facility-based refills has decreased with the standardized integration of glucose testing and hypertension medication refills across CHCD sites, some people living with HIV who require more comprehensive medical management continue to prefer facility-based care.

Due to supply chain difficulties resulting in low NCD medication supply, clients sometimes purchase from private pharmacies or receive only 1-month supplies from CHCD.

The lack of funding for client transportation is another challenge. Financial sustainability is an ongoing challenge as much of its funding is from implementing partners.

2.2 | South Africa: Central Chronic Medicines Dispensing and Distribution

2.2.1 | Programme design

Launched in 2014, South Africa's National Department of Health's Central Chronic Medicine Dispensing and Distribution (CCMDD) flagship programme for national health insurance provides people with well-controlled NCDs and people living with HIV with virologic suppression with medications to control chronic diseases, including HIV via community-based PUPs, facility "fast lanes" and adherence clubs. Now expanded nationally, the programme has more than 4.9 million clients registered [16]. CCMDD is fully funded through the South African government, the Global Fund and PEPFAR, ensuring no out-of-pocket payments for medications or testing commodities. Transportation subsidies are not offered.

CCMDD governance incorporates the Ministerial National Essential Medicines List Committee, the Pharmaceutical Therapeutics Committees, a National CCMDD Task Team, provincial and district task teams, and facilities committees. CCMDD uses public-sector health facilities, 6-month medication prescriptions and private-sector partnerships to promote programme sustainability. Through contracted private sector central medication dispensing and private couriers, it reaches 2855 PUPs at independent and community pharmacies, doctors' rooms, smart lockers and participating retailers.

CCMDD eligibility criteria include people ages 18 years and older, on medical treatment for at least 6 months, clinician confirmation of client eligibility and client's voluntary desire to participate; tuberculosis or other medical conditions requiring regular clinical consultation are exclusionary [17].

Pre-dispensed medications are provided through differentiated models, facility- or community-based adherence clubs and external PUPs, including private pharmacies, lockers and community points [18]. Person-centred innovations include clients selecting their own language for written medication instructions; clients deciding where they want to collect their medicine parcel; clients choosing the exact date of medication pickup (within a 7-day window); and client feedback informing the design of medication packaging and labelling.

Community representatives identify potential PUPs, provide input to programmatic standard operating procedures, ensure that client concerns are responded to and ensure that medication shortages are promptly reported.

A recent multisite study of 1642 CCMDD participants living with HIV who were virally suppressed at the time of enrolment evaluated the impact of PUP type on maintaining 12-month virologic suppression. The choice of PUP, whether community-based ART PUPs (i.e. private pharmacies, schools and churches) or facility-based ART PUP (separate fast-track lane), was not significantly associated with virologic suppression, with 86% of participants with viral load data available maintaining viral suppression [19].

CCMDD aimed to reduce perceived stigma for people living with HIV in participating private pharmacies by integrating NCD/ART medication pickup, using uniformly labelled medication packages, and ensuring visual and audio privacy in dispensing areas [20].

2.2.2 | Programme outcomes

By October 2021, more than 3.2 million people were registered on the CCMDD programme with 2,645,945 (83%) recipients receiving ART and other chronic disease medications, and 556,625 (17%) receiving only chronic disease medications [18]. The most commonly prescribed NCD medications for people living with HIV are for hypertension (35.4%), diabetes (12.0%) and angina (8.7%); less commonly prescribed medications are for asthma/chronic obstructive pulmonary disease, chronic kidney disease and mental health disorders (Table 1).

Less than 1% of prescriptions for people living with HIV are for family planning and depressive disorder; plans to scale up prescribing for these components are underway. Isoniazid preventive therapy accounts for only 4.4% of prescriptions for people living with HIV because most of these clients have already completed this therapy by the time of CCMDD enrolment. Future plans include incorporating insulin and tuberculosis screening and treatment into CCMDD.

By October 2021, among those receiving ART and other chronic disease medications, 25% utilized facility PUPs, 19% participated in adherence clubs and 56% used external PUPs. Of note, many clients originally assigned to adherence clubs in the pre-COVID era collected medications through facility PUPs due to limitations of COVID-19 lockdown regulations discouraging social gatherings during this timeframe [18]. Community-based PUPs were prioritized in response to COVID-19 precautions, with the proportion of clients using community-based PUPs increasing from 36% to 56% from January 2020 to May 2021 [17].

Seventy-seven percent of CCMDD clients report less than 5-minute waiting times, compared to average wait times of 4–6 hours at public facilities.

2.2.3 | Programme challenges

CCMDD has been transitioning to web-based electronic prescribing because hand-written prescriptions were found to be more frequently rejected for incorrect medication dosage, incomplete instructions, illegibility, lack of clinician signature

Table 1. Most common comorbidities among people living with HIV on ART in South Africa's Chronic Medicines Dispensing and Distribution: January, 2016–December, 2021 (total exceeds 100% as some people obtain medications for more than one NCD)

Condition	Number of people living with HIV who also received medications for other conditions (% of total 2,645,945 people living with HIV enrolled in CCMDD during this period)
Hypertension	936,564 (35.4%)
Diabetes	316,707 (12.0%)
Angina	229,098 (8.7%)
Isoniazid preventive therapy	116,028 (4.4%)
Osteoarthritis	87,500 (3.3%)
Ischaemic heart disease	82,170 (3.1%)
Pain	58,493 (2.2%)
Congestive cardiac failure	42,101 (1.6%)
Asthma	32,690 (1.2%)
Hyperlipidaemia	31,259 (1.2%)
Epilepsy	27,950 (1.1%)
Depressive disorder	12,697 (0.5%)
Family planning	9999 (0.4%)

Abbreviations: ART: antiretroviral therapy; NCD: non-communicable disease; CCMDD, Central Chronic Medicine Dispensing and Distribution.

or because they were written for a medication that was not on the CCMDD formulary. Web-based prescriptions have significantly decreased the amount of rejected prescriptions. To date, the electronic system has only been rolled out to certain Districts, but funds have been secured for 2023–2024 to roll out the electronic system to the remaining 1026 facilities.

South Africa's energy crisis causing disruptions in electricity availability negatively impacted the repacking of electrified smart lockers, and additional batteries were added to these units. The lack of internet connectivity in some facilities is another country challenge which impacts the use of web-based prescribing.

Client feedback collected through monitoring and evaluation revealed people living with HIV experienced stigma from private sector site employees, including negative attitudes from staff when handing out medication parcels, and CCMDD clients being made to wait while private sector clients were serviced first. Specific PUPs were identified and client perceptions of stigma were discussed during routine quarterly meetings with each PUP team. Trainings were implemented for the affected PUP teams and sites were monitored for improvement. If client feedback did not improve, the PUPs were considered for closure. Subsequent monitoring and evaluation have shown marked improvements in perceptions of service.

Additional challenges at private sector sites included the lack of sufficient storage space, particularly at popular PUPs with more than 2000 clients. When PUPs reach capacity, they are temporarily unavailable in the electronic system until storage issues stabilize.

3 | CONCLUSIONS

Decentralized drug distribution, a client-centred approach that adapts medication delivery to better serve individual needs and decongest centralized health facilities, permits the

efficient integration and delivery of NCD care and has the potential to reduce healthcare costs borne by clients with multiple comorbidities. Eswatini and South Africa demonstrate scalable programmes for HIV and NCD integration through decentralized drug distribution programming. Public–private partnerships among government agencies, health ministries, non-governmental agencies, federal programmes and international donors were crucial to the success of both programmes, as was the absence of out-of-pocket costs to clients in both programmes.

Because of the different time periods of data available, direct inter-programme comparisons are not possible. However, one common theme is both programmes' use of HIV and NCD medication co-dispensing to reduce HIV-related stigma around use of community PUPs. In Eswatini's programme, initially designated for people living with HIV without comorbidities, clients were at first discouraged from utilizing community-based PUPs due to perceived stigma, but NCD care was included with the hope of decreasing stigma and improving uptake. In South Africa, despite CCMDD's provision of both ART and NCD medications for people living with HIV since programme inception, clients still reported HIV stigma from providers at private sector sites; this was later resolved with staff training. Integration of ART and NCD medications alone is not sufficient to address HIV-related stigma, and investments in trainings and close monitoring and supervision are necessary. However, the integration of services may help alleviate the challenges.

Another factor in both programmes' success was the use of community leaders and Expert Clients in the community throughout programme design and implementation—to select PUP sites; to enrol clients; and to ensure client complaints were adequately addressed—which allowed for person-centred service delivery models that are continuously adapted and modified to respond to client needs, comfort and convenience.

These data confirm the high prevalence of hypertension and diabetes, among other NCDs, among people living with HIV in South Africa's CCMDD. However, this analysis is limited by a lack of data from Eswatini's CHCD on clients' HIV status and by the lack of NCD prevalence data among people living with HIV. Additional analysis is needed to better understand factors contributing to Eswatini's low rate of PUP utilization for ART clients; to evaluate whether programme expansion to include people living with HIV with well-controlled comorbidities has increased PUP utilization for ART; and to identify other successful strategies to increase PUP use. Future studies should evaluate the impact of sex on programme participation and HIV outcomes data; provide HIV outcomes data; and detail the programmatic impact on HIV retention in care.

Further evaluation to help inform other countries' plans for integrated HIV/NCD drug distribution programmes includes analysis of factors correlated with improved retention in care; patterns of service uptake or site preferences among people living with HIV compared to people with NCDs; analysis of HIV clinical outcomes by mode of decentralized drug distribution (DDD) programme utilized and by demographic factors, including gender and age, including risk factors for loss of viral suppression; and client preference data on stigma, provider trust and factors influencing the choice of facility type.

PEPFAR's infrastructure is successfully utilized to support NCD and HIV integration through decentralized drug distribution, including the establishment of data systems, supply chain, policies and regulations to support dispensing outside of facilities; joint training systems and materials; demand creation; and engaging stakeholders. To bolster programme uptake in southern Africa, additional reporting of integrated NCD and HIV decentralized drug distribution models is needed on client-level clinical outcomes, including blood pressure and glycaemic control, HIV, including 95-95-95 benchmarks, and longer-term mortality trends through modelling studies.

AUTHORS' AFFILIATIONS

¹Office of HIV/AIDS, USAID, Washington, DC, USA; ²Global HIV, Hepatitis and Sexually Transmitted Infections Programmes, World Health Organization, Geneva, Switzerland; ³Eswatini National AIDS Program, Mbabane, Eswatini; ⁴ICAP, Columbia University, Mbabane, Eswatini; ⁵National Department of Health, Pretoria, South Africa; ⁶FHI 360, Durham, North Carolina, USA; ⁷Resolve to Save Lives, Abuja, Nigeria; ⁸ICAP, Columbia University Mailman School of Public Health, New York, New York, USA

COMPETING INTERESTS

No competing interests to report.

AUTHORS' CONTRIBUTIONS

DG: conceptualization; writing—original draft; writing—review & editing. NF: writing—review & editing. NK: investigation; writing—review & editing. MM: investigation; writing—review & editing. LN: writing—review & editing, project administration. KO: writing—review & editing. HK: writing—review & editing. TM: conceptualization, writing—review & editing. MB: Supervision, writing—review & editing. All authors have approved the final version of the manuscript.

ACKNOWLEDGEMENTS

None.

DISCLAIMER

This does not represent the opinion of USAID or the U.S. Government.

REFERENCES

1. UNAIDS. HIV and ageing. UNAIDS Programme Coordinating Board (39)/16.26. Issue date: 22 November 2016. Thirty-Ninth Meeting. 6–8 December 2016. Available from: https://www.unaids.org/sites/default/files/media_asset/20161125_UNAIDS_PCB39_HIV-Ageing_EN.pdf. access: October 1, 2022.
2. Smit M, Olney J, Ford NP, Vitoria M, Gregson S, Vassall A, et al. The growing burden of noncommunicable disease among persons living with HIV in Zimbabwe. *AIDS*. 2018;32(6):773–82.
3. Kibuuka H, Musingye E, Mwesigwa B, Semwogerere M, Iroezindu M, Bahemana E, et al.; AFRICOS Study Group. Predictors of all-cause mortality among people with HIV in a prospective cohort study in East Africa and Nigeria. *Clin Infect Dis*. 2022. Sep 10;75(4):657–664. <https://doi.org/10.1093/cid/ciab995> Epub ahead of print
4. Patel P, Rose CE, Collins PY, Nuche-Berenguer B, Sahasrabudde VV, Peprah E, et al. Noncommunicable diseases among HIV-infected persons in low-income and middle-income countries: a systematic review and meta-analysis. *AIDS*. 2018;32(Suppl 1):S5–20.
5. Chang D, Esber A, Dear N, Iroezindu M, Bahemana E, Kibuuka H, et al. Non-communicable diseases in older persons living with and without HIV in four African countries [abstract]. Presented at International Workshop on HIV & Aging; 2021 Sep 23–24. Abstract 0–7. Available from: <https://academicmedicaleducation.com/meeting/international-workshop-hiv-aging-2021/abstract/o-7-chang-david-non-communicable-diseases>. Accessed: October 3, 2022.
6. Gouda HN, Charleson F, Sorsdahl K, Ahmadzadeh S, Ferrari AJ, Erskine H, et al. Burden of non-communicable diseases in sub-Saharan Africa, 1990–2017: results from the Global Burden of Disease Study 2017. *Lancet Glob Health*. 2019;7:e1375–87.
7. Njuguna B, Vorkoper S, Patel P, Reid MJ, Vedanthan R, Pfaff C, et al. Models of integration of HIV and noncommunicable disease care in sub-Saharan Africa: lessons learned and evidence gaps. *AIDS*. 2018;32(Suppl 1):S33–42.
8. McCombe G, Lim J, Hout MCV, Lazarus JV, Bachmann M, Jaffar S, et al. Integrating care for diabetes and hypertension with HIV care in sub-Saharan Africa: a scoping review. *Int J Integr Care*. 2022;22(1):1–22.
9. Ford N, Eshun-Wilson I, Ameyan W, Newman M, Vojnov L, Doherty M, et al. Future directions for HIV service delivery research: research gaps identified through WHO guideline development. *PLoS Med*. 2021;18(9):e1003812.
10. Rohwer A, Uwimana Nicol J, Toews I, Young T, Bavuma CM, Meerpohl J. Effects of integrated models of care for diabetes and hypertension in low-income and middle-income countries: a systematic review and meta-analysis. *BMJ Open*. 2021;11:e043705.
11. Bukenya D, Van Hout M-C, Shayo EH, Kitabye I, Junior BM, Kasidi JR, et al. Integrated healthcare services for HIV, diabetes mellitus and hypertension in selected health facilities in Kampala and Wakiso districts, Uganda: a qualitative methods study. *PLOS Glob Public Health*. 2022;2(2):e0000084.
12. Van Hout MC, Bachmann M, Lazarus JV, Shayo EH, Bukenya D, Picchio CA, et al. Strengthening integration of chronic care in Africa: protocol for the qualitative process evaluation of integrated HIV, diabetes and hypertension care in a cluster randomised controlled trial in Tanzania and Uganda. *BMJ Open*. 2020;10(10):e039237.
13. Eswatini Ministry of Health. HIV annual performance report. Mbabane: Eswatini Ministry of Health, Monitoring, and Evaluation Unit, Strategic Information Department; 2020.
14. Meeting Targets and Maintaining Epidemic Control (EpiC) and FHI 360. Leveraging the DDD infrastructure to provide integrated HIV/NCD care [webinar]. Durham, NC: FHI 360; 2022.
15. Kisyeri N, Gulwako S, Kamiru H, Preko P, Reidy W, Rabkin M, et al. Differentiated service delivery in Eswatini: adaptation, scale-up and monitoring. Poster presented at AIDS. July, 2022, Montreal, Canada. Available from: <https://programme.aids2022.org/Abstract/Abstract/?abstractid=6379>. Accessed: October 1, 2022.
16. Liu L, Christie S, Munsamy M, Roberts P, Pillary M, Shenoi SV, et al. Expansion of a national differentiated service delivery model to support people living with HIV and other chronic conditions in South Africa: a descriptive analysis. *BMC Health Serv Res*. 2021;21:463.
17. Pini Z. Providing HIV, diabetes and hypertension treatment refills outside of health facilities in South Africa. Presented July, 2021 virtually at IAS 2021.

18. Manganye M. Differentiated service delivery for people with HIV and non-communicable diseases: South African policy enabler for integration. Presented July, 2022 at AIDS; Montreal, Canada.
19. Bassett IV, Yan J, Govere S, Khumalo A, Shazi Z, Nzuzi, et al. Does type of pickup-point influence 12-month virologic suppression in South Africa? Poster 1039. Presented at CROI 2023; Seattle, Washington.
20. Dorward J, Msimango L, Gibbs A, Shoji H, Tonkin-Crine S, Hayward G, et al. Understanding how community antiretroviral delivery influences engagement in HIV care: a qualitative assessment of the Centralised Chronic Medication Dispensing and Distribution programme in South Africa. *BMJ Open*. 2020;10:e035412.

SHORT REPORT

Facilitating person-centred care: integrating an electronic client feedback tool into continuous quality improvement processes to deliver client-responsive HIV services in the Democratic Republic of Congo

Cyprien Tendo-Bugondo^{1, #}, Osée Lieke², Pierre Kasongo³, Baudouin Diur⁴, Davina S. Canagasabay^{5, §, #} , Ibou Thior^{5, #}, Pascal K. Milenge² and Jean-Claude Kiluba¹

§ **Corresponding author:** Davina S. Canagasabay, 455 Massachusetts Avenue NW, Suite 1000, Washington, DC 20001, USA. (dcanagasabay@path.org)

These authors have contributed equally to the work.

Abstract

Introduction: Engaging communities in the design, implementation and monitoring of health services is critical for delivering high-quality, person-centred services that keep people living with HIV engaged in care. The USAID-funded Integrated HIV/AIDS Project in Haut-Katanga (IHAP-HK) integrated an electronic client feedback tool into continuous quality improvement (CQI) processes. We aimed to demonstrate this system's impact on identifying and improving critical quality-of-care gaps.

Methods: Through stakeholder and empathy mapping, IHAP-HK co-designed a service quality monitoring system—comprising anonymous exit interviews and ongoing monitoring through CQI cycles—with people living with HIV, facility-based providers and other community stakeholders. IHAP-HK trained 30 peer educators to administer oral, 10- to 15-minute exit interviews with people living with HIV following clinic appointments, and record responses via the KoboToolbox application. IHAP-HK shared client feedback with facility CQI teams and peer educators; identified quality-of-care gaps; discussed remediation steps for inclusion in facility-level improvement plans; and monitored implementation of identified actions. IHAP-HK tested this system at eight high-volume facilities in Haut-Katanga province from May 2021 through September 2022.

Results: Findings from 4917 interviews highlighted wait time, stigma, service confidentiality and viral load (VL) turnaround time as key issues. Solutions implemented included: (1) using peer educators to conduct preparatory tasks (pre-packaging and distributing refills; pulling client files) or escort clients to consultation rooms; (2) limiting personnel in consultation rooms during client appointments; (3) improving facility access cards; and (4) informing clients of VL results via telephone or home visits. Due to these actions, between initial (May 2021) and final interviews (September 2022), client satisfaction with wait times improved (76% to 100% reporting excellent or acceptable wait times); reported cases of stigma decreased (5% to 0%); service confidentiality improved (71% to 99%); and VL turnaround time decreased (45% to 2% informed of VL results 3 months after sample collection).

Conclusions: Our results showed the feasibility and effectiveness of using an electronic client feedback tool embedded in CQI processes to collect client perspectives to improve service quality and advance client-responsive care in the Democratic Republic of Congo. IHAP-HK recommends further testing and expansion of this system to advance person-centred health services.

Keywords: person-centred care; quality improvement; client feedback; digital tools; peer-led; HIV

Received 13 October 2022; Accepted 9 May 2023

Copyright © 2023 The Authors. *Journal of the International AIDS Society* published by John Wiley & Sons Ltd on behalf of the International AIDS Society. This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

1 | INTRODUCTION

Comprehensive community engagement is critical for delivering high-quality, person-centred care (PCC) that supports the continued engagement of people living with HIV in care and facilitates better health outcomes. PCC is critical to achieving high quality of care, improving clinical outcomes and pro-

moting quality of life [1], with Berwick noting that “the experience of patients” should serve as “the fundamental source of the definition of quality [2].” Understanding patient satisfaction is increasingly recognized as critical for improving continuity in HIV care and enhanced outcomes [3,4], especially in the context of differentiated HIV service models [5]. Client feedback mechanisms are included in HIV-PCC frameworks,

with the literature noting “client feedback mechanisms [to be] integral components...and hold potential for people to shape services based upon their own needs [6,7].” Numerous studies have also highlighted the efficacy of using continuous quality improvement (CQI) to improve healthcare quality [8], including to promote person-centred HIV services [9–11].

We consider person-centred HIV care to be HIV services that are informed by and respect the expressed preferences of people living with HIV. Through the US Agency for International Development-funded Integrated HIV/AIDS Project in Haut-Katanga (IHAP-HK) in the Democratic Republic of Congo (DRC), we aimed to co-design a client feedback tool with people living with HIV and healthcare providers and deploy it as part of a service quality monitoring system to facilitate person-centred HIV services at project-supported facilities.

This paper describes the electronic client feedback tool and its integration into CQI processes to ensure facility-level service delivery and quality improvement (QI) initiatives reflect client perspectives. It aims to demonstrate the feasibility and effectiveness of this service quality monitoring system in identifying and addressing quality-of-care gaps not aligned with client needs and preferences.

2 | METHODS

2.1 | Application of human-centred design to create feedback tool

IHAP-HK applied human-centred design, using PATH’s Living Labs approach [12], to co-create a service quality monitoring system to ensure that community priorities drove intervention design. Using stakeholder mapping to ensure a representative sampling of perspectives was included during design, IHAP-HK convened 20 individuals (five community-based organization representatives; four facility-based providers; eight people living with HIV; two DRC Ministry of Health representatives; and one religious leader) to co-design a client feedback tool.

The group opted to use an anonymous, electronic exit interview to gather client feedback. IHAP-HK used empathy mapping [13]—a process for gathering user insight on their experiences with services or products—with stakeholders to identify frequent pain points encountered by clients and prioritize service delivery aspects the exit interview should focus on. Empathy maps are created in early design stages, following initial research and before ideation, to help design teams better understand clients being reached [14].

Stakeholders drafted interview questions in small groups, with draft questions finalized together in a large group and validated by the MOH. The final questionnaire comprised the following questions:

- **Wait time:** How long did you wait before being received by a healthcare provider?
- **Medication dispensing:** Did you receive all prescribed medications?

- **Provider attitude:** What was the provider’s attitude towards you? Did you feel stigmatized by facility staff? Were services offered to you in complete confidentiality?
- **Viral load (VL) services:** Have you had a VL sample taken in the past 6 months? Did you receive your results, and if so, how long did it take to receive your results?
- **Recommendations:** Do you have suggestions to improve the quality of services received?

The interview questionnaire was programmed in French and Swahili into the KoBoToolbox digital application (an open-source data collection tool used in low-resource environments). Thirty people living with HIV serving as peer educators (70% female) were trained to conduct exit interviews (ranging 10–15 minutes) and record responses into the application using project-supplied tablets or phones.

2.2 | Incorporation into CQI processes

To ensure that issues raised by clients were systematically addressed, we embedded the electronic client feedback tool into IHAP-HK’s facility-level CQI system. Figure 1 highlights how the tool was integrated into project CQI processes to create a continuous service monitoring feedback loop. IHAP-HK staff shared client feedback with facility QI teams and peer educators monthly to identify key quality-of-care challenges and client recommendations. IHAP-HK staff, facility QI teams and peer educators then brainstormed approaches to address challenges, implemented these strategies and monitored the impact on identified challenges, following a Plan-Do-Study-Act methodology [15] to iteratively assess impact through data gathered via the electronic client feedback tool and adjust solutions over time. Successful strategies were also shared among IHAP-HK facility QI teams during quarterly learning sessions for adoption at other facilities with similar care challenges.

2.3 | Data capture and analysis

IHAP-HK tested this service quality monitoring system at eight project-supported, high-volume healthcare facilities across six health zones of Haut-Katanga. To mitigate selection bias, all clients were offered the opportunity to provide feedback following clinic appointments. We analysed anonymous interview data collected between May 2021 and September 2022, using descriptive statistics and Stata 13.1 to compare results between initial interviews (May 2021) and final interviews (September 2022) to understand changes in perceived client satisfaction against prioritized service delivery components/questionnaire variables during system implementation (outcome measure). Our analysis included testing for equality of median waiting time distribution across exit interviews using the Kruskal-Wallis test and recoding clients’ suggestions to identify additional service quality challenges and recommended solutions.

Client participation was voluntary, with clients invited to participate for QI purposes; individual verbal consent was obtained before interviews were administered. Ethical approval was not required as interviews were used to yield

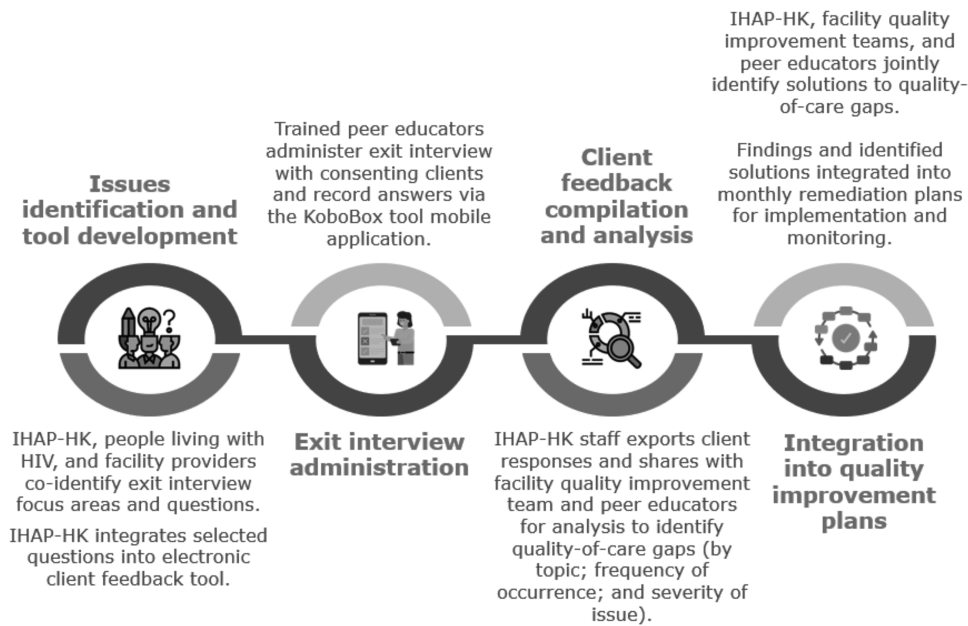


Figure 1. Service quality monitoring feedback loop. Abbreviation: IHAP-HK, International Development-funded Integrated HIV/AIDS Project in Haut-Katanga.

knowledge used for immediate local action through project CQI activities.

3 | RESULTS

Four thousand nine hundred and seventeen exit interviews were conducted with clients receiving antiretroviral treatment (ART) at pilot facilities. Most clients providing feedback were female (65%) and the median age was 38 (interquartile range [29–47]), both reflective of the general composition of IHAP-HK’s ART cohort.

3.1 | Quality gaps and QI solutions

Clients identified appointment wait times, stigma, confidentiality and VL services (specifically long turnaround times [TAT]) as the highest priority issues to be addressed at these facilities, which align with service delivery aspects that tend to be predictors of client satisfaction [16–18]. Additional recommendations included more flexible physical access to facility compounds and more welcoming waiting rooms.

IHAP-HK, people living with HIV and facility QI teams identified and integrated the following solutions to address identified quality gaps:

- **Long wait time:** (1) leveraging peer educators to conduct appointment preparatory tasks (e.g. pulling medical records; pre-packaging medications); (2) coaching providers to use appointment agendas to better triage needed services for clients for; (3) escorting clients to consultation rooms, pharmacies and/or laboratories; (4) improving waiting room conditions (e.g. providing chairs).
- **Reported stigma:** (1) removing HIV status from access cards used by clients to enter facilities; (2) in-service

coaching for providers on delivering services in a non-stigmatizing manner.

- **Confidentiality:** limiting individuals permitted in consultation rooms during client appointments (e.g. essential providers; caregivers).
- **Long TAT for VL results:** (1) conducting daily follow-up with the two referral laboratories to ensure timely analysis of IHAP-HK client samples; (2) providing results to clients on 3- to 6-month ART dispensing by short message service, telephone call or home visits, based on client preference.

3.2 | Outcomes

Implementing QI solutions led to observed improvements to quality-of-care gaps between initial and final interviews.

3.2.1 | Wait time

Median wait time during initial interviews ranged from 5 to 9 minutes, with significant variability; the longest reported wait time was 3 hours. The mean and median wait times reported at final interviews was 7 minutes; the longest wait time was 17 minutes.

Reported client satisfaction with wait times improved, with 100% reporting wait times to be excellent or acceptable (final) compared to 76% (initial).

3.2.2 | Reported stigma

The percentage of clients reporting that providers’ attitudes were not good decreased between initial and final interviews, from 9% to 1%. Similarly, the percentage of clients reporting cases of stigma decreased from 5% to 0%.

3.2.3 | Perceptions of confidentiality

Clients reported improved confidentiality during appointments, from 71% (initial) to 99% (final).

3.2.4 | VL services

In May 2021, only 11 clients reported receiving their VL results following sample collection, with 45% reporting a more-than-3-month TAT. In September 2022, 125 clients received their VL results, with only 2% after 3 months and 79% within 1 month, indicating decreased TAT.

4 | DISCUSSION

The use of this client-driven service quality monitoring system enabled IHAP-HK to pinpoint key HIV service and quality-of-care gaps and rapidly deploy solutions. After applying QI solutions to identified quality-of-care challenges, we observed decreases in client wait time, reported stigma and VL result TAT, and increases in client satisfaction with wait time and service confidentiality. This highlights our system's effectiveness in improving HIV service quality at targeted facilities, echoing similar findings from other studies on the use of client-driven CQI models to address service quality gaps, such as the use of Community Score Cards to improve services to prevent perinatally acquired HIV in Malawi [19], use of electronic self-interviews integrated into rapid QI process to improve client-provider relationships in Eswatini [20] and use of CQI cycles to minimize service delays at HIV clinics in Kenya [9].

This service quality monitoring system also enabled IHAP-HK to more rapidly flag and deploy corrective measures to address service delivery and quality issues. For example, exit interviews in early-mid May 2021 revealed that clients in one health zone were not receiving expected ART/cotrimoxazole refills. Within 1 week, IHAP-HK confirmed this was due to stock-outs, requested urgent re-supply and redistributed available stocks from nearby facilities to immediately provide clients with their medicines (compared to 1 month through normal commodity supply monitoring processes).

The use of peer educators to conduct preparatory tasks and escort clients was critical to improving the overall care experience while reducing provider administrative burden, enabling physicians and laboratory staff to provide timelier services. Our experience reinforces similar findings [21,22] on the increased role that peer educators can play in healthcare delivery—both in service monitoring to gather client feedback and service provision by helping to refine delivery models and provide punctual, higher-quality services.

4.1 | Limitations

Our study had several limitations. First, the integration of this feedback tool as part of the iterative CQI methodology precluded us from isolating which aspects of our QI solutions drove our results.

Second, the use of anonymous feedback that cannot be tied back to individual clients limited exploration of patient-level factors that may have affected service perception, such

as enrolment in differentiated care and/or duration on ART. Anonymous feedback also impeded assessing the number of unique clients participating in exit interviews, meaning the same clients could be providing feedback in successive periods. As this system was devised as part of programmatic CQI efforts, we did not capture metrics to understand those who declined participation and rationale, although some clients informally noted declining due to lack of time. These aspects prevented us from gauging the true acceptability of this tool for gathering client feedback and adequately identifying potential biases.

Finally, our pilot did not assess cost-effectiveness although measures were taken to minimize associated costs (e.g. leveraging existing peer educators; electronic [vs. paper-based] data capture via a free app that enabled real-time data availability and analysis through embedded visualization capabilities, which saved costs associated with manual data compilation and analysis).

With additional time, further analysis could assess the impact of implemented QI solutions on broader programmatic indicators, such as service continuity and VL coverage, to better assess the link between person-centred approaches and HIV service delivery outcomes.

5 | CONCLUSIONS

Our use of an electronic client feedback tool embedded in iterative CQI approaches as a client-driven service quality monitoring system proved to be feasible and effective at rapidly identifying and deploying solutions that led to improved perception of service quality by clients receiving HIV care at eight pilot facilities in DRC. These findings indicate our system's success in highlighting HIV service delivery aspects not aligned with client needs, enabling IHAP-HK to promote delivery models tailored to the preferences of people living with HIV. While this system holds promise to support the advancement of person-centred HIV services to meet HIV epidemic control goals in DRC, further testing is required to inform scalability. Critical next steps will be to expand testing of this system in other provinces and compare its effectiveness (including cost-effectiveness) with other client feedback systems used in DRC.

AUTHORS' AFFILIATIONS

¹PATH, Lubumbashi, Democratic Republic of the Congo; ²Independent Consultant, Lubumbashi, Democratic Republic of the Congo; ³Macro-Eyes, Kinshasa, Democratic Republic of the Congo; ⁴Union Congolaise des Organisations des Vivant avec VIH, Lubumbashi, Democratic Republic of the Congo; ⁵PATH, Washington, DC, USA

COMPETING INTERESTS

The authors declare that they have no competing interests or conflicts of interest to declare.

AUTHORS' CONTRIBUTIONS

CT-B, PK and OL led the creation, deployment and implementation of the electronic client feedback monitoring system, and PKM and J-CK provided technical input and leadership throughout the process on behalf of IHAP-HK. BD was heavily involved in co-designing the system as a representative from an association of

people living with HIV and conducted interviews as a peer educator at the Sendwe Center of Excellence. CT-B, PK and OL oversaw data compilation, and CT-B, OL and IT led data analysis. DSC, IT and CT-B conceived the paper, and DSC drafted the manuscript with contributions from IT and CT-B.

ACKNOWLEDGEMENTS

Although the authors remain solely responsible for this manuscript, this work benefited from the contributions and dedicated work of the 20 stakeholders involved in the co-creation process from the *Union Congolaise des Organisations des Vivant avec VIH*, World Production, *Réseau National d'Organisations Assises Communautaire*, Association of Women for Community Development, CRISEM, *Église du Christ au Congo*, *Programme National de Lutte contre le SIDA*, *Programme Multisectoral National de Lutte contre le SIDA*, Kamalondo General Referral Hospital (HGR) and Kenya HGR; the healthcare providers and QI teams at the eight pilot facilities (*Clinique Universitaire Lubumbashi*, Hakika HGR, Kamalondo HGR, Kampemba HGR, *Kasumablesa Douane* Referral Health Center, Kenya HGR, Rosalie Health Center and Sendwe Center of Excellence); and current and former IHAP-HK staff who supported electronic feedback tool design and operations, QI activities and data collection efforts, in particular Cecile Edambolo, Stella Muyano, Mireille Kawen, Gracia Tabu, Mamie Ngoie, Phacochère Kabwe, Simon Luisi, Thierry Mateta and Andre Kabongo. The authors would also like to thank Lisa Mueller Scott for her technical and editorial review. And finally, none of this work would have been possible without the tireless efforts and dedication of the following 30 peer educators conducting exit interviews across the eight facilities implementing the service quality monitoring system: Pauline Bitota; Baodouin Diur; Dorcas Esaho; Dorcas Ilunga; Carmel Mbelu Iwabeya; Béa Kabisa; Pascal Kakudji; Jelly Kalambay; Lyna Kalambayi; Kashiwa Kankelembwe; Bizuri Manassé; Sarah Kapinga; Françoise Kasongo; Henriette Kilufya Kiwaya; Bibiche Kimanu; Liliane Masengo; Mélanie Mpanga; Nanou Mpoyi; Jean Mubenga; Evelyne Mujinga; Anacleto Mulunda; Rosie Musao; Fernand Mutombo; Irene Mwika; Veronique Ndaya; Shango Omer; Benny Shonongo; Judith Tshabu; Pascaline Yav; and Ilunga Walk.

FUNDING

Financing for the work described in this article and the IHAP-HK project were made possible by the American people through the United States Agency for International Development (USAID CoAg. # AID-660-A-17-00001) and the US President's Emergency Plan for AIDS Relief.

DISCLAIMER

The views expressed herein and the contents of this manuscript do not necessarily reflect the views of the United States Agency for International Development or the United States government.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.







REFERENCES

1. Simmons S, Rahman A. Next steps for achieving person-centered care in nursing home. *J Am Med Dir Assoc*. 2014;15(9):615–9.
2. Berwick D. A user's manual for the IOM's "Quality Chasm" report. *Health Aff*. 2002;21(3):80–90.
3. Mukamba N, Chilyabanyama O, Beres L, Simbeza S, Sikombe K, Padian N, et al. Patients' satisfaction with HIV care providers in public health facilities in Lusaka: a study of patients who were lost-to-follow-up from HIV care and treatment. *AIDS Behav*. 2020;24(4):1151–60.

4. Bich ND, Westbrook RA, Black WC, Rodriguez-Barradas MC, Guirdano TP. Examining the link between patient satisfaction and adherence to HIV care: a structural equation model. *PLoS One*. 2013;8(1):e54729. <https://doi.org/10.1371/journal.pone.0054729>.
5. Grimsrud A, Barnabas R, Ehrenkranz P, Ford N. Evidence for scale up: the differentiated care research agenda. *J Int AIDS Soc*. 2017;20(Suppl 4):22024.
6. Duffy M, Madevu-Matson C, Posner J, Zwick H, Sharer M, Powell AM. Systematic review: development of a person-centered care framework within the context of HIV treatment settings in sub-Saharan Africa. *Trop Med Int Health*. 2022;27(5):479–93.
7. Davis K, Schoenbaum S, Audet AM. A 2020 vision of patient-centered primary care. *J Gen Intern Med*. 2005;20(10):953–7.
8. Taylor M, McNicholas C, Nicolay C, Darzi A, Bell D, Reed JE. Systematic review of the application of the plan-do-study-act method to improve quality in healthcare. *BMF Qual Saf*. 2014;23:290–8.
9. Nturibi EM, Mecha JO, May B, Makau G, Kaara F, Mwita R, et al. Promoting patient-centered care—a continuous quality improvement (CQI) initiative utilizing the Plan-Do-Study-Act (PDSA) cycle at a HIV care clinic in Kenya. *J Kenya Assoc Phys*. 2020;3(1):24–8.
10. Dougherty G, Boccanera R, Boyd MA, Gantt T, Ksaonka SC, Kasonde P, et al. A quality improvement collaborative for adolescents living with HIV to improve immediate antiretroviral therapy initiation at 25 health facilities in Zambia. *J Assoc Nurses AIDS Care*. 2021;32(6):701–12.
11. Doan A, Chau MHV, Nguyen T, Green K, Huong TTP, Kasonde P, et al. Caring for the whole person: transgender-competent HIV pre-exposure prophylaxis as part of integrated primary healthcare services in Vietnam. *J Int AIDS Soc*. 2022;25(Suppl 5):e25996.
12. PATH Living Labs Initiative [Internet]. Seattle, WA: PATH; 2022 [cited 2022 Oct 12]. Available from: <https://www.path.org/programs/mdht/living-labs-initiative/>
13. Gray D, Brown S, Macanujo J. *Gamestorming: a playbook for innovators, rule-breakers, and changemakers*. Sebastopol, CA: O'Reilly Media, Inc; 2010.
14. Curedale R. *Empathy maps: step-by-step guide* (2nd ed.). Topanga, CA: Design Community College Inc; 2019.
15. Taylor M, McNicholas C, Nicolay C, Darzi A, Bell D, Reed JE. Systematic review of the application of the plan-do-study-act method to improve quality in healthcare. *BMF Qual Saf*. 2014;23:290–8.
16. Saleem S, Ali S, Ghouri N, Maroof Q, Jamal M, Aziz T, et al. Patient perception regarding private and confidentiality: a study from the emergency department of a tertiary care hospital in Karachi, Pakistan. *Pak J Med Sci*. 2022;38(2):351–5.
17. Nikitha OS, Sushant MK. Client satisfaction of antiretroviral therapy service delivery: a cross-sectional study at an antiretroviral therapy center. *Int J Appl Basic Med Res*. 2021;11(2):14–20. https://doi.org/10.4103/ijabmr.IJABMR_46_20
18. Somi N, Dear N, Reed D, Parikh A, Lwilla A, Baemana E, et al. Perceived satisfaction with HIV care and its association with adherence to antiretroviral therapy and viral suppression in the African Cohort Study. *AIDS Res Ther*. 2021;18:89. doi: <https://doi.org/10.1186/s12981-021-00414-3>.
19. Latererra A, Callahn T, Msiska T, Woelk G, Chowdhary P, Gullo S, et al. Bringing women's voices to PMTCT CARE: adapting CARE's Community Score Card© to engage women living with HIV to build quality health systems in Malawi. *BMF Health Serv Res*. 2020;20(1):679.
20. Teasdale CA, Geller A, Shongwe S, Mafukidze A, Choy M, Magaula B, et al. Patient feedback surveys among pregnant women in Eswatini to improve antenatal care retention. *PLoS One*. 2021;16(3):e0248685.
21. Kebede H, Gesesew H, Mwanri L, Ward P. The impact of peer educators or community health workers on the progress of the UNAIDS 90-90-90 targets in Africa: a systematic review and meta-analysis protocol. *Int J Environ Res Public Health*. 2021;18(8):3917.
22. Born L, Wamulume C, Neroda K, Quiterio N, Giganti M, Morris M, et al. Evaluation of a task-shifting strategy involving peer educators in HIV care and treatment clinics in Lusaka, Zambia. *J Public Health Afr*. 2012;3(1):e3.

RESEARCH ARTICLE

Uptake of a patient-centred dynamic choice model for HIV prevention in rural Kenya and Uganda: SEARCH SAPPHIRE study

Jane Kabami^{1,2,§} , Elijah Kakande¹ , Gabriel Chamie³ , Laura B. Balzer⁴, Maya L. Petersen⁴, Carol S. Camlin⁵ , Marilyn Nyabuti⁶, Catherine A. Koss³, Elizabeth A. Bukusi⁶, Moses R. Kamya², Diane V. Havlir³  and James Ayieko⁶ 

§Corresponding author: Jane Kabami, P.O. Box 7475, Kampala, Uganda. Tel: +256706315810. (kabajane@yahoo.com)

Abstract

Introduction: Person-centred HIV prevention delivery models that offer structured choices in product, testing and visit location may increase coverage. However, data are lacking on the actual uptake of choices among persons at risk of HIV in southern Africa. In an ongoing randomized study (SEARCH; NCT04810650) in rural East Africa, we evaluated the uptake of choices made when offered in a person-centred, dynamic choice model for HIV prevention.

Methods: Using the PRECEDE framework, we developed a person-centred, Dynamic Choice HIV Prevention (DCP) intervention for persons at risk of HIV in three settings in rural Kenya and Uganda: antenatal clinic (ANC), outpatient department (OPD) and in the community. Components include: provider training on product choice (predisposing); flexibility and responsiveness to client desires and choices (pre-exposure prophylaxis [PrEP]/post-exposure prophylaxis [PEP], clinic vs. off-site visits and self- or clinician-based HIV testing) (enabling); and client and staff feedback (reinforcing). All clients received a structured assessment of barriers with personalized plans to address them, mobile phone access to clinicians (24 hours/7 days/week) and integrated reproductive health services. In this interim analysis, we describe the uptake of choices of product, location and testing during the first 24 weeks of follow-up (April 2021–March 2022).

Results: A total of 612 (203 ANC, 197 OPD and 212 community) participants were randomized to the person-centred DCP intervention. We delivered the DCP intervention in all three settings with diverse populations: ANC: 39% pregnant; median age: 24 years; OPD: 39% male, median age 27 years; and community: 42% male, median age: 29 years. Baseline choice of PrEP was highest in ANC (98%) vs. OPD (84%) and community (40%); whereas the proportion of adults selecting PEP was higher in the community (46%) vs. OPD (8%) and ANC (1%). Personal preference for off-site visits increased over time (65% at week 24 vs. 35% at baseline). Interest in alternative HIV testing modalities grew over time (38% baseline self-testing vs. 58% at week 24).

Conclusions: A person-centred model incorporating structured choice in biomedical prevention and care delivery options in settings with demographically diverse groups, in rural Kenya and Uganda, was responsive to varying personal preferences over time in HIV prevention programmes.

Keywords: antenatal; HIV prevention; outpatient and community; PEP; PrEP

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

Received 13 October 2022; Accepted 15 May 2023

Copyright © 2023 The Authors. *Journal of the International AIDS Society* published by John Wiley & Sons Ltd on behalf of the International AIDS Society. This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

1 | INTRODUCTION

Despite a significant reduction in the number of new HIV acquisitions globally, progress has slowed significantly with a drop of only 3.6% in 2021 compared to 2020 [1]. The coverage of HIV prevention interventions is still suboptimal among persons at risk of HIV highlighting the need of innovative approaches to increase HIV prevention coverage. Multiple biomedical HIV prevention options are now available, includ-

ing oral pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP), as well as long-acting injectable cabotegravir (CAB-LA) in some countries. Additional options in prevention service delivery include a choice of HIV testing modality (HIV rapid antibody test or self-test) and the option for clinic-based or out-of-facility delivery. Extensive literature documents the importance of offering choice as a cornerstone of patient-centred care delivery in other health contexts, such as reproductive health services [2–6]. In HIV prevention, multiple

discrete choice experiments (DCEs) have documented variation in stated prevention preferences, both between persons and settings, suggesting that a one-size-fits all approach to HIV prevention is unlikely to serve all patients well [7–9]. While existing literature supports the need to integrate patient choice as a core element of HIV person-centred delivery models, very little literature to date documents the choices in prevention product and delivery modality that people who identify themselves as at-risk for HIV actually make when presented with options [10, 11].

Further, effective integration of prevention options in HIV prevention delivery models requires understanding how to effectively embed choices within person-centred care. To address these gaps, we developed a Dynamic Choice HIV Prevention (DCP) delivery model that offers structured choices in product, HIV test modality and location of service delivery, together with patient-centred staffing, service provision and client support. Within one arm of the study, the intervention arm, we evaluated the uptake of a person-centred, DCP model among persons at risk of HIV identified at antenatal clinics (ANC), outpatient departments (OPD) and in the community in rural Uganda and Kenya (SEARCH: NCT04810650).

2 | METHODS

2.1 | Study setting, design and population

The study population includes persons randomized to the intervention arms of three ongoing pilot trials to evaluate the effect of DCP intervention versus the standard of care. The studies are being conducted in some of the highest seroprevalence areas in rural Southwestern Uganda and Western Kenya [12, 13]. The first trial recruited participants presenting to ANC; the second trial recruited from the OPD (primary care clinics) and the third trial recruited from the community (eight in Uganda villages and another eight in Kenya).

The inclusion criteria for the ANC, OPD and community trials were the same: HIV-negative status, age 15 years or more and current or anticipated HIV risk. Baseline HIV risk was assessed by asking potential participants if they were at risk for HIV using the country Ministry of Health PrEP screening tool and self-assessment. The Ministry of Health screener was country-specific and included questions about having a partner with HIV, diagnosis of a sexually transmitted infection, repeated use of PEP and sex in exchange for money (Supporting Information: SAPPHERE risk screening tool). Additionally, we asked participants to self-assess if they were currently at risk or anticipated being at risk in the next 3 months. Exclusion criteria were age less than 15 years, inability to provide consent or participation in another Sustainable East Africa Research in Community Health (SEARCH) study. Eligible participants were randomized to the patient-centred DCP intervention, described next, or the control, which included standard referrals to HIV prevention services.

2.2 | Study intervention

The person-centred “Dynamic Choice HIV Prevention” (DCP) implementation strategy for delivering existing evidence-

based, biomedical prevention interventions was developed using the PRECEDE framework for health promotion strategies to address “predisposing” factors (i.e. knowledge, attitudes or beliefs) that impact behaviour, “enabling” factors to facilitate behaviour and “reinforcing” factors that include consequences of following a behaviour (Table 1). Intervention components were selected based on qualitative and survey data and include structured choices in biomedical prevention product, HIV test modality and location of service delivery, together with person-centred staffing, service provision and client support. Specifically, the DCP model offers participants choices on prevention modality on an ongoing basis: oral PrEP or oral PEP, and the option to switch between products.

The intervention is being delivered using a person-centred approach designed to be sensitive and responsive to the choice and preference of the clients. The intervention is being delivered by clinical officers and nurses in the ANC and OPD and by community health workers (CHWs) who facilitate intervention by clinical officers from the local health centre in the community trial. All clinical and community health team staff (i.e. clinical officers, nurses, coordinators and health workers) are trained and equipped for HIV prevention care in the clinical setting, appropriate to their role. Service delivery is deliberately designed to be offered in a warm and friendly atmosphere aimed at making clients feel comfortable during the participant–provider interactions. The intervention is designed to enhance flexibility and convenience by presenting choice to participants with the following components:

- (a) Biomedical product choice: the option of oral PrEP or PEP.
- (b) Service location choice: the options of the location of service delivery, including home, clinic, other community locations and phone/virtual visits.
- (c) Testing choice: the options of HIV rapid blood test and oral-based self-testing (HIVST) with clinician-assisted testing in cases where participants need help during self-testing.
- (d) Refill duration choice: the option to select the duration of their refill (1–3 months) based on their personal preference which hinges on factors, such as travel.

2.3 | Measures

Demographics and self-reported use of any PrEP or PEP in the prior 6 months were collected by survey at the study baseline. At intervention visits weeks 4, 12 and 24, participant selection of structured choice of prevention option (PrEP, PEP, condoms only and no selection), HIV testing modality (oral self-test or clinician administered rapid antibody) and preferred location for next visit (clinic vs. out-of-facility) was recorded. At week 24, PrEP and PEP use and HIV risk (report of sexual partners with HIV or unknown status and/or self-identification as being at risk) for each of the prior 6 calendar months were assessed via a structured survey. Enrolment began in April 2021, and the data collection for week 24 concluded in March 2022.

Table 1. Person-centred, Dynamic Choice Prevention (DCP) delivery model.

Intervention	Population and frequency of delivery	Purpose
Education, case studies and discussion on concept of dynamic prevention and on the profile of each prevention option product	Health centre leadership and staff, clinicians, provided the initial and ongoing training and education to the study participants.	Predisposing
Dynamic Choice Prevention (DCP) package (risk assessment and choice of product, HIV testing, service delivery site and refill duration) integrated into ANC and OPD clinics, and through routine community health worker visits. Clients also receive support services for reproductive health and gender-based violence, travel packs and access to a 24-hour hotline for client logistical or medical questions.	Study participants at the visits to ANC, visits to OPD and in the communities served by the community health workers are offered the DCP with scheduled check-ins every 3 months or more frequently based on participants choice.	Enabling
Provider text or phone check-in to participant 1 week after starting new prevention product option, and supportive adherence counselling.	Participants are provided with a phone contact of the clinician/provider to consult and ask any questions during the study. This contact is available 24 hours/7 days per week. In addition, staff contact all participants who initiate PrEP or PEP by phone to assess adherence and any other concerns every 2 weeks in the first month, and monthly thereafter.	Reinforcing

Abbreviations: ANC, antenatal clinics; OPD, outpatient departments.

2.4 | Analysis

Visit attendance was assessed at weeks 4, 12 and 24 among participants enrolled in the three trials. We excluded all participants who seroconverted and withdrew from the trial. We evaluated the proportion of participants selecting each DCP option at each scheduled visit, and the proportion of participants who ever selected PrEP and PEP during 24-week follow-up at each of the three settings. The proportion of follow-up time covered by biomedical prevention (“biomedical covered time”) for a given participant was calculated as the number of months during which a participant reported PrEP or PEP use divided by the number of months for which self-reported use was assessed. Participants who acquired HIV were assumed not to be covered during the period prior to seroconversion. “At risk” biomedical covered time was calculated analogously, but restricted to months for which a participant reported HIV risk. We report mean, median, first quartile (Q1) and third quartile (Q3) of both measures across participants.

2.5 | Ethical considerations

Ethical approval to conduct the study was received from the University of California, San Francisco Committee on Human Research (UCSF—Sept 2020), Makerere University School of Medicine Research and Ethics Committee (SOMREC—March 2021), Uganda National Institute of Science and Technology (UNCST—April 2021) and the Scientific Ethical Review Unit of the Kenya Medical Research Institute (KEMRI—April 2021). All participants involved provided written consent to participate in the study.

3 | RESULTS

3.1 | Study population

A total of 612 (203 ANC, 197 OPD and 212 community) participants were randomized to the person-centred prevention intervention (Table 2 and Figure S1). The most common job was farming (ANC 32%, OPD 39% and community 42%); a substantial minority were students (9%, 15% and 18%, respectively). ANC participants were younger (52% aged 15–24 years) than participants in the OPD and community settings (39% and 36% aged 15–24 years, respectively). In the OPD and community trials, 39% and 42% of participants were male; 38% of ANC participants were pregnant at baseline. Despite the self-reported risk of HIV at study start, fewer than 10% of participants reported any use of PrEP or PEP in the 6 months prior to study enrolment (5% ANC, 10% OPD and 2% community).

3.2 | Visit adherence

Between baseline and week 24, 202/203 (99.5%) of participants in ANC, 192/197 (97.5%) in OPD and 210/212 (99.1%) in community settings remained eligible for intervention delivery (four withdrew and four seroconverted; zero died). At week 4 following randomization, 84% of ANC, 89% of OPD and 98% of eligible community participants were seen and offered a dynamic choice of product, test modality and location for the next visit. Visit adherence remained high across all trial settings at weeks 12 (95% ANC, 92% OPD and 91% community participants seen) and 24 (92% ANC, 89% OPD and 89% community).

Table 2. Baseline characteristics of 612 participants enrolled in the person-centred Dynamic HIV Choice Prevention (DCP) intervention in three trials: antenatal clinic (ANC), outpatient department (OPD) and the community.

	ANC n = 203	OPD n = 197	Community n = 212	Total N = 612
Country, n (%)				
-Kenya	103 (51)	97 (49)	110 (52)	310 (51)
-Uganda	100 (49)	100 (51)	102 (48)	302 (49)
Age 15–24, n (%)	106 (52)	76 (39)	76 (36)	258 (42)
Male, n (%)	0 (0)	77 (39)	88 (42)	165 (27)
Occupation^a, n (%)				
-Farmer	64 (32)	76 (39)	88 (42)	228 (37)
-Student	18 (9)	30 (15)	37 (18)	85 (14)
-Shopkeeper/market vendor	26 (13)	19 (10)	17 (8)	62 (10)
-Housewife	33 (16)	4 (2)	11 (5)	48 (8)
-No job	14 (7)	23 (12)	7 (3)	44 (7)
-Manual labour/construction	1 (0)	7 (4)	11 (5)	19 (3)
-Fishing/fishmonger	4 (2)	1 (1)	4 (2)	9 (1)
-Other	42 (21)	36 (18)	36 (17)	114 (19)
Marital status^a, n (%)				
-Single (unmarried)	49 (24)	51 (26)	64 (30)	164 (27)
-Married/cohabitating	154 (76)	136 (70)	134 (63)	424 (70)
-Divorced/separated/widowed	0 (0)	8 (4)	14 (7)	22 (4)
Alcohol use (any, prior 3 months), n (%)	14 (7)	24 (12)	20 (9)	58 (9)
Nights away^a in past 3 months, median [Q1,Q3]	0 [0,0]	0 [0,3]	0 [0,3]	0 [0,2]
Pregnant^a (female only), n (%)	80 (39)	3 (3)	11 (9)	94 (21)
Used PrEP/PEP in past 6 months, n (%)	11 (5)	19 (10)	5 (2)	35 (6)

^aMissing occupation for three participants, marital status for two participants, mobility (nights away) for 26 participants and pregnancy (among women) for seven participants.

Abbreviations: PrEP, pre-exposure prophylaxis; PEP, post exposure prophylaxis.

3.3 | Selections among dynamic prevention choices over time

At baseline, PrEP was selected as an initial prevention product by 98% of participants in ANC, 84% of participants in OPD and 40% of participants in the community (Figure 1); over the course of the 24-week follow-up, 100% of ANC, 86% of OPD and 50% of community participants selected PrEP at least once. The initial choice of PEP for HIV prevention was highest in the community setting (46%) compared to the OPD and ANC settings (9% and 1%, respectively). Selection of PEP remained highest in the community setting over time (23% at week 24); in the ANC and OPD settings, only 3% and 11%, respectively, ever selected PEP. In all settings, participant selection of an active biomedical prevention product (PrEP or PEP) declined over time (97% of ANC, 55% of OPD and 57% of community participants at week 24 selected either PrEP or PEP).

Participants from the three study settings differed in preference for visit location; off-site delivery of prevention services was initially selected by 93% of community participants, compared to 22% of ANC and 8% of OPD participants. Personal preference for off-site visits remained high in the community setting (99% at week 24) and increased over time in ANC and OPD (with 51% in ANC and 36% in OPD opting

for off-site delivery at week 24). Across the trials, the most common choice for off-site visits was homes (86%), followed by phone/virtual visits (7%), trading centres (2%) and schools (2%).

At baseline, HIV self-testing was selected by 34% of ANC participants, 26% of OPD participants and 52% of community participants. In all three settings, personal/individual interest in alternative HIV testing modalities increased over time (57% ANC, 52% OPD and 65% community at week 24).

3.4 | Biomedical covered time and dynamic risk

At week 24, the structured survey to assess the use of PrEP or PEP and HIV risk over the prior 6 months was completed by 91% (554/612) participants overall: 94% ANC participants, 87% OPD participants and 90% community participants. Mean biomedical covered time (proportion of 24-week follow-up during which a participant reported the use of either PrEP or PEP) was 80% in ANC (median 100%, Q1: 67%, Q3 100%), 60% in OPD (median 67%, Q1 33%, Q3 100%) and 32% in the community setting (median 0%, Q1 0%, Q3 67%). While all participants reported current or anticipated HIV risk at baseline, self-reported HIV risk experienced, assessed retrospectively at week 24, varied over time (Figure 2). Across the three trials, an average of 88% of

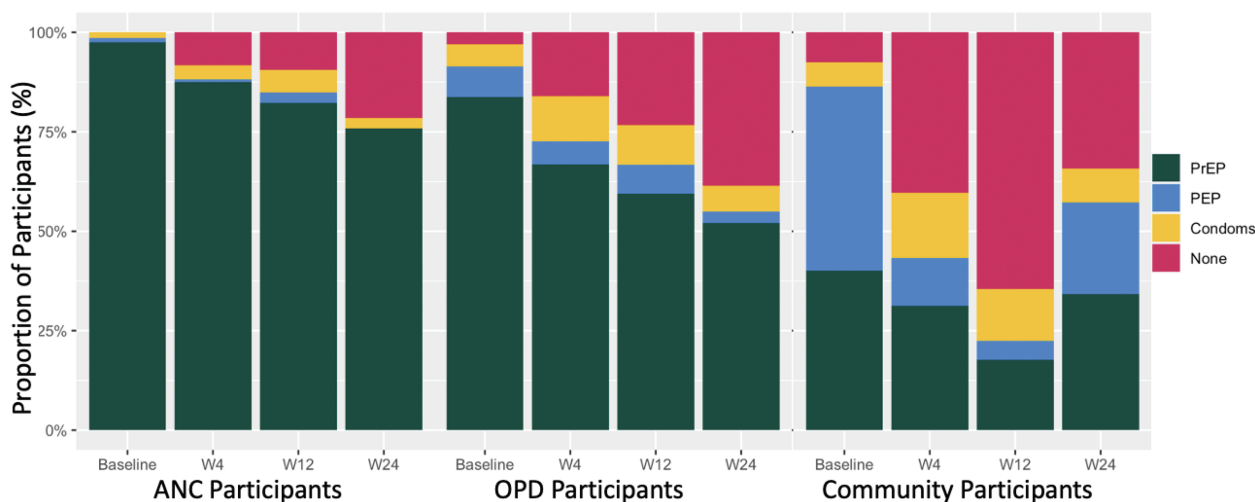


Figure 1. Choice of prevention options: (PrEP—pre-exposure prophylaxis; PEP—post exposure prophylaxis, condoms or nothing) with each bar representing choices among participants seen at baseline, week 4 (W4), week 12 (W12) and week 24 (W24) in the ANC (left), OPD (middle) and community (right) settings. The different colours represent the different preferences and choice of prevention option. Abbreviations: ANC, antenatal clinics; OPD, outpatient departments.

follow-up time at risk of HIV was covered by PrEP or PEP use in the ANC trial (median 100%, Q1 100%, Q3 100%), as compared to 75% in OPD (median 100%, Q1 50%, Q3 100%) and 42% in the community setting (median 17%, Q1 0%, Q3 100%).

4 | DISCUSSION

We implemented a person-centred model for dynamic choice in HIV biomedical prevention in three distinct settings with demographically diverse groups and found that uptake of intervention components, including product, product delivery and HIV testing modality, varied between locations and over time. This model was responsive to client preferences and resulted in higher retention in prevention services than has been observed in previous studies conducted among subgroups of high acquisition risk [14, 15].

We observed the highest uptake of biomedical prevention among women receiving services at ANC. Reflecting ongoing HIV risk, PrEP was the preferred option for nearly all women. As has been reported by others, PrEP use waned over time [16]. A Maternal Child Health ANC clinic platform for PrEP delivery presents built-in advantages, such as existing services for the prevention of perinatal transmission and integrated HIV testing and retesting of women living with HIV, as has been noted in previous studies [16]. These may have contributed to the high uptake and retention observed as compared to the OPD and community delivery approaches. Our ANC model further presented a choice of service location delivery and testing, women increasingly chose to receive PrEP via out-of-clinic delivery options over time, and utilize self-testing which enabled them to engage in biomedical prevention and monitor for HIV without having to travel to a clinic. This option may have been particularly convenient postpartum, when women were caring for one or more newborn

infants. Previous studies have reported increasing uptake of self-testing [17] due to convenience. In the Partners Demonstration Project sub-study, participants reported that HIVST between PrEP clinic visits reduced anxiety while waiting to return for a PrEP clinic visit [18]. In the Empower study, participants felt that HIVST between PrEP clinic visits empowered them economically by reducing costs of visiting the clinic for testing, restored trust and intimacy between sexual partners, addressed barriers, such as stigma, associated with accessing sexual health services and encouraged behaviours that prevent HIV acquisition, such as condom use [19]. Most recently, the JiPime-JiPrEP trial found that adherence and visit attendance were non-inferior among persons randomized to 6-monthly visits with HIVST versus standard of care [20].

Like in the ANC setting, persons in the OPD setting also preferred oral PrEP with a small proportion opting for PEP as the prevention option of choice at subsequent study visits. Surprisingly, unlike the ANC that has inbuilt retention mechanisms for subsequent pregnancy-related follow-up visits, we still observed a high proportion of participants accessing prevention at the OPD clinic setting, which may have been as a result of the patient-centred care delivery model. Participants also increasingly opted for out-of-facility delivery over time, possibly allowing for retention of those who would potentially have dropped off from care if service access was restricted to the clinic. As observed in the ANC clinic, the proportion of participants using the self-testing option increased with time, enhancing convenience and engagement in continued access to prevention services. We speculate that our uptake and retention was high as compared to other PrEP studies because we offered PrEP in HIV-status-neutral settings such as OPD and ANC as opposed to the standard practice of offering PrEP at the HIV clinic in these rural settings, a practice that is associated with increased stigma towards PrEP acknowledging that fear or worry of stigma have been expressed as motivations not to use PrEP [21].

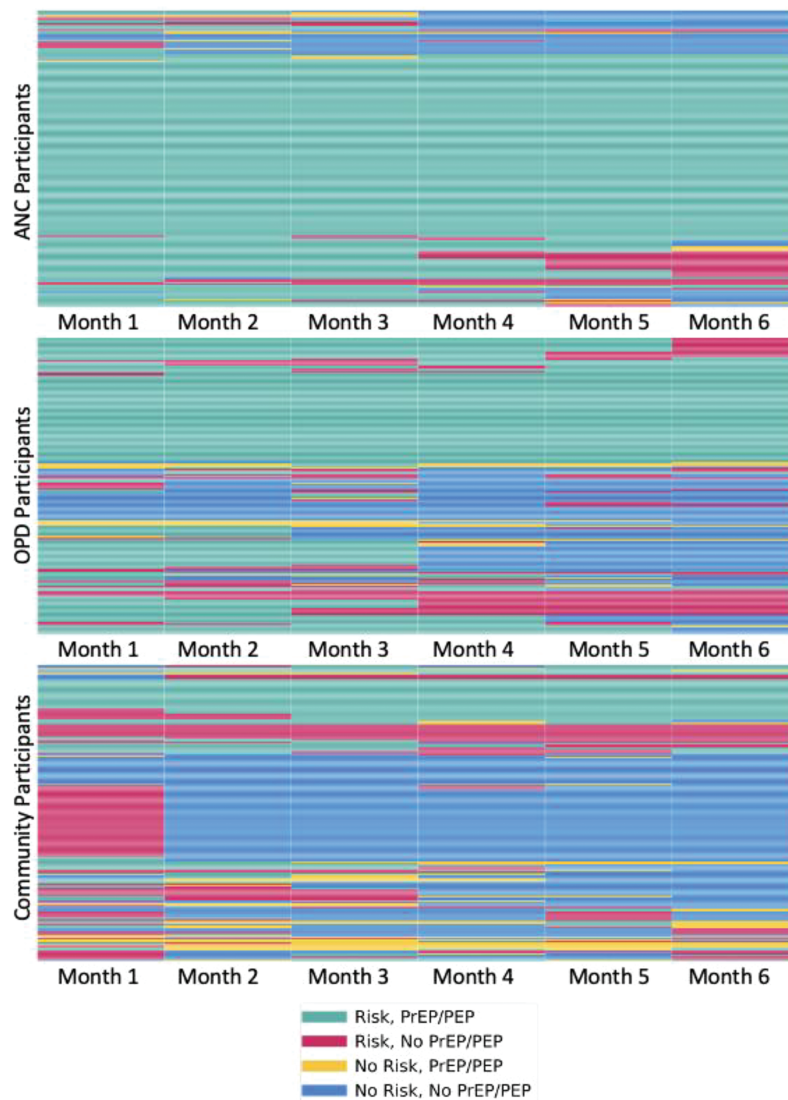


Figure 2. Heat maps of use of biomedical prevention by HIV risk over the 24-week follow-up period in the ANC (top), OPD (middle) and community (bottom) settings. Each row corresponds to a participant, and each column to a follow-up month. Green represents HIV risk with biomedical coverage (i.e. use of oral PrEP or PEP); red represents HIV risk without biomedical coverage; yellow represents no HIV risk but with biomedical coverage; and blue represents no HIV risk and no coverage. Abbreviations: ANC, antenatal clinics; OPD, outpatient departments.

In the community setting, overall uptake of biomedical prevention was much lower than in the two clinic-based settings. Unlike studies conducted using a community mobile clinic or at community locations besides the household that reported high acceptability [22, 23], our model delivered prevention at the household. We posit that the uptake was lower in this model compared to ANC and OPD because the household setting may not present a conducive environment to explore HIV risk and the selection and uptake of appropriate interventions because of unintended discussion of risky sexual behaviour to other family members in a largely conservative rural context. We observed the highest proportion of PEP as the choice for prevention at baseline for the community

model when compared to the ANC and OPD, but limited use of PEP during follow-up.

Our dynamic choice model included options for product, testing and delivery on the background of supportive patient-centred services. Training of providers and CHWs on offering choices without imposing their own views on what might be best for the client was an important part of the intervention. This training included not only the principles of choice but also case studies to illustrate how providers can support the agency for client decision-making. The training emphasized the delivery of warm patient-friendly services to foster provider–client trust in discussing HIV risk and the best available option without fear of feeling judged. All providers were

trained on patient-centred delivery prior to the baseline visit. There were monthly meetings of providers, as well as scheduled on-job booster trainings during the course of the study.

Our dynamic choice model increased biomedical covered time during self-reported HIV risk, but fell short of optimal coverage. The opportunity to add novel, emerging biomedical prevention products such as CAB-LA as one of the choices for prevention holds promise to increase HIV prevention covered time with this option that has been shown to have higher efficacy than oral PrEP and an ability to confer protection over an 8-week period following a single administration [24]. Previous studies have reported daily oral pill fatigue, forgetting to take the pill and the stigma associated with taking antiretroviral pills as some of the major barriers to uptake and adherence to oral PrEP [25, 26]. Injectable CAB-LA surmounts these barriers and is expected to increase prevention coverage for those at risk by altering the route and frequency of PrEP administration [28]. Furthermore, it is expected to enhance convenience and broaden the range of options in the HIV prevention toolkit [26, 27]. Reassuringly, CAB-LA trials have demonstrated safety with minor side effects being reported, the most common being injection site reactions that tended to decrease over time [24]. Presenting CAB-LA in different settings in the context of a patient-centred choice model holds promise to increase prevention coverage further for persons at risk of HIV exposure.

Our study has a number of strengths and weaknesses. It is among the first to provide evidence from the real world on biomedical choices selected when offered in different contexts (in contrast to theoretical choices via DCEs). Moreover, this study provides evidence of the implementation of PrEP and PEP in ANC, in OPD clinics (primary care settings) and in the community through a CHW-led model in regions with high HIV prevalence. It presented an opportunity to explore innovative delivery approaches and demonstrate the value of choice in HIV prevention. Limitations of this study include the short duration of follow-up and reliance on self-report. In other words, recall bias is a potential concern, which we aimed to minimize by including prompts in our surveys and limiting them to discrete periods (i.e. months). Additionally, the ongoing trial is confirming that clients were actually ingesting PrEP and PEP with objective biomarkers. In this interim analysis, we are able to show that prevention coverage increased from baseline over 24 weeks among intervention participants, but the comparison to a contemporary control population is lacking in this analysis. Upon each trial's completion, we will compare biomedical covered time, overall and during periods of risk, by the randomized arm; this will help quantify the effect of this model on uptake and retention over a longer duration. These results combined with ongoing qualitative studies of provider and client attitudes can shed light on contributions of various elements of our intervention.

5 | CONCLUSIONS

This is one of the first studies to systematically offer a structured intervention for biomedical prevention options using a theory-based, person-centred dynamic choice model that adapted services based on client risk and life circumstances

over time. This interim analysis demonstrated the intervention was successfully delivered in a variety of settings that are entry points for HIV prevention and can be adapted as new prevention options such as CAB LA become available.

AUTHORS' AFFILIATIONS

¹Infectious Diseases Research Collaboration, Kampala, Uganda; ²Department of Medicine, Makerere University, Kampala, Uganda; ³Department of Medicine, University of California, San Francisco, California, USA; ⁴Department of Biostatistics, University of California, Berkeley, California, USA; ⁵Department of Obstetrics, Gynecology & Reproductive Sciences, University of California, San Francisco, California, USA; ⁶Center for Microbiology Research, Kenya Medical Research Institute, Nairobi, Kenya

COMPETING INTERESTS

The authors report no competing interests in this work.

AUTHORS' CONTRIBUTIONS

JK, EK, CAK, MN and JA contributed to the study design, data analysis and interpretation, literature search and writing of the manuscript. LBB and MLP contributed to the study design, data analysis and interpretation, literature search and writing of the manuscript. MRK, GC and DVH contributed to the study design, data interpretation and writing of the manuscript. EAB and CSC contributed to the interpretation of the data and writing of the manuscript. All authors have read and approved the final version.

ACKNOWLEDGEMENTS

We thank the Ministry of Health of Uganda and Kenya; our research and administrative teams in the United States, Uganda and Kenya; collaborators and advisory boards; and especially all the communities and participants involved. We acknowledge funding support from the National Institute of Health Grant# 1U01AI150510-01A1 (Havlir).

FUNDING

Research reported in this manuscript was supported by the U.S. National Institute of Allergy and Infectious Diseases (NIAID), the National Heart, Lung, and Blood Institute (NHLBI) and the National Institute of Mental Health (NIMH) and co-funded under award number U01AI150510.

DISCLAIMER

The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

REFERENCES

1. The Joint United Nations Programme on HIV/AIDS. In Danger: UNAIDS Global AIDS Update 2022. Accessed 26 March 2022. Available at: https://www.unaids.org/sites/default/files/media_asset/2022-global-aids-update_en.pdf
2. De Labrusse C, Ramelet A-S, Humphrey T, Maclennan SJ. Patient-centered care in maternity services: a critical appraisal and synthesis of the literature. *Womens Health Issues*. 2016;26(1):100–9.
3. Shorter JM, Atrio JM, Schreiber CA. Management of early pregnancy loss, with a focus on patient centered care. *Semin Perinatol*. 2019; Mar 1 (Vol. 43, No. 2, pp. 8–489). WB Saunders.
4. Steffensen KD. The promise of shared decision making in healthcare. *AMS Rev*. 2019;9(1):105–9.
5. Charosaei F, Rostami S, Esmaeili M, Molavynjad S, Vanaki Z. Effective strategies for implementing patient-centered care in cardiac care unit: an opportunity for change. *J Educ Health Promot*. 2021;10:380.

6. Berry LL, Danaher TS, Beckham D, Awdish RL, Mate KS. When patients and their families feel like hostages to health care. *Mayo Clin Proc.* **2017**; Sept 1 (Vol. 92, No. 9, pp. 1373-1381). Elsevier.
7. Quaife M, Eakle R, Cabrera Escobar MA, Vickerman P, Kilbourne-Brook M, Mvundura M, et al. Divergent preferences for HIV prevention: a discrete choice experiment for multipurpose HIV prevention products in South Africa. *Med Decis Making.* **2018**;38(1):120-33.
8. Terris-Prestholt F, Hanson K, MacPhail C, Vickerman P, Rees H, Watts C. How much demand for new HIV prevention technologies can we really expect? Results from a discrete choice experiment in South Africa. *PLoS One.* **2013**;8(12):e83193.
9. Minnis AM, Browne EN, Boeri M, Agot K, Van Der Straten A, Ahmed K, et al. Young women's stated preferences for biomedical HIV prevention: results of a discrete choice experiment in Kenya and South Africa. *J Acquir Immune Defic Syndr.* **2019**;80(4):394.
10. Minnis AM, Montgomery ET, Napierala S, Browne EN, van der Straten A. Insights for implementation science from 2 multiphased studies with end-users of potential multipurpose prevention technology and HIV prevention products. *J Acquir Immune Defic Syndr.* **2019**;82:S222-9.
11. Mulubwa C, Hensen B, Phiri MM, Shanaube K, Schaap AJ, Floyd S, et al. Community based distribution of oral HIV self-testing kits in Zambia: a cluster-randomised trial nested in four HPTN 071 (PopART) intervention communities. *Lancet HIV.* **2019**;6(2):e81-92.
12. (NASCO). NAaSCp. Kenya Population-based HIV Impact Assessment(KENPHIA) 2018 Final Report. Nairobi: NASCO; **2022**.
13. National AIDS and STI Control Programme (NASCO). **2022**. Accessed 26 March 2022. Available at: https://phia.icap.columbia.edu/wp-content/uploads/2020/04/KENPHIA-2018_Preliminary-Report_final-web.pdf.
14. Uganda Ministry of Health. Uganda Population Based HIV Impact Assessment UPHIA 2016-2017. Accessed 7 November 2019. Available at: https://phia.icap.columbia.edu/wp-content/uploads/2019/07/UPHIA_Final_Report_Revise_07.11.2019_Final_for-web.pdf. Uganda Ministry of Health; **2019**.
15. Mudau DO, Mulaudzi FM, Sepeng NV, Anokwuru R. Assessing HIV pre-exposure prophylaxis uptake and retention amongst young females in Gauteng Province. *AIDS Behav.* **2023**;April;27(4):118-27.
16. Mayanja Y, Kamacooko O, Lunkuse JF, Muturi-Kioi V, Buzibye A, Omali D, et al. Oral pre-exposure prophylaxis preference, uptake, adherence and continuation among adolescent girls and young women in Kampala, Uganda: a prospective cohort study. *J Int AIDS Soc.* **2022**;25(5):e25909.
17. Kinuthia J, Pintye J, Abuna F, Mugwanya KK, Lagat H, Onyango D, et al. Pre-exposure prophylaxis uptake and early continuation among pregnant and post-partum women within maternal and child health clinics in Kenya: results from an implementation programme. *Lancet HIV.* **2020**;7(1):e38-48.
18. Hoagland B, Torres TS, Bezerra DR, Benedetti M, Pimenta C, Veloso VG, et al. High acceptability of PrEP teleconsultation and HIV self-testing among PrEP users during the COVID-19 pandemic in Brazil. *Brazil J Infect Dis.* **2021**; April 28; 25(1).
19. Ngunjiri K, Heffron R, Mugo N, Thomson KA, Irungu E, Njuguna N, et al. Feasibility and acceptability of HIV self-testing among pre-exposure prophylaxis users in Kenya. *J Int AIDS Soc.* **2017**;20(1):21234.
20. Mujugira A, Nakyanzi A, Kasiita V, Kamusiime B, Nalukwago GK, Nalumansi A, et al. HIV self-testing and oral pre-exposure prophylaxis are empowering for sex workers and their intimate partners: a qualitative study in Uganda. *J Int AIDS Soc.* **2021**;24(9):e25782.
21. Ngunjiri K, Ortblad KF, Mogere P, Bardon AR, Thomas KK, Mangale D, et al. Efficacy of 6-month PrEP dispensing with HIV self-testing in Kenya: an open-label, randomised, non-inferiority, implementation trial. *Lancet HIV.* **2022**;9(7):e464-73.
22. O'Malley TL, Krier SE, Bainbridge M, Hawk ME, Egan JE, Burke JG. Women's perspectives on barriers to potential PrEP uptake for HIV prevention: HIV risk assessment, relationship dynamics and stigma. *Cult Health Sex.* **2022**; Jul 6: 1-5.
23. Rousseau E, Bekker L-G, Julies RF, Celum C, Morton J, Johnson R, et al. A community-based mobile clinic model delivering PrEP for HIV prevention to adolescent girls and young women in Cape Town, South Africa. *BMC Health Serv Res.* **2021**;Dec;21(1):1-10.
24. Medina-Marino A, Bezuidenhout D, Ngwepe P, Bezuidenhout C, Facente SN, Mabandla S, et al. Acceptability and feasibility of leveraging community-based HIV counselling and testing platforms for same-day oral PrEP initiation among adolescent girls and young women in Eastern Cape, South Africa. *J Int AIDS Soc.* **2022**;25(7):e25968.
25. Durham SH, Milam A, Waer D, Chahine EB. Cabotegravir: the first long-acting injectable for HIV preexposure prophylaxis. *Annals of Pharmacotherapy.* **2023** Mar;57(3):306-16.
26. Beesham I, Dovel K, Mashele N, Bekker L-G, Gorbach P, Coates TJ, et al. Barriers to oral HIV pre-exposure prophylaxis (PrEP) adherence among pregnant and post-partum women from Cape Town, South Africa. *AIDS Behav.* **2022** Sept;26(9):307-987.
27. Beckham SW, Mantsios A, Galai N, Likindikoki S, Mbwambo J, Davis W, et al. Acceptability of multiple modalities of pre-exposure prophylaxis (PrEP) among female sex workers in Tanzania: a mixed-methods study. *BMJ Open.* **2022**;12(8):e058611.
28. Tran NK, Martinez O, Scheim AI, Goldstein ND, Welles SL. Perceived barriers to and facilitators of long-acting injectable HIV PrEP use among Black, Hispanic/Latino, and White gay, bisexual, and other men who have sex with men. *AIDS Educ Prev.* **2022**;34(5):365-78.

SUPPORTING INFORMATION




Additional information may be found under the Supporting Information tab for this article:

Supporting Information: SAPPHERE risk screening tool

Supporting Information Figure S1: CONSORT Diagram

RESEARCH ARTICLE

Clients in Uganda accessing preferred differentiated antiretroviral therapy models achieve higher viral suppression and are less likely to miss appointments: a cross-sectional analysis

Esther K. Karamagi Nkolo¹ , Jessica Clinkscales Ejike², Simon Sensalire³, Juliana Nabwire Ssali³, Immaculate Ddumba¹ , Jacqueline Calnan¹, Carolina Gonzalez², Nelly Maina², Melaku Dessie⁴, Lauren Bailey², Ugochukwu Amanyeiwe², Thomas Minior⁴, Karishma Srikanth², Herbert Kadama⁵, Khushi Patel⁶ and Dina Patel^{2,§} 

§ **Corresponding author:** Dina Patel, United States Agency for International Development, Bureau for Global Health, Office of HIV/AIDS (OHA), 500 D Street, SW, Washington, DC 20547, USA. (dipatel@usaid.gov, dina0521@gmail.com)

Abstract

Introduction: The Uganda Ministry of Health recommends facility- and community-based differentiated antiretroviral therapy (DART) models to support person-centred care for eligible clients receiving antiretroviral therapy (ART). Healthcare workers assess client eligibility for one of six DART models upon initial enrolment; however, client circumstances evolve, and their preferences are not routinely adjusted. We developed a tool to understand the proportion of clients accessing preferred DART models and compared the outcomes of clients accessing preferred DART models to the outcomes of clients not receiving preferred DART models.

Methods: We conducted a cross-sectional study. A sample of 6376 clients was selected from 113 referrals, general hospitals and health centres purposely selected from 74 districts. Clients receiving ART accessing care from the sampled sites were eligible for inclusion. Healthcare workers interviewed clients (caretakers of clients under 18), over a 2-week period between January and February 2022 using a client preference tool to elicit whether clients were receiving DART services through their preferred model. Treatment outcomes of viral load test, viral load suppression and missed appointment date were extracted from clients' medical files before or immediately after the interview and de-identified. The descriptive analysis determined the interaction between client preferences and predefined treatment outcomes by comparing outcomes of clients whose care aligned with their preferences to outcomes of clients whose care misaligned with their preferences.

Results: Of 25% (1573/6376) of clients not accessing their preferred DART model, 56% were on facility-based individual management and 35% preferred fast-track drug refills model. Viral load coverage was 87% for clients accessing preferred DART models compared to 68% among clients not accessing their preferred model. Viral load suppression was higher among clients who accessed the preferred DART model (85%) compared to (68%) clients who did not access their preferred DART model. Missed appointments were lower at 29% for clients who accessed preferred DART models compared to 40% among clients not enrolled in the DART model of their choice.

Conclusions: Clients who accessed their preferred DART model have better clinical outcomes. Preferences should be integrated throughout health systems, improvement interventions, policies and research efforts to ensure client-centred care and client autonomy.

Keywords: ART; client preference; DART; missed appointment; Uganda; viral load suppression

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

Received 2 November 2022; Accepted 12 May 2023

Copyright © 2023 The Authors. *Journal of the International AIDS Society* published by John Wiley & Sons Ltd on behalf of the International AIDS Society. This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

1 | INTRODUCTION

With the number of people living with HIV (PLHIV) accessing treatment increasing, the growing ageing population of PLHIV and with the move closer to epidemic control, implementation and scale-up of innovative, efficient and simplified service delivery models to ensure lifelong antiretroviral therapy (ART)

adherence and virologic suppression are essential to providing quality person-centred care while also reducing strain on the healthcare system [1].

Historically, HIV service delivery was based on a one-size fits all approach, where clients received undifferentiated services, which required multiple visits to a health facility for clinical consultations and to obtain ART [2]. Now, service delivery

takes a person-centred approach in which the diverse preferences, needs and expectations of clients are taken into consideration, allowing for reduced visits to a health facility, enhanced quality of care, improved treatment outcomes for clients and redirecting of resources to focus on those most at need of more intensive support [2, 3].

The Uganda Ministry of Health (MoH) first recommended differentiated service delivery (DSD) in their 2016 consolidated HIV prevention, care and treatment guidelines as a critical strategy to enable Uganda to achieve the UNAIDS 90-90-90 goals [4]. In addition to supporting efforts to rapidly expand the provision of ART to individuals, the Uganda MoH recommends six facility and community-based differentiated antiretroviral therapy (DART) models to ensure that clients are empowered to manage their own care, reduce wait times at facilities, support continuity of treatment and linkage to supportive services [1]. The six DART models include: facility-based individual management (FBIM), a more intensive model designed for clinically unstable and complex clients; facility-based group (FBG) for unstable/complex or clinically stable clients; and four less-intensive models for clinically stable clients, including facility-based, fast-track drug refill (FTDR), community client-led ART delivery (CCLAD), community drug distribution point (CDDP) and community pharmacy [1].

Healthcare workers assess client eligibility criteria per Uganda MoH guidelines for DART models upon initial enrolment. Clients are clinically unstable if their viral load is unsuppressed, if they are newly enrolled receiving ART or if their viral load is unknown. Clients who do not yet meet the definition of clinically stable are placed into a more intensive DART model, such as FBIM or FBG, by their provider irrespective of their preferences to facilitate closer clinical monitoring. Clinically stable clients receive information about all available models and may opt for any DART model, including intensive and less-intensive models. Client preference varies, and circumstances evolve thus requiring healthcare providers to adjust the model of service delivery. By routinely assessing client preferences for DART models, we can provide an evidence base of which models work for clients based on certain demographic factors and an understanding of the evolving needs of clients [5].

To evaluate whether a client receiving their preferred model is associated with clinical outcomes, we developed a DSD client preference, quality improvement tool to quantify the proportion of clients accessing their preferred DART model and compare the clinical outcomes of clients currently in their preferred DART models and those not in their preferred DART models.

2 | METHODS

2.1 | Study design and participants

A cross-sectional study was conducted between January and February 2022 using the DSD client preference tool to understand client preferences for DART models and community linkages for support services. Our study included clients accessing care from the selected 113 referrals, general hospitals and health centres. Sample calculation estimated that 79% of all adult ART clients had been enrolled in one of the

six DART models (FBG, FBIM, FTDR, CCLAD, CDDP or community pharmacy). With a normal standard deviation (1.96 and 95 CI), precision corresponding to a confidence interval of 5% and a design effect of three, a sample of 735 was needed for the study. To perform subgroup analyses, the sample was recomputed to factor DART models (FBG, FBIM, FTDR, CCLAD, CDDP and community pharmacy). Thus, the sample of 735 was multiplied by the seven sets required for disaggregated analysis to obtain 5145. Adjusting for a non-response of 5% gives a sample of 5402. The sample was adjusted to cater for facility type (private not-for-profit [PNFP] and public health facilities), yielding a sample of 6137 clients. The study was approved by The AIDS Support Organization (TASO) Institutional Review Board under approval #TASOREC/030/2021-UG-REC-009.

2.2 | Study sites

The study was conducted in 113 sites in nine regions and included public and PNFP health facilities (sites). Study sites were selected to capture the variations in regional settings and levels of health facilities. All levels of health facilities were included, namely; regional referral hospital, general hospital, Health Center IV (HCIV) and Health Center III (HCIII), to include clients in all service delivery models, such as CCLAD and CDDP, who would otherwise not be found in regional referral hospitals or some general hospitals. Purposive sampling was used to select 10 health facilities from each region to reflect variation in model type, facility ownership and implementing partner (region). Thus, two general hospitals, four HCIV and four HCIII were selected from each region. No more than one health facility was selected per district except for the purpose of boosting the sample to reflect various geographical areas.

2.3 | Sampling procedure

The sample frame included patients who received antiretroviral treatment in each selected facility. Sampling was purposive to include clients enrolled in different DSD models and age categories of 0–14, 15–24 and 25+ that would best answer the study questions. The selection and interviewing of clients were conducted over a period of 1 month when the desired sample was attainable across DSD models and age categories. We used cell-based weighting on the predetermined sample size for each DSD group and age category so that results represent the clients in the selected sites. Relatedly, sites were purposively selected to include sites with all the DSD models attaining a participation rate of 97% of the desired clients.

2.4 | The DSD client preference tool

The client preference tool (Figure 1) was drafted and discussed with subject matter experts through three iterative review meetings to generate the pre-testing version. The tool was then pre-tested, and the final tool was then adapted. The tool was composed of 17 questions divided into three sections: (1) background information; (2) clinical outcomes and retention; and (3) service delivery assessment. Sections 1 and 2 were abstracted from the client files by the health worker before or immediately after the interview. Section 1

DSD Client Preference Tool for HIV clients in Care This tool is designed to understand the client preferences for the models of HIV service delivery and community linkages for support services.																
IDENTIFICATION TAGS																
DISTRICT:																
HEALTH FACILITY: LEVEL:																
Instructions: 1) PART 1 & 2 to be filled by a health worker. 2) PART 3 to be asked from a client. 3) Enter the response code in the boxes for each client in the column. 4) Each client should be interviewed once. 5) Observe instructions regarding skip patterns for specific questions in the tool																
SECTION 1: BACKGROUND INFORMATION (To be filled by the health worker)																
1. Client ID	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	
2. Current Age of Client (<i>Write age in complete years e.g., 21</i>)																
3. Gender (<i>1=Male, 2=Female</i>)																
4. Year of HIV diagnosis (<i>Year when Client was diagnosed with HIV, e.g., 2010</i>)																
5. Duration of Treatment (<i>1=Less than 3 months, 2=Between 3 and 6 months, 3=Between 6 months and a year, 4=More than one year</i>)																
Section 2: CLINICAL OUTCOME & RETENTION (To be filled by the health worker)																
6. Does the client have an updated viral load? (<i>1=Yes, 2=No</i>)																
7. Is the client currently virally suppressed (<i>1=Yes, 2=No</i>)																
8. Has the client missed any appointments in the last 12 months? (<i>1=Yes, 2= No</i>)																
Section 3: SERVICE DELIVERY ASSESSMENT (Ask the client)																
9. Person to whom the tool is administered (<i>1=Client, 2=Caretaker</i>)																
10. How many months of ART were you dispensed at your last contact or visit? (<i>1=Less than one month of ART, 2=1-2 months, 3=3-5 months, 4=6+ months</i>)																
11. What is your preferred number of months of ART that should be dispensed at a time? (<i>1=Less than one month of ART, 2=1-2 months, 3=3-5 months, 4=6+ months</i>)																
12. What is the current method through which you get ARVs? <i>1= Facility-based individual management (FBIM) 2= Facility-based group (FBG) 3= Fast track refill (FTDR) 4= Community client-led ART delivery (CCLAD) 5= Community drug distribution point (CDDP) 6= Community pharmacy 7= Other (specify) _____</i>	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	
13. There are other methods available through which you can get ARVs such as (<i>DESCRIBE OTHER METHODS IN QN 12. EXCLUDING THE ONE MENTIONED BY CLIENT</i>) Is the current method through which you get HIV services your preferred choice? (<i>1=Yes, 2=No</i>)																
14. <i>ONLY ASK IF RESPONSE IN QN 13 IS NO</i> What is your preferred method through which you can receive ARVs? <i>1= Facility-based individual management (FBIM) 2= Facility-based group (FBG) 3= Fast track refill (FTDR) 4= Community client-led ART delivery (CCLAD) 5= Community drug distribution point (CDDP) 6= Community pharmacy 7= Other (specify) _____</i>																
15. Are you attached to a community health worker? (<i>1=Yes, 2=No</i>) <i>IF 'YES', THANK CLIENT AND END THE DISCUSSION. IF NO, GO TO QN 16</i>																
16. Would you like to be attached to the Community Health Worker for monthly follow-up support? (<i>1=Yes, 2=No, 3=Not sure/not yet decided</i>) <i>ONLY ASK IF RESPONSE TO QN 15 IS 'YES'</i>																
17. How would you want to be contacted in case you need follow-up support? <i>1= Phone call, 2= Short message service (SMS), 3= Home visit, 4= Virtual follow-up, 5= WhatsApp groups, 6= Linkage facilitator/Peer/Health worker, 7=Email, 8=Not interested in being followed up</i>																

Figure 1. DSD client preference tool shows the client preference tool which contains 17 questions split into three sections, and it aims to compare client preferences for different DART models and their impact on HIV viral load suppression. The tool uses missed appointment data to gauge continuity of treatment, with clients who have not missed an appointment in the past year considered to have continuous treatment (see File S1 for copy of tool). Abbreviations: DSD, differentiated service delivery; DART, differentiated antiretroviral therapy.

Table 1. Baseline cohort demographics.

	Overall (N = 6376)
Age	
Mean (SD)	32.9 (16.3)
Median [Min, Max]	33.0 [1.00, 92.0]
Missing	4 (0.1%)
Age category	
<15	1022 (16.0%)
15+	5350 (83.9%)
Missing	4 (0.1%)
Sex	
Female	3741 (58.7%)
Male	2565 (40.2%)
Missing	70 (1.1%)
Region	
Central	1 (0.0%)
East Central	1062 (16.7%)
Karamoja	590 (9.3%)
Mid-Eastern	635 (10.0%)
Mid-Northern	1656 (26.0%)
Mid-Western	1 (0.0%)
South Western	1363 (21.4%)
UPMB/LSDA*	984 (15.4%)
West Nile	84 (1.3%)
Missed appointments in last 12 months	
No missed appointment	4280 (67.1%)
Missed appointment	2007 (31.5%)
Missing	89 (1.4%)
Current ARV mode	
Community client-led ART delivery (CCLAD)	781 (12.2%)
Community drug distribution point (CDDP)	809 (12.7%)
Community pharmacy	184 (2.9%)
Facility-based group (FBG)	776 (12.2%)
Facility-based individual management (FBIM)	2018 (31.7%)
Fast-track drug refill (FTDR)	1808 (28.4%)
ARV mode preference	
No	1573 (24.7%)
Yes	4803 (75.3%)
Viral load suppression	
No	1071 (16.8%)
Yes	5113 (80.2%)
Missing	192 (3.0%)

*UPMB/LSDA refers to Uganda Protestant Medical Bureau Local Service Delivery for Health and HIV/AIDS Activity, a partner organization that was analysed as a region because they work with all private not-for-profit institutions.

contained information regarding client ID, current age, gender, year of HIV diagnosis and duration of treatment broken down by periods of 3 months. This information was used to compare what groups of people prefer certain DART models and the effect on HIV viral load suppression. The second section pertained to treatment outcomes of viral load tests, viral load suppression (<1000 copies/ml) and missed appointments; a proxy for continuity of treatment and defined as a client who did not miss an appointment in the last 12 months at the time of the study.

2.5 | Dissemination of client preference tool

The tool, as well as standardized guidelines for data collection across the regions, was disseminated to USAID-supported implementing partners through an orientation. One-on-one dissemination meetings with implementing partner data collection teams followed. The only inclusion or exclusion criteria for the clients to be interviewed using the DSD client preference tool was that the client was a current member of either a community or facility-based DART model. Each client was only interviewed once.

2.6 | Data collection

Data were collected from 113 referral and general hospitals and health centres purposely selected to capture all DSD client categories from 74 districts. Clients receiving ART accessing care from the sampled sites were eligible for inclusion. Selection of clients was done conveniently by interviewing clients within the period of data collection of 2 weeks irrespective of their appointment date until the desired number was attained.

Each participating health facility interviewed all their community pharmacy clients, a minimum of 16 CCLAD clients and 16 CDDP clients, 32 FBIM and 32 FTDR clients. The study set out to interview an equal number of men and women out of the sample allocated per facility per the DART model. However, in some cases, more women than men were interviewed when there were no more men in the model. If clients were infants, youth or adolescents, parents or guardians responded to the interview questions. Patient preference analysis was done during routine care by providers to align services to client preferences and, therefore, client consent was waived. When the total number of clients to be interviewed per model was not achieved in a selected health facility, the number was boosted by clients in the same DART model in another health facility. The tool was administered by a health worker or a community health worker to the eligible clients as part of routine care. All the completed data tools were collected for processing and analysis at a central place.

2.7 | Data analysis

Descriptive statistics were used to analyse client demographic characteristics, clinical outcomes and clients' preferences for care and presented as numbers and proportions. Sub-population analyses were done to distinguish current DART models, client preferences and outcomes. Cross-sectional comparisons of clinical outcomes and patient preferences were done to determine the interaction between

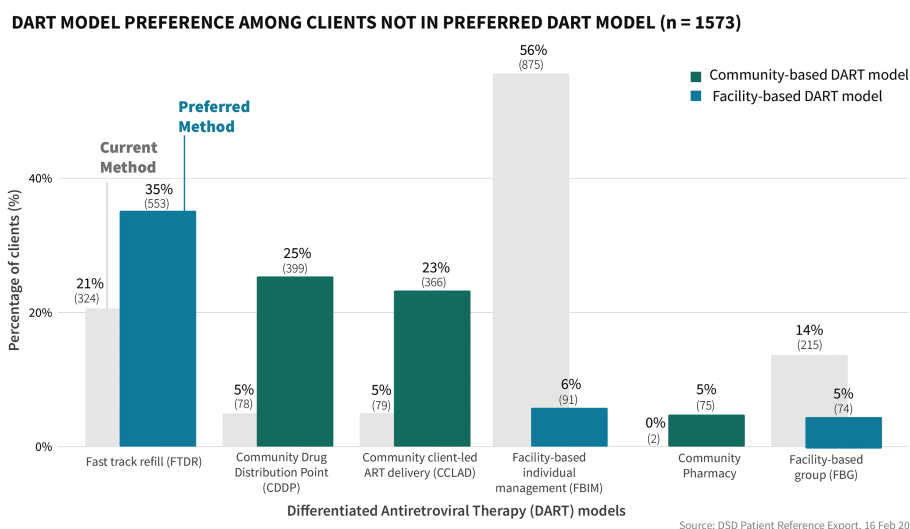


Figure 2. Differentiated antiretroviral therapy (DART) model preference among clients not in preferred DART model illustrates the distribution of clients' preferred DART model among clients who were not currently enrolled in their preferred model.

client preferences and predefined treatment outcomes by comparing the outcomes of clients.

3 | RESULTS

3.1 | Characteristics of clients

The overall study cohort included 6376 clients ages 1–92 years (Table 1). The clients were selected from 113 facilities across nine regions, with the Mid-Northern and Southwestern regions accounting for 1656 (26%) and 1363 (21%) of the sample, respectively. Table 1 illustrates the demographic distribution of clients by age (<15 and 15+), gender, region of residence and current Antiretroviral (ARV) mode. This table also highlights the frequency of missed appointments, community health worker presence and viral load suppression as binary outcomes. Age distribution varied widely, with adults (15+) accounting for almost 84% of the sample population and children (<15) accounting for 16%. More than half (58%) of the clients in the sample identified as female. Two thousand and seven (32%) of the clients had a reported missed appointment in the last 12 months and over 5113 (80%) of clients were virally suppressed. While most clients reported that they were in their preferred ARV model, 1573 (25%) reported that they were not in their preferred method.

3.2 | Client DART preferences and clinical outcomes

Of the 25% (1573) of clients in the sample who were not accessing their preferred DART model, 91% were currently receiving facility-based DART and 875 (56%) were currently accessing FBIM (Figure 2). Most clients not accessing their preferred model preferred community-based DART models 840 (53%), 553 (35%) of clients in this group preferred the fast-track refill model. Viral load suppression was higher among clients accessing their preferred DART model at 87% (4043/4623) (Figure 3) compared to clients not accessing

their preferred DART model at 68% (1007/1482) (Table 2). The rate of missed appointments was lower at 69% (133) for clients accessing their preferred DART models compared to 31% (601) (Table 3) among clients not enrolled in the DART model of their choice. Over half of the cohort was enrolled in FBIM and FTDR methods, at 1872 (31%) clients and 1765 (29%) clients, respectively.

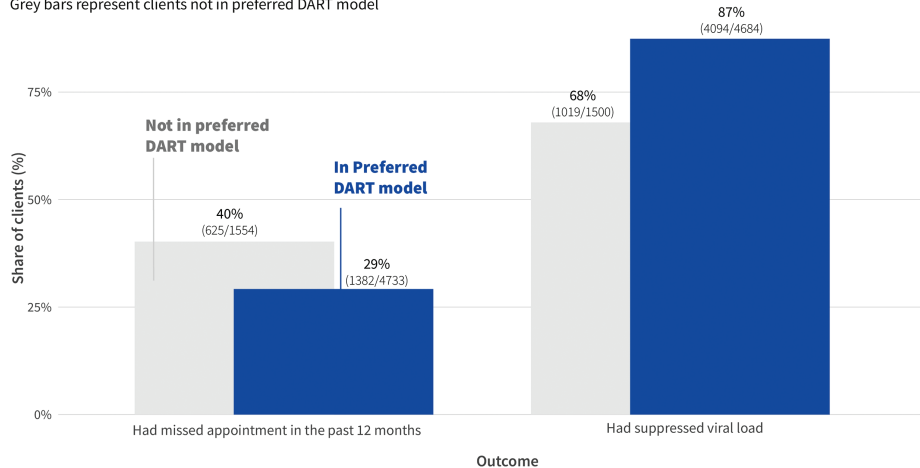
4 | DISCUSSION

Despite the large-scale rollout of DART models in various formats across multiple countries, there is a shortage of evidence to document the purported benefits of the new models in routine implementation or clinical outcomes [6]. Our study, therefore, explored client DART preference in relation to clinical outcomes, based on the hypothesis that client care needs change throughout the life course, clients bring an understanding of their own needs, client participation in decision-making can facilitate greater engagement and HIV outcomes are better when clients are in their preferred DART model. We found better clinical outcomes among clients accessing their preferred DART models. This finding could be explained by the fact that differentiated models of service delivery are tailored to addressing retention and access needs, generate greater client satisfaction, lower cost to both providers and clients, and create efficient and convenient service delivery [7, 8]. A major strength of this study is that it was done in a routine healthcare setting and covered sub-population types from FBIM, FBG, FTDR, CCLAD and community pharmacy [4]. The results are, therefore, generalizable as far as they represent perspectives across the recommended DART models in Uganda.

Studies have found that DART models substantially reduce costs to clients, primarily for transport and time [9]. We, therefore, suggest both from our study and from other jurisdictions, a need to scale-up the dispensing of 6 or more months of drugs for clients to reduce the frequency of

VIRAL SUPPRESSION AND MISSED APPOINTMENT OUTCOMES BY DART MODEL PREFERENCE

Grey bars represent clients not in preferred DART model



Source: DSD Patient Reference Export, 16 Feb 2022

Figure 3. Viral suppression and missed appointment outcomes by Differentiated antiretroviral therapy (DART) model preference compares the viral load suppression rates and missed appointments outcomes between clients accessing their preferred DART model and those not accessing their preferred model.

medication refill visits, especially in resource-constrained settings, such as in Uganda, especially if preferred by the clients.

The World Health Organization recommends monitoring ART efficacy using VL testing performed at 6 months following initiation, and annually afterwards [10]. In Uganda, all clients living with HIV should receive a viral load test 6 months after initiating treatment and annually thereafter; for adult clients who are suppressed and 6 monthly for non-suppressed clients and children and adolescents. Our study determined whether clients eligible for viral load had received a repeated viral load test. We discovered that clients accessing their preferred DART model mostly had an up-to-date viral load. DART-related interventions to support VL monitoring could explain in part the observed results and help address barriers to VL testing, especially among children. Enrolling clients to access a DART model of their preference would have complementary benefits of overcoming constraints associated with VL testing, such as long distances and costs associated with travelling to the health facilities. Other studies have documented a myriad of barriers to HIV care from both provider, client and health system perspectives [6], such as frequent clinic visits for clinical evaluations and drug refills, long waiting times in ART clinics, long distances and costs to travel to the health facilities [11].

One-quarter of clients are not accessing their preferred model, which presupposes a proportion of clients remaining in a more intensive model of care, whose outcomes may be worse. The gap in enrolment according to client choice is partly explained by the reservations to enrol unstable clients to access other models other than FBIM. Clients not accessing their preferred model could miss one or more benefits, such as higher adherence to ART and continuity on treatment, reduced per-client cost of providing ART and decreased waiting time. These among other benefits have been well-postulated in other studies on differentiated models of HIV treatment [12].

4.1 | Limitations of the study

Our study had some limitations, which are common with client preference studies. The study was cross-sectional and could not explore how long clients were in their current DART model at the time of the survey, changes in a client's DART preferences and clinical outcomes over time. Stemming from this limitation, future studies should consider longer-term follow-up as it is critical to observe any changes to clinical outcomes due to evolving client preferences. Secondly, there is some selection bias in our participant inclusion criteria because we only included clients attending a healthcare visit at the facility, thus excluding many clients in the community and those who had missed their appointment or fallen out of care and we extended participation to clients enrolled in FBIM, a DART model for clinically unstable/complex clients needing intensive support. The highest proportion of clients not in the model of their choice were enrolled in FBIM; and because FBIM includes clients who are largely virologically non-suppressed, unlike the other models, this may skew viral load suppression results by group. However, when we exclude the FBIM patients, viral load suppression was still higher among clients accessing their preferred DART model (95%) compared to clients not accessing their preferred DART model (90%). Additionally, to address the limitation on including clients in the community who missed appointments and could not have their preference assessed, we analysed all clients who attended the clinic during the project period, whether or not they were on appointment. Table 1 illustrates that 31.5% of the clients included in the analysis had missed an appointment in the 12 months prior to the data collection.

Although the study included clients who attended the clinic during the study period, regardless of whether or not they had a scheduled appointment, the convenience sampling methodology used in this study limits its ability to generalize the findings to the broader population of PLHIV. As a

Table 2. Viral suppression outcomes by demographic and clinical characteristics.

	No (n = 1055)	Yes (n = 5050)	Overall (N = 6105)
Age category			
<15	222 (21.0%)	760 (15.0%)	982 (16.1%)
15+	833 (79.0%)	4286 (84.9%)	5119 (83.8%)
Missing	0 (0%)	4 (0.1%)	4 (0.1%)
Sex			
Female	574 (54.4%)	3005 (59.5%)	3579 (58.6%)
Male	467 (44.3%)	1993 (39.5%)	2460 (40.3%)
Missing	14 (1.3%)	52 (1.0%)	66 (1.1%)
ARV mode preference			
No	475 (45.0%)	1007 (19.9%)	1482 (24.3%)
Yes	580 (55.0%)	4043 (80.1%)	4623 (75.7%)
Current ARV mode			
Community client-led ART delivery (CCLAD)	28 (2.7%)	728 (14.4%)	756 (12.4%)
Community drug distribution point (CDDP)	48 (4.5%)	743 (14.7%)	791 (13.0%)
Facility-based group (FBG)	92 (8.7%)	647 (12.8%)	739 (12.1%)
Facility-based individual management (FBIM)	809 (76.7%)	1063 (21.0%)	1872 (30.7%)
Fast-track refill (FTDR)	78 (7.4%)	1687 (33.4%)	1765 (28.9%)
Community pharmacy	0 (0%)	182 (3.6%)	182 (3.0%)

Table 3. Missed appointment outcomes (in the last 12 months) by demographic and clinical characteristics.

	No missed appointment (n = 4169)	Missed appointment (n = 1936)	Overall (N = 6105)
Age category			
<15	591 (14.2%)	391 (20.2%)	982 (16.1%)
15+	3576 (85.8%)	1543 (79.7%)	5119 (83.8%)
Missing	2 (0.0%)	2 (0.1%)	4 (0.1%)
Sex			
Female	2438 (58.5%)	1141 (58.9%)	3579 (58.6%)
Male	1679 (40.3%)	781 (40.3%)	2460 (40.3%)
Missing	52 (1.2%)	14 (0.7%)	66 (1.1%)
ARV mode preference			
No	881 (21.1%)	601 (31.0%)	1482 (24.3%)
Yes	3288 (78.9%)	1335 (69.0%)	4623 (75.7%)
Current ARV mode			
Community client-led ART delivery (CCLAD)	613 (14.7%)	143 (7.4%)	756 (12.4%)
Community drug distribution point (CDDP)	624 (15.0%)	167 (8.6%)	791 (13.0%)
Community pharmacy	126 (3.0%)	56 (2.9%)	182 (3.0%)
Facility-based group (FBG)	458 (11.0%)	281 (14.5%)	739 (12.1%)
Facility-based individual management (FBIM)	1119 (26.8%)	753 (38.9%)	1872 (30.7%)
Fast-track refill (FTDR)	1229 (29.5%)	536 (27.7%)	1765 (28.9%)

cross-sectional study, the design did not allow for causal inference, and the results should be interpreted with caution.

Nevertheless, the descriptive analysis provided valuable insights into the prevalence of missed appointments and their association with client preferences for appointment scheduling. To further explore the relationship between client preferences and clinical outcomes, future research using more robust study designs, such as randomized controlled trials or longitudinal studies, would be needed.

5 | CONCLUSIONS

One-fourth of clients' current DART model were not enrolled in their preferred choice, and clients enrolled in their preferred choice had higher rates of viral load suppression and fewer missed appointments. Some of these observed findings may be driven by fewer stable clients being required to remain in more intensive models until clinical milestones are met; however, it may also reflect a slowness to move eligible clients back into a preferred model. While clients in their preferred model of service delivery had timely viral load monitoring, these clients are also mostly enrolled in less-intensive models with fewer clinical touchpoints. Knowing that different DART models bring different benefits (e.g. social support, anonymity and extra engagement with HCWs), and that clients likely have the best understanding of their changing individual needs, clients should be actively engaged in deciding how they receive care. Continuous assessment of client preferences for DART models using a quality improvement tool, counselling and assignment of clients to models of choice is essential in improving client experience of care and ultimately clinical outcomes. Additionally, a longitudinal study of client preferences is essential to better understand the impact of client preferences for DART models on clinical outcomes.

AUTHORS' AFFILIATIONS

¹U.S. Agency for International Development (USAID), Kampala, Uganda; ²GHTASC, Credence Management Solutions LLC, supporting the United States Agency for International Development (USAID), Office of HIV/AIDS, Washington, DC, United States; ³University Research Co., LLC, USAID RHITES N-Acholi Activity Kampala, Kampala, Uganda; ⁴U.S. Agency for International Development (USAID), Office of HIV/AIDS, Prevention Care and Treatment Division, Washington, DC, USA; ⁵Ministry of Health, AIDS Control Program, Kampala, Uganda; ⁶Brown University [USAID Intern], Providence, Rhode Island, USA

COMPETING INTERESTS

The authors declare that they have no competing interests.

AUTHOR CONTRIBUTION

Conceived, designed the analysis and collected the data: Esther K. Karamagi Nkolo, Simon Sensalire, Juliana Nabwire Ssali, Immaculate Ddumba, Jacqueline Calnan Contributed to the data & performed the analysis: Nelly Maina, and Karishma Srikanth Wrote the paper: Esther K. Karamagi Nkolo, Jessica Clinkscales Ejike, Simon Sensalire, Juliana Nabwire Ssali, Immaculate Ddumba, Jacqueline Calnan, Carolina Gonzalez, Nelly Maina, Melaku Dessie, Lauren Bailey, Ugochukwu Amanyeiwe, Thomas Minior, Karishma Srikanth, Herbert Kadama, Khushi Patel, Dina Patel

ACKNOWLEDGEMENTS

We appreciate all clients for providing their insightful experiences and choices, all health workers who participated in data collection at the study sites, the regional

implementing partner teams for supporting this activity and all technical experts who reviewed the DSD client preference tool and manuscript for this study.

FUNDING

This article was made possible by the support of the American people through the United States Agency for International Development (USAID) under the U.S. President's Emergency Plan for AIDS Relief (PEPFAR).

DISCLAIMER

The views in this abstract are those of the authors and do not necessarily represent the views of the U.S. Agency for International Development, University Research Corporation LLC or the Uganda Ministry of Health.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

REFERENCES

1. Implementation guide for differentiated service delivery models of HIV and TB services in Uganda. 2020.
2. World Health Organization. Updated recommendations on service delivery for the treatment and care of people living with HIV. Geneva; 2021. Accessed 28 April 2021. Available at: <https://www.who.int/publications/i/item/9789240023581>
3. International AIDS Society. Differentiated service delivery. 2022. Accessed September 26, 2022. Available at: <http://www.differentiatedservice.org>
4. Ministry of Health, Uganda (MOH). Consolidated guidelines for the prevention and treatment of HIV and AIDS in Uganda. Kampala; 2018.
5. Eshun-Wilson I, Mukumbwa-Mwenechanya M, Kim HY, Zanolini A, Mwamba CP, Dowdy D, et al. Differentiated care preferences of stable patients on antiretroviral therapy in Zambia: a discrete choice experiment. *J Acquir Immune Defic Syndr*. 2019;81(5):540–6.
6. Reidy WJ, Rabkin M, Syowai M, Schaaf A, El-Sadr WM. Patient-level and program-level monitoring and evaluation of differentiated service delivery for HIV: a pragmatic and parsimonious approach is needed. *AIDS*. 2018;32(3):399–401.
7. Long L, Kuchukhidze S, Pascoe S, Nichols BE, Fox MP, Cele R, et al. Retention in care and viral suppression in differentiated service delivery models for HIV treatment delivery in sub-Saharan Africa: a rapid systematic review. *J Int AIDS Soc*. 2020;23(11):1–2
8. Fatti G, Ngorima-Mabhena N, Mothibi E, Muzenda T, Choto R, Kasu T, et al. Outcomes of three- versus six-monthly dispensing of antiretroviral treatment (ART) for stable HIV patients in community ART refill groups: a cluster-randomized trial in Zimbabwe. *J Acquir Immune Defic Syndr*. 2020;84:162–72.
9. Long L, Kuchukhidze S, Pascoe S, Nichols BE, Cele R, Govathson C, et al. Retention in care and viral suppression in differentiated service delivery models for HIV treatment in sub-Saharan Africa: a rapid systematic review. *J Int AIDS Soc*. 2020;23:e25640.
10. World Health Organization. Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: recommendations for a public health approach. World Health Organization; 2016.
11. Nhassengo P, Cataldo F, Magaço A, Hoffman RM, Nerua L, Saide M, et al. Barriers and facilitators to the uptake of Test and Treat in Mozambique: a qualitative study on patient and provider perceptions. *PLoS One*. 2018;13(12):e0205919.
12. Geng EH, Nash D, Kambugu A, Zhang Y, Braitstein P, Christopoulos KA, et al. Retention in care among HIV-infected patients in resource-limited settings: emerging insights and new directions. *Curr HIV AIDS Rep*. 2010;7(4):234–44.








SUPPORTING INFORMATION

Additional information may be found under the Supporting Information tab for this article:

Supporting Information S1: DSD client preference tool. Tool used to assess client preference for DART models.

RESEARCH ARTICLE

Patterns of person-centred communications in public HIV clinics: a latent class analysis using the Roter interaction analysis system

Njekwa Mukamba^{1,§} , Chanda Mwamba¹, Salil Redkar², Marksman Foloko¹, Kasapo Lumbo¹, Herbert Nyirenda¹, Debra L. Roter³, Musunge Mulabe¹, Anjali Sharma¹, Sandra Simbeza¹, Kombatende Sikombe¹ , Laura K. Beres⁴, Jake M. Pry^{1,5} , Katerina Christopoulos⁶, Charles B. Holmes^{7,8} , Elvin H. Geng² , Izukanji Sikazwe¹, Carolyn Bolton-Moore¹  and Aaloke Mody² 

§Corresponding author: Njekwa Mukamba, Centre for Infectious Disease Research in Zambia (CIDRZ), P.O. Box 34681, Lusaka, Zambia.
(Njekwa.Mukamba@cidrz.org or Njekwa.Mukamba@gmail.com)

Abstract

Introduction: Poor client–provider communication is a critical barrier to long-term retention in care among people living with HIV. However, standardized assessments of this key metric are limited in Africa. We used the Roter Interaction Analysis System (RIAS) to quantitatively characterize patterns of person-centred communication (PCC) behaviours in Zambia.

Methods: We enrolled pairs of people living with HIV making routine HIV follow-up visit and their providers at 24 Ministry of Health-facilities supported by the Centre for Infectious Disease Research in Zambia in Lusaka province between August 2019 and November 2021. Client–provider encounters were audio-recorded and coded using RIAS by trained research staff. We performed latent class analysis to identify interactions with distinctive patterns of provider PCC behaviours (i.e. rapport building, person-centred counselling, PCC micropractices [e.g. brief empathy statements], assessing barriers to care, shared decision-making and leveraging discretionary power) and compared their distribution across client, provider, interaction and facility characteristics.

Results: We enrolled 478 people living with HIV and 139 providers (14% nurses, 73.6% clinical officers, 12.3% were medical officers). We identified four distinct profiles: (1) “Medically Oriented Interaction, Minimal PCC Behaviours” (47.6% of interactions) was characterized by medical discussion, minimal psychosocial/non-medical talk and low use of PCC behaviours; (2) “Balanced Medical/Non-medical Interaction, Low PCC Behaviours” (21.0%) was characterized by medical and non-medical discussion but limited use of other PCC behaviours; (3) “Medically Oriented Interaction, Good PCC Behaviours” (23.9%) was characterized by medically oriented discussion, more information-giving and increased use of PCC behaviours; and (4) “Highly person-centred Interaction” (7.5%) was characterized by both balanced medical/non-medical focus and the highest use of PCC behaviours. Nurse interactions were more likely to be characterized by more PCC behaviours (i.e. Class 3 or 4) (44.8%), followed by medical officers (33.9%) and clinical officers (27.3%) ($p = 0.031$). Longer interactions were also more likely to integrate more PCC behaviours ($p < 0.001$).

Conclusions: PCC behaviours are relatively uncommon in HIV care in Zambia, and often limited to brief rapport-building statements and PCC micropractices. Strengthening PCC, such as shared decision-making and leveraging discretionary power to better accommodate client needs and preferences, may be an important strategy for improving the quality in HIV treatment programmes.

Keywords: patient–provider communication; Roter interaction analysis system (RIAS); patient experience; latent class analysis; HIV; retention in care

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

Received 27 October 2022; Accepted 15 May 2023

Copyright © 2023 The Authors. *Journal of the International AIDS Society* published by John Wiley & Sons Ltd on behalf of the International AIDS Society.

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

1 | INTRODUCTION

The encounter with healthcare providers is a pivotal moment in the client experience, but negative experiences with providers have remained one of the critical drivers of loss to follow-up among people living with HIV [1–13]. Attention to the client experience is emerging as a key global public health priority as a means of providing whole-person care, fostering lifelong engagement, and improving treatment and quality of life-related outcomes [14, 15]. Emerging efforts to improve the person-centredness of care delivery (e.g. differentiated service delivery) have primarily focused on changing the care infrastructure [16–18], but relatively less emphasis has been placed on targeting the underlying nature of client–provider interactions and integration of person-centred communication (PCC) behaviours (e.g. shared decision-making, attention to empathy, open-ended questions and using discretionary power to accommodate client needs) [15, 19–25]. A deeper understanding of these interactions and patterns, frequencies and typologies of client–provider communication behaviours can help inform strategies to improve the person-centredness and quality of care delivery, and, ultimately, long-term outcomes in public health HIV facilities [7, 10, 15, 19, 26–30].

Standardized assessments of client–provider communication that seek to quantify and characterize patterns of communications can yield insights into the frequency and types of different communication behaviours that help contextualize the experiences and gaps reported by clients and providers. Qualitative evidence suggests that rude behaviour and scolding drive people out care and also discourage them from returning after lapses, but it is not immediately clear how prevalent and frequent these behaviours are [1–13]. Furthermore, communication can often be hierarchical, directive and dominated by the provider with limited efforts to elicit input from clients regarding preferences or anticipated challenges with care/treatment, which can further exacerbate other ongoing barriers (e.g. competing obligations and stigma) [13, 21–23, 29, 31–36]. Due to different roles and responsibilities in overburdened health systems, these behaviours and interaction dynamics may also manifest differently across healthcare worker (HCW) cadres [21, 22, 31, 37–39]. Systematically characterizing the different patterns of client–provider communication can thus reveal valuable insights about its current state in public health HIV clinics and help to build a better understanding of the road forward for delivering truly person-centred care.

In this study, we used the Roter interaction analysis system (RIAS) to systematically parse and characterize patterns of PCC behaviours in Zambia. RIAS is a validated method for assessing and quantifying aspects of client–provider communication that has been used globally across diverse settings [29, 32, 33, 39–45]. We then used latent class analysis (LCA) to identify distinctive profiles of communication during routine HIV follow-up visits in public health facilities in Zambia and assessed how they vary across client, provider, interaction and facility characteristics.

2 | METHODS

2.1 | Study population and setting

We enrolled dyads of adults living with HIV (18 years or older) making a routine visit for HIV care and their HIV care providers for that visit between August 2019 and November 2021 from 24 facilities in Lusaka province. Facilities were run by the Ministry of Health and received technical assistance from the Centre for Infectious Disease Research in Zambia (CIDRZ). Each facility provided similar HIV treatment services and cared for populations requiring similar levels of care (site selection was driven primarily by proximity), although catchment area demographics, staffing, HCW cadre representation and facility infrastructure could vary (Table S1).

All care providers conducting routine HIV monitoring visits at facilities were offered enrolment and consented at study initiation during staff meetings. This included nurses, clinical officers (similar to physician assistant) and medical officers (similar to a medical doctor). Due to the task-shifting for Antiretroviral Therapy (ART) scale-up, each HCW cadre is trained to provide appropriate care for routine HIV follow-up (i.e. visits scheduled every 3–6 months for monitoring) in public health HIV facilities in Zambia.

On days that previously enrolled providers were in clinic, people living with HIV presenting to facilities for a routine HIV follow-up visit were conveniently sampled from the waiting room and consented prior to entering the consultation room (typically 20–30 minutes beforehand). As providers and clients were consented independently, some enrolled providers may not have seen an enrolled client due to normal staff rotations and transfers. These procedures provided for a sample that was representative of routine public health HIV services in Zambia. Those presenting for more specialized or focused visits (e.g. enhanced adherence counselling visits, tuberculosis or maternal and child health) were not included. Due to COVID-19, all study activities and recruitment were paused from 24 March to 16 June 2020, which also coincided with when a majority of healthcare disruptions occurred [46, 47]. After this period, healthcare and in-person visits began to normalize, but individuals were often provided longer refills to reduce facility traffic; this practice continued even after the initial COVID-19 lockdown period [46]. The official “lockdown” period lasted until 30 August 2020 in Zambia.

2.2 | Procedure and measurements

After obtaining consent, we audio-recorded the routine HIV follow-up interaction between clients and their providers. We used remote-controlled audio-recorders that were discretely placed in provider rooms to remotely start and stop recording when an enrolled client entered and left the consultation room. These procedures allowed for unobtrusive recording in order to mitigate changes to client or provider communication behaviours due to awareness of being observed (i.e. Hawthorne effect).

Audio-recorded visits were linked to the participant and visit data from the national electronic health record (EHR) used in routine HIV care in Zambia. This EHR contains

Table 1. Description of Roter interaction analysis system (RIAS) codes

RIAS composite code	Description
Partnership (Doc)	Percent of statements that are partnering statements by provider (e.g. asking opinion, checking understanding and positive statement)
Medical question (Doc)	Percent of statements that are questions about medical/therapeutic topics
Psychosocial question (Doc)	Percent of statements that are questions about psychosocial/lifestyle topics
Medical information (Doc)	Percent of statements that are information/counselling about medical/therapeutic topics
Psychosocial information (Doc)	Percent of statements that are information/counselling about psychosocial/lifestyle topics
Psychosocial-medical ratio	Ratio of psychosocial to medical questions/statement
Provider speech ratio (Doc)	Percent of utterances from provider
Open-ended question (Doc)	Percent of questions that were open-ended (vs. close-ended)
Rapport building	Percent of interactions with at least one provider statement meant to build rapport with the client
PCC micropractice	Percent of interactions with at least one small client-centred practice by provider (e.g. asking for feedback, providing encouragement and explaining decision rationale)
Barriers to HIV care	Percent of interactions where barriers to HIV care were assessed by provider
Person-centred counselling	Percent of interactions where principles from PCC were integrated into counselling (e.g. empathy, offering encouragement and asking for understanding)
Shared decision-making	Percent of interactions where providers used shared decision-making (i.e. jointly decided care plan with input from client)
Discretionary power	Percent of interactions where providers leveraged discretionary power to better align care with client needs

Abbreviations: PCC, Person-centred communication; Doc, Doctor.

socio-demographic (e.g. age, sex and clinic site), clinical (date of ART initiation and WHO stage) and visit history (dates and scheduled appointment) measurements. Individuals were linked using identification numbers; visits were linked if they were within 5 days of each other to account for minor discrepancies in data entry into the EHR.

2.3 | Analyses

Audio-recordings of client–provider interactions were coded using RIAS. RIAS is a quantitative method of coding designed to parse and classify client and provider communication into operationally defined codes and standardized dimensions [40–42, 45]. It has been previously validated across a wide range of clinical and cultural settings, and quantifies aspects of communication that have been associated with outcomes, such as satisfaction and adherence [29, 32, 33, 39–44]. The RIAS method involves coders assigning each utterance (i.e. a statement representing a complete thought) made by the client or provider into one of 37 mutually exclusive and exhaustive categories based on standardized definitions, such as question-asking (e.g. open vs. closed), information-giving (e.g. clinical vs. psychosocial), socio-emotional communication (e.g. empathy statements and rapport building) and provider:client speech ratio [40–42]. We also generated study-specific codes to use with the RIAS method that identified occurrences of PCC behaviours emphasized in our previous formative work and PCC frameworks (Tables 1 and S2) [1, 4, 15, 19, 21, 23, 25]. These included rapport building, PCC micropractices (i.e. brief PCC behaviours, such as offering encouragement, checking for understanding), assessing barriers to HIV care, person-centred counselling (i.e. counselling

incorporating PCC behaviours like empathy, validation), use of shared decision-making and leveraging discretionary power (i.e. using discretion in decision-making to better meet client needs) [1, 4, 15, 19–23, 25].

Coding was conducted by three CIDRZ qualitative researchers who were fluent in local languages (i.e. Nyanja, Bemba and English). Coders were trained in the RIAS method during a 3-day intensive workshop held in August 2019 in Lusaka, Zambia, and demonstrated a high degree of inter-coder reliability during training (Pearson correlation 0.8).

2.4 | Statistical analyses

We performed LCA to identify and characterize interactions with distinctive profiles of PCC behaviours using data generated from RIAS coding. LCA is a well-established data-driven method to empirically identify groups that have distinctive patterns in their data that are not readily observed or identified [48]. In our LCA, we included variables on the frequency of different types of speech (e.g. medical/psychosocial questions or information giving, partnering statements), ratios of different types of speech (e.g. provider-client utterance ratio, psychosocial-medical utterance ratio, percent open- vs. closed-ended questions) and the PCC-specific RIAS codes (Tables 1 and S2). After systematically tested model fit with differing number of classes, we selected a final model that was optimized for fit and parsimony—using Akaike’s Information Criterion and Bayesian Information Criterion—and interpretability—using contextual knowledge [48, 49]. From this final data-driven model, we then estimated the probability of each client–provider interaction belonging to a

specific latent class (i.e. communication profile) based on their observed patterns (i.e. estimated posterior probabilities) and assigned them to the latent class to which they were most likely to belong (i.e. the maximal probability rule) [48, 49]. We assessed the adequacy and fit of the final model and group assignment using several established metrics [48, 49]. Lastly, each profile was named to descriptions of communication patterns observed.

We describe RIAS patterns for client–provider interactions overall as well as by HCW cadre. To identify associations with client, provider, interaction, and facility characteristics and communication profiles, we describe the distribution of latent classes (i.e. communication profiles) and assess variability across these characteristics. For both, we used Kruskal–Wallis and Pearson chi-square tests, as appropriate. As a sensitivity analysis, we used multinomial logistic regression to assess the association between communication profiles and client, provider, interaction and facility-level characteristics after also *adjusting* for these characteristics. Lastly, as an exploratory analysis among visits that could be linked to the EHR, we assessed whether the communication profile at the current visit was associated with being more than 30 days late for the next appointment using mixed-effects Poisson regression with robust variances (Supplementary Appendix).

Additional details on our statistical analyses are provided in the Supplementary Appendix.

All analyses were conducted using Stata (Version 17.0, College Station, Texas). This descriptive substudy represents a secondary analysis embedded within a larger parent stepped-wedge cluster-randomized trial–Leveraging Person-Centred Public Health (PCPH) to improve HIV outcomes in Zambia (PACTR202101847907585). Sample size calculations were for the primary trial; there were no formal calculations for this secondary analysis. The study was approved by the University of Zambia Biomedical Research Ethics Committee (UNZ-ABREC) (March 2019) in Zambia and institutional review boards at the University of Alabama, Birmingham School of Medicine (June 2019) and Washington University in St. Louis (July 2019) in the United States. This paper was prepared according to STROBE guidelines.

3 | RESULTS

3.1 | Client, provider, interaction and facility characteristics

Between 1 August 2019 and 1 November 2021, we enrolled and audio-recorded interactions between 478 people living with HIV and 139 providers from 24 facilities (Figure 1). 14% of HCWs were nurses, 73.6% were clinical officers and 12.3% were medical officers. Among clients, 62.6% were female, and most were between 30 and 50 years old. 52.7% of interactions occurred in Nyanja, 31.8% in English and 15.5% in Bemba. The median length of interactions was 7.8 minutes (IQR 5.5–11.9). 17.8% of interactions occurred prior to the COVID-19 pandemic (1 August 2019–31 March 2020), 11.9% occurred during the initial lockdown period (1 April 2020–31 August 2020) and 70.3% of interactions occurred afterwards (1 September 2020–1 November 2021) (Table 2).

Interactions, in general, focused primarily on medical topics with providers speaking a majority of the time. Open-ended questions were very rare compared to close-ended questions (although slightly more common among clinical officers). Clinical officers asked more questions (particularly medical), whereas nurses provided more information statements. PCC behaviours, such as rapport building, and PCC micropractices were more common, but more complex behaviours, such as using shared decision-making and discretionary power, were rarer. Nurses spent more time with clients compared to clinical and medical officers (Tables 3 and S3).

3.2 | Description of latent classes

We selected the model with four latent classes (i.e. profiles of client–provider interactions) based on model fit and interpretability (Figure 2, Tables S4 and S5). 47.6% (95% CI 41.5–53.8%) of interactions were characterized by discussion predominately around medical topics, minimal discussion of psychosocial topics and relatively low use of PCC behaviours, such as shared decision-making and leveraging discretionary power (“Medically Oriented Interaction, Minimal PCC Behaviours”). The second class (“Balanced Medical/Non-medical Interaction, Low PCC Behaviours” group, 21.0% of interactions [95% CI 16.5–26.4%]) was characterized by more balance between medical and psychosocial topics, but still low use of PCC behaviours. The third class (“Medically Oriented Interaction, Good PCC Behaviours” group, 23.9% of interactions [95% CI 19.1–29.4%]) was characterized again by predominately medically oriented discussion, but greater use of PCC behaviours, including integrating PCC principles into counselling, using more PCC micropractices, assessing barriers to HIV care and using shared decision-making. The final class (“Highly person-centred Interaction” group) represented only 7.5% (95% CI 5.2–10.6%) of interactions but was characterized by discussion of both medical and psychosocial topics and the highest use of PCC behaviours. Several diagnostic metrics indicated that this final model had very good fit and separation between classes (Table 4).

3.3 | Characteristics associated with latent classes

There were a few notable associations between client, provider, interaction, and facility characteristics and different communication profiles. Interactions integrating more PCC behaviours (“Medically Oriented, Good PCC Behaviours” and “Highly person-centred Interaction” groups) were more frequent with nurses, while less person-centred interactions (“Medically Oriented Interaction, Minimal PCC Behaviours” and “Balanced Medical/Non-medical Interaction, Low PCC Behaviours” groups) were more common with clinical officers. Profiles with more PCC behaviours were also more common at hospital-based and small clinics compared to medium and large clinics as well as integrated compared to non-integrated ART clinics. Third, the increased length of the interaction was associated with profiles with more PCC behaviours. In general, interactions with younger age groups (18–30 and 31–40 year-olds) tended to integrate more PCC behaviours compared to older clients. There was no association with client or

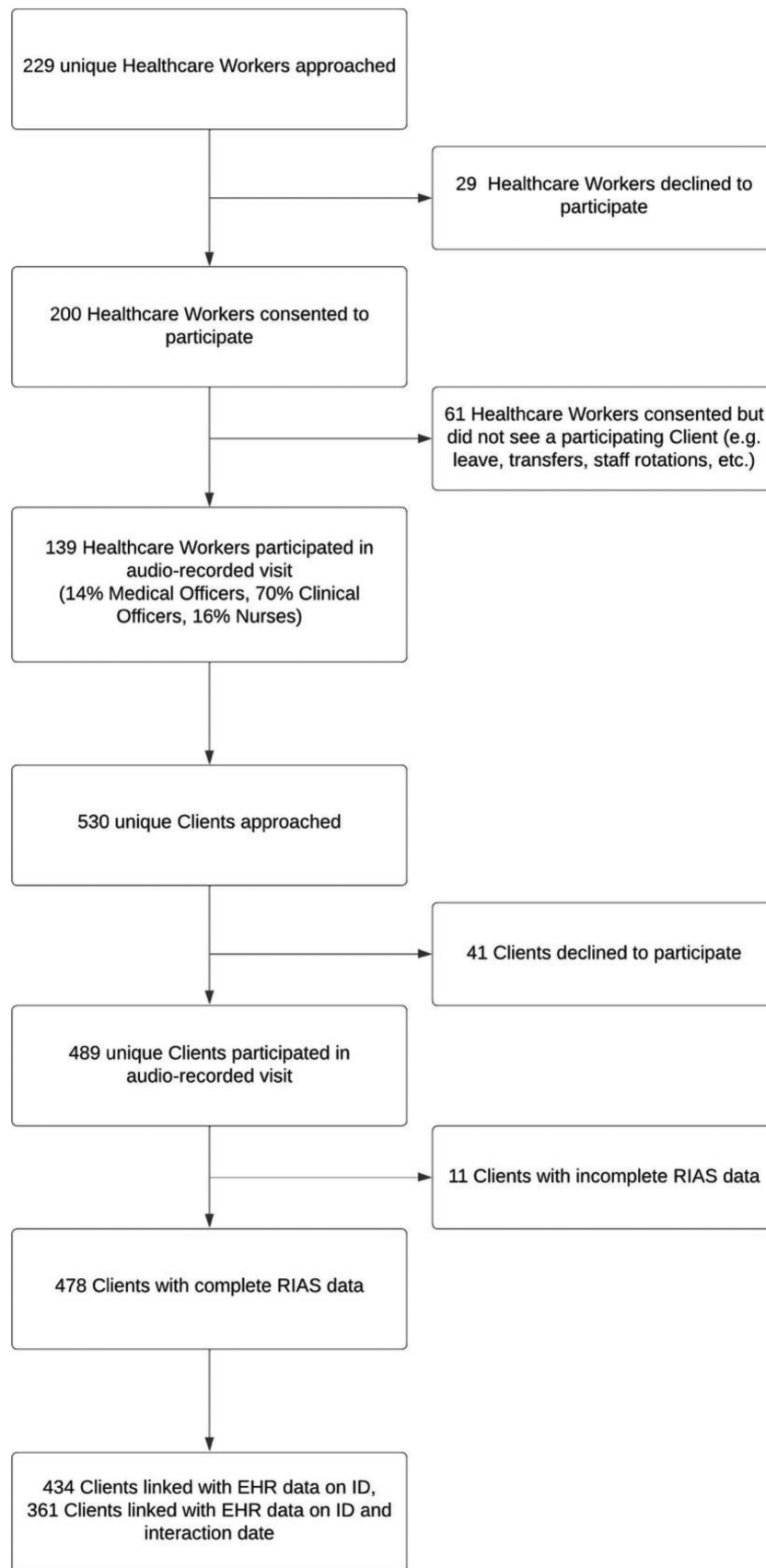


Figure 1. Participant flowchart. Abbreviations: EHR, electronic health record; RIAS, Roter interaction analysis system

Table 2. Client, provider, interaction and facility characteristics (N = 478)

Client	Overall (N = 478)	Nurse (n = 67)	Clinical officer (n = 352)	Medical officer (n = 59)	p-value
Client					
Sex, n (%)					
Female	299 (62.6%)	41 (61.2%)	220 (62.5%)	38 (64.4%)	0.93
Male	179 (37.4%)	26 (38.8%)	132 (37.5%)	21 (35.6%)	
Age, n (%)					
18–30 years	89 (18.6%)	10 (14.9%)	71 (20.2%)	8 (13.6%)	0.76
31–40 years	160 (33.5%)	23 (34.3%)	116 (33.0%)	21 (35.6%)	
41–50 years	137 (28.7%)	20 (29.9%)	98 (27.8%)	19 (32.2%)	
>50 years	59 (12.3%)	11 (16.4%)	40 (11.4%)	8 (13.6%)	
Missing	33 (6.9%)	3 (4.5%)	27 (7.7%)	3 (5.1%)	
Marital status, n (%)					
Single	67 (14.0%)	12 (17.9%)	44 (12.5%)	11 (18.6%)	0.40
Married	244 (51.0%)	30 (44.8%)	187 (53.1%)	27 (45.8%)	
Divorced	50 (10.5%)	10 (14.9%)	32 (9.1%)	8 (13.6%)	
Widowed	34 (7.1%)	6 (9.0%)	25 (7.1%)	3 (5.1%)	
Missing	83 (17.4%)	9 (13.4%)	64 (18.2%)	10 (16.9%)	
Education, n (%)					
None	17 (3.6%)	4 (6.0%)	12 (3.4%)	1 (1.7%)	0.012
Primary	115 (24.1%)	14 (20.9%)	85 (24.1%)	16 (27.1%)	
Secondary	233 (48.7%)	31 (46.3%)	169 (48.0%)	33 (55.9%)	
University	24 (5.0%)	10 (14.9%)	11 (3.1%)	3 (5.1%)	
Missing	89 (18.6%)	8 (11.9%)	75 (21.3%)	6 (10.2%)	
Time since enrolment in care, n (%)					
<6 months	42 (8.8%)	7 (10.4%)	30 (8.5%)	5 (8.5%)	0.99
6 months–1 year	44 (9.2%)	7 (10.4%)	31 (8.8%)	6 (10.2%)	
1–2 years	53 (11.1%)	8 (11.9%)	38 (10.8%)	7 (11.9%)	
2–5 years	114 (23.8%)	16 (23.9%)	81 (23.0%)	17 (28.8%)	
> 5 years	190 (39.7%)	26 (38.8%)	143 (40.6%)	21 (35.6%)	
Missing	35 (7.3%)	3 (4.5%)	29 (8.2%)	3 (5.1%)	
Enrolment WHO Stage, n (%)					
WHO Stage 1	197 (41.2%)	27 (40.3%)	147 (41.8%)	23 (39.0%)	0.37
WHO Stage 2	54 (11.3%)	12 (17.9%)	38 (10.8%)	4 (6.8%)	
WHO Stage 3	42 (8.8%)	4 (6.0%)	31 (8.8%)	7 (11.9%)	
WHO Stage 4	3 (0.6%)	0 (0.0%)	2 (0.6%)	1 (1.7%)	
Missing	182 (38.1%)	24 (35.8%)	134 (38.1%)	24 (40.7%)	
Provider					
Sex, n (%)					
Female	236 (49.4%)	51 (76.1%)	159 (45.2%)	26 (44.1%)	<0.001
Male	242 (50.6%)	16 (23.9%)	193 (54.8%)	33 (55.9%)	
Provider type, n (%)					
Nurse	67 (14.0%)	–	–	–	–
Clinical officer	352 (73.6%)	–	–	–	–
Medical officer	59 (12.3%)	–	–	–	–
Interaction					
Interaction language, n (%)					
Nyanja	252 (52.7%)	32 (47.8%)	198 (56.2%)	22 (37.3%)	0.012
English	152 (31.8%)	28 (41.8%)	97 (27.6%)	27 (45.8%)	
Bemba	74 (15.5%)	7 (10.4%)	57 (16.2%)	10 (16.9%)	

(Continued)

Table 2. (Continued)

Client	Overall (N = 478)	Nurse (n = 67)	Clinical officer (n = 352)	Medical officer (n = 59)	p-value
Sex concordance (client–provider), n (%)					
Female–female	159 (33.3%)	33 (20.7%)	109 (68.5%)	17 (10.7%)	<0.001
Female–male	140 (29.3%)	8 (5.7%)	111 (79.3%)	21 (15%)	
Male–female	77 (16.1%)	18 (23.3%)	50 (64.9%)	9 (11.7%)	
Male–male	102 (21.3%)	8 (7.8%)	82 (80.3%)	12 (11.7%)	
Time period, n (%)					
01 Aug 2019–31 Mar 2020	85 (17.8%)	14 (20.9%)	55 (15.6%)	16 (27.1%)	0.11
01 Apr 2020–30 Aug 2020	57 (11.9%)	4 (6.0%)	47 (13.4%)	6 (10.2%)	
01 Sept 2020–30 Nov 2021	336 (70.3%)	49 (73.1%)	250 (71.0%)	37 (62.7%)	
Facility					
Facility type ^a , n (%)					
Small clinic	98 (20.5%)	19 (28.4%)	79 (22.4%)	0 (0.0%)	<0.001
Medium clinic	180 (37.7%)	16 (23.9%)	136 (38.6%)	28 (47.5%)	
Large clinic	81 (16.9%)	8 (11.9%)	55 (15.6%)	18 (30.5%)	
Hospital-based clinic	119 (24.9%)	24 (35.8%)	82 (23.3%)	13 (22.0%)	
ART integration ^b , n (%)					
Non-integrated	319 (66.7%)	53 (79.1%)	212 (60.2%)	54 (91.5%)	<0.001
Integrated	159 (33.3%)	14 (20.9%)	140 (39.8%)	5 (8.5%)	
Client:provider ratio ^c , median (IQR)	328 (223, 547)	249 (176, 605)	328 (223, 547)	266 (184, 496)	0.47

^aSmall clinic–0–2500 clients; Medium clinic–2500–10,000 clients; Large clinic–>10,000 clients; Hospital-based clinic–outpatient clinic based at facility that also provided inpatient hospital services.

^bNon-integrated–ART services provided during standalone clinic session; Integrated–ART services integrated with other primary care services.

^cNumber of clients in a facility clinic population over number of providers offering ART services at that facility, averaged quarterly.

Abbreviations: ART, antiretroviral therapy; WHO, World Health Organization.

Table 3. Client–provider communication across healthcare worker cadre using RIAS (N = 478)

	Overall (N = 478)	Nurse (n = 67)	Clinical officer (n = 352)	Medical officer (n = 59)	p-value
Partnership (Doc), mean (SD)	0.24 (0.12)	0.23 (0.11)	0.25 (0.12)	0.21 (0.11)	0.055
Medical question (Doc), mean (SD)	0.20 (0.11)	0.15 (0.09)	0.21 (0.11)	0.18 (0.09)	<0.001
Psychosocial question (Doc), mean (SD)	0.05 (0.05)	0.05 (0.04)	0.05 (0.05)	0.06 (0.05)	0.20
Medical information (Doc), mean (SD)	0.29 (0.16)	0.32 (0.18)	0.28 (0.16)	0.29 (0.19)	0.14
Psychosocial information (Doc), mean (SD)	0.04 (0.06)	0.06 (0.08)	0.04 (0.05)	0.05 (0.06)	0.014
Psychosocial-medical ratio, mean (SD)	0.16 (0.14)	0.18 (0.16)	0.15 (0.13)	0.20 (0.14)	0.018
Provider speech ratio, mean (SD)	0.59 (0.07)	0.59 (0.07)	0.59 (0.07)	0.59 (0.07)	0.85
Open-ended questions (Doc), mean (SD)	0.02 (0.04)	0.01 (0.02)	0.03 (0.04)	0.01 (0.02)	<0.001
Rapport building, n (%)	425 (88.9%)	61 (91.0%)	313 (88.9%)	51 (86.4%)	0.71
PCC micropractice	320 (66.9%)	52 (77.6%)	234 (66.5%)	34 (57.6%)	0.055
Barriers to HIV care, n (%)	196 (41.0%)	22 (32.8%)	144 (40.9%)	30 (50.8%)	0.12
Person-centred counselling, n (%)	198 (41.4%)	33 (49.3%)	146 (41.5%)	19 (32.2%)	0.15
Shared decision-making, n (%)	114 (23.8%)	16 (23.9%)	86 (24.4%)	12 (20.3%)	0.79
Discretionary power, n (%)	45 (9.4%)	9 (13.4%)	30 (8.5%)	6 (10.2%)	0.44
Interaction length in minute, median (IQR)	7.8 (5.5–11.9)	12.3 (7.0–18.1)	7.4 (5.2–11.0)	8.5 (5.8–12.1)	<0.001

Abbreviations: SD, standard deviation; IQR, interquartile range; Doc, doctor.

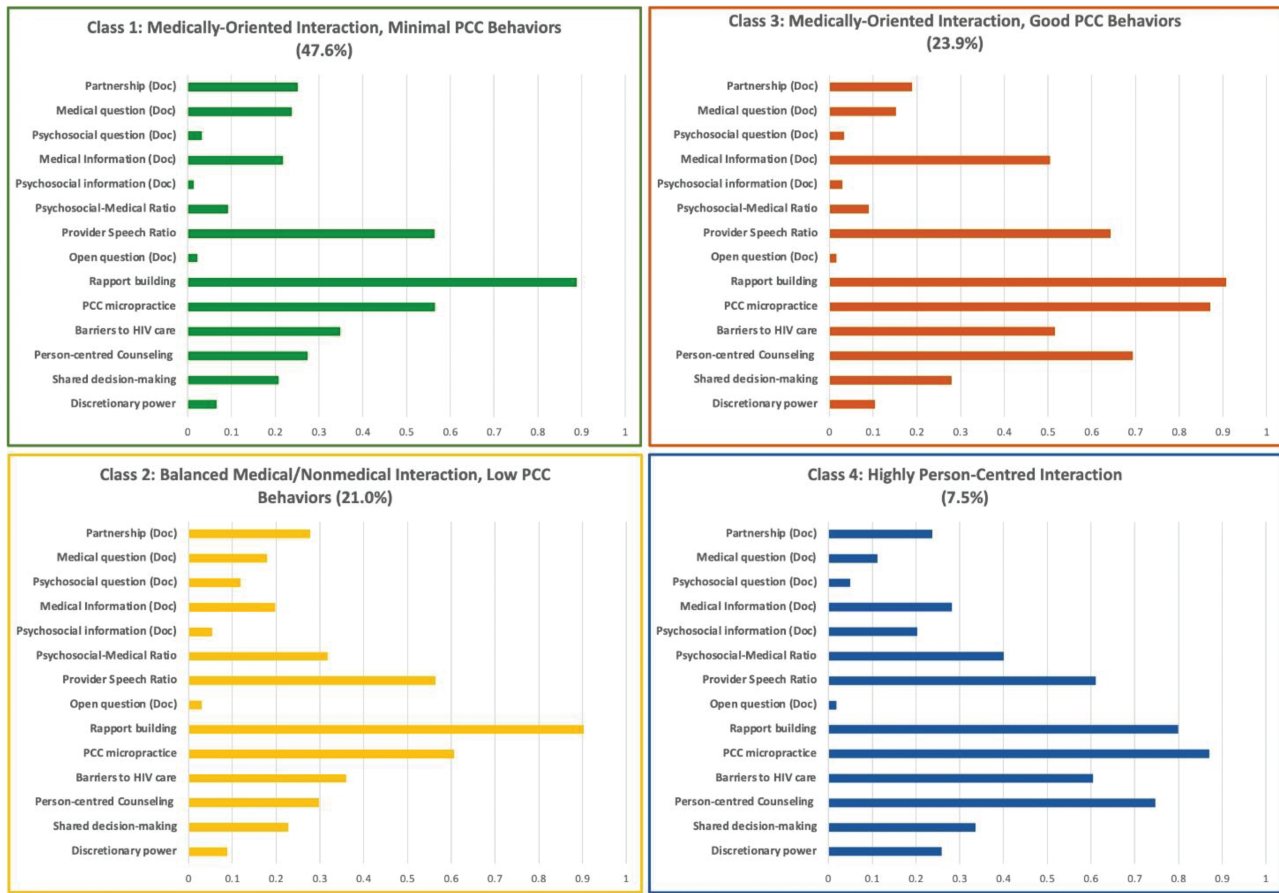


Figure 2. Profiles of client-provider communication using Roter interaction analysis system (RIAS) (N = 478). Communication profiles are based on latent class models using measurements from RIAS coding. Abbreviations: Doc, doctor; PCC, person-centred communication

Table 4. Metrics of adequacy and fit of latent class model

Class	Class size	Group average posterior probability	Odds ratio for correct classification	Estimated group distribution using maximal probability rule	Estimated group distribution based on initial model	Entropy
Medically oriented interaction, minimal PCC behaviours	237	0.918	12.4	0.496	0.476	0.87
Balanced medical/non-medical interaction	95	0.937	56.0	0.199	0.210	
Medically oriented interaction, good PCC behaviours	111	0.92	36.5	0.232	0.239	
Highly person-centred interaction	35	0.961	306	0.073	0.075	

Note: Good model fit indicated by (1) average posterior probability greater than 0.7 for each group; (2) odds ratio of correct classification greater than 5 for each group; (3) close correspondence between the estimated group distribution based on using posterior probabilities and the maximal probability rule compared with the estimated group distribution from the initial model; and (4) an entropy greater than 0.8. Abbreviation: PCC, Person-centred communication.

provider sex nor sex concordance and PCC behaviour profiles. Last, integration of PCC behaviours increased over time, with no change in trend during COVID-19 (Table 5). These patterns were similar in adjusted sensitivity analyses (Table S6).

3.4 | Association between latent class and missing the next visit

Interactions during the COVID-19 lockdown period and longer interactions were associated with a higher likelihood of being more than 30 days late for the next visit. There were few other client, provider, interaction or facility characteristics associated with being late, including provider communication profile (Table S7).

4 | DISCUSSION

We identified four distinctive client–provider communication profiles in public HIV clinics in Zambia: 47.6% were predominately medically oriented with minimal PCC behaviours; 21.0% had a balance of medical and psychosocial discussion, but still low use of PCC; 23.9% were predominately medically oriented but had high use of PCC behaviours; and 7.5% demonstrated very high use of PCC behaviours, including shared decision-making, use of discretionary power or integrating PCC principles into their counselling. Interactions with nurses and those that were longer tended to incorporate more PCC behaviours. These results provide deeper insights into the frequency and patterns of communication behaviours between clients and providers, and offer an important window into one of the key determinants of the client experience in public HIV clinics in Zambia.

Our study uses standardized procedures to parse and quantify communication behaviours during routine HIV monitoring visits in Zambia. Poor client–provider communication and interactions (e.g. rude behaviour and scolding) have been identified as a key determinant of the client experience and retention in care in these settings [1–13]. Our assessment extends and complements this existing evidence by characterizing the frequencies and typologies of these known gaps between client–provider communication and what clients desire [1, 7, 10, 21, 23, 25, 32]. We note that a majority of interactions focus primarily on medical topics, although a small but noticeable percentage of interactions give significant attention to psychosocial topics. Open-ended questions were relatively infrequent compared to closed-ended questions. Second, we find that more complex person-centred behaviours, such as shared decision-making, leveraging discretionary powers and integrated person-centred practices into counselling, are still quite rare in public HIV clinics in Zambia. This may be a manifestation of the time and cognitive/emotional effort often required for these behaviours, which can be limited in overburdened facilities [31, 37, 50]. Nevertheless, the use of shared decision-making and discretionary power can facilitate alignment of care delivery with clients' needs and preferences, and thus may have meaningful impacts on the client experience [7, 15, 19–23, 25, 32]. Third, we find that providers practice rapport building (e.g. greetings and welcoming statements) and PCC micropractices with high frequency and that overtly negative interactions were

also rare, which aligns with prior studies using client satisfaction surveys [10–12, 51]. Still, even occasional lapses (approximately 10% of interactions lacked any rapport-building statements in our study) will cumulatively expose a substantial proportion of individuals over their care journey to a potentially negative interaction that could trigger a lapse in care. Lastly, these communication patterns, generally, fairly consistent across client, provider, interaction and facility characteristics (with some notable exceptions), and the totality of these findings also align remarkably well with client–provider communication patterns that have been previously identified, even across very different clinical and cultural settings [32, 34, 40, 42, 43, 45]. Still, it will be key to contextualize and validate these findings further, particularly to understand how these profiles reflect client experiences and capture what is relevant and desirable to them in our setting.

Patterns of communication appeared to differ across HCW cadres. Nurses tended to spend more time with clients and have interactions characterized by more person-centred behaviours (and to a lesser extent medical officers). This is in contrast to clinical officers who had shorter interactions and fewer interactions classified with person-centred behaviours. These differences may in part be attributable to our finding that nurses spent more time providing information or counselling as opposed to question-asking (which was more frequent among clinical and medical officers). Moreover, differences in the hierarchy between clients and providers may have influenced these communication patterns [13, 21–23, 31–34]. Importantly, it should also be recognized that these patterns may relate to the underlying reason for the visit and staffing at different facilities, rather than behaviours attributable to the cadre itself. For example, we found an association between longer visits and an increased likelihood of being late for the next visit, but this may have been driven by an increased complexity or challenges faced by those clients. Also, although we did not find clear evidence of this in our study, in Zambia, medical and clinical officers may sometimes be tasked to see individuals with more complex disease compared to their nurse colleagues, altering the nature of the interaction. Thus, it is critical to understand the primary drivers of these different patterns of communication behaviours (e.g. higher quality communication behaviour vs. nature of interaction vs. facility culture and climate) so that the appropriate improvement efforts can be targeted and prioritized.

Communication between client and provider is complex—varying across roles, purpose, setting and circumstances—and this dimensionality needs to be considered in strategies to improve the client experience and person-centredness of care delivery. Negative HCW interactions impact long-term retention in HIV care [1–12], so it is imperative that health systems continuously foster the awareness and skills in providers for improving the care experience [14, 15, 23, 29, 30, 34]. Integrating skills to nurture trust and confidence throughout HCW training may help PCC behaviours become normalized skills at an earlier stage. Our findings suggest that providers do frequently use rapport-building and brief person-centred behaviours, but there is likely a need to prioritize more open-ended questions and attention to psychosocial factors to facilitate more holistic discussions.

Table 5. Client, provider, interaction and facility characteristics by latent class (N = 478)

	Medically oriented interaction, minimal PCC behaviours (n = 237)	Balanced medical/ non-medical interaction, low PCC behaviours (n = 95)	Medically oriented interaction, good PCC behaviours (n = 111)	Highly person-centred interaction (n = 35)	p-value
Client					
Sex, n (%)					
Female	147 (49.1%)	65 (21.7%)	69 (23.0%)	18 (6.0%)	0.35
Male	90 (50.2%)	30 (16.7%)	42 (23.4%)	17 (9.5%)	
Age, n (%)					
18–30 years	37 (41.6%)	17 (19.1%)	29 (32.6%)	6 (6.7%)	0.025
31–40 years	67 (41.9%)	35 (21.9%)	41 (25.6%)	17 (10.6%)	
41–50 years	75 (54.7%)	32 (23.4%)	21 (15.3%)	9 (6.6%)	
>50 years	34 (57.6%)	8 (13.6%)	16 (27.1%)	1 (1.7%)	
Marital status, n (%)					
Single	30 (44.8%)	16 (23.9%)	16 (23.9%)	5 (7.5%)	0.64
Married	122 (50%)	47 (19.3%)	57 (23.4%)	18(7.4%)	
Divorced	21 (42%)	13 (26%)	9 (18%)	7 (14%)	
Widowed	19 (55.9%)	4 (11.8%)	9 (26.5%)	2 (5.9%)	
Education, n (%)					
None	10 (58.8%)	1 (5.9%)	5 (29.4%)	1 (5.9%)	0.097
Primary	59 (51.3%)	29 (25.2%)	18 (15.7%)	9 (7.8%)	
Secondary	96 (41.2%)	52 (22.3%)	65 (27.9%)	20 (8.6%)	
University	13 (54.2%)	1 (4.2%)	8 (33.3%)	2(8.3%)	
Time since enrolment in care, n (%)					
<6 months	19 (45.2%)	9 (21.4%)	10 (23.8%)	4 (9.5%)	0.85
6 months–1 year	20 (45.5%)	9 (20.5%)	11 (25%)	4 (9.1%)	
1–2 years	26 (49.1%)	12 (22.6%)	13 (24.5%)	2 (3.8%)	
2–5 years	48 (42.1%)	21 (18.4%)	35 (30.7%)	10 (8.8%)	
> 5 years	98 (51.6%)	41 (21.6%)	38 (20%)	13 (6.8%)	
Enrolment WHO Stage, n (%)					
WHO Stage 1	102 (51.8%)	36 (18.3%)	47 (23.9%)	12 (6.1%)	0.56
WHO Stage 2	26 (48.2%)	8 (14.8%)	15 (27.8%)	5 (9.3%)	
WHO Stage 3	24 (57.1%)	8 (19.1%)	6 (14.3%)	4 (9.5%)	
WHO Stage 4	2 (66.7%)	0 (0%)	0 (0%)	1 (33.3%)	
Provider					
Sex, n (%)					
Female	106 (44.9%)	52 (22%)	59 (25%)	19 (8.1%)	0.25
Male	131 (54.1%)	43 (17.8%)	52 (21.5%)	16 (6.6%)	
Provider type, n (%)					
Nurse	26 (38.8%)	11 (16.4%)	23 (34.3%)	7 (10.5%)	0.031
Clinical officer	189 (53.7%)	67 (19%)	74 (21%)	22 (6.3%)	
Medical officer	22 (37.3%)	17 (28.8%)	14 (23.7%)	6 (10.2%)	
Interaction					
Interaction language, n (%)					
Nyanja	128 (50.8%)	50 (19.8%)	51 (20.2%)	23 (9.1%)	0.12
English	67 (44.1%)	30 (19.7%)	47 (30.9%)	8 (5.3%)	
Bemba	42 (56.8%)	15 (20.3%)	13 (17.6%)	4 (5.4%)	

(Continued)

Table 5. (Continued)

	Medically oriented interaction, minimal PCC behaviours (n = 237)	Balanced medical/non-medical interaction, low PCC behaviours (n = 95)	Medically oriented interaction, good PCC behaviours (n = 111)	Highly person-centred interaction (n = 35)	p-value
Sex concordance (client–provider), n (%)					
Female–female	75 (47.2%)	35 (22%)	39 (24.5%)	10 (6.3%)	0.37
Female–male	72 (51.4%)	30 (21.4%)	30 (21.4%)	8 (5.7%)	
Male–female	31 (40.3%)	17 (22.1%)	20 (26%)	9 (11.7%)	
Male–male	59 (57.8%)	13 (12.8%)	22 (21.6%)	8 (7.8%)	
Time period, n (%)					
01 Aug 2019–31 Mar 2020	64 (75.3%)	14 (16.5%)	3 (3.5%)	4 (4.7%)	<0.001
01 Apr 2020–30 Aug 2020	29 (50.9%)	12 (21.1%)	14 (24.6%)	2 (3.5%)	
01 Sept 2020–30 Nov 2021	144 (42.9%)	69 (20.5%)	94 (28%)	29 (8.6%)	
Interaction length, minute, median (IQR)	7.0 (4.9–10.1)	7.48 (5.8–13.6)	9.4 (6.7–12.7)	11.2 (7.1–17.8)	<0.001
Facility					
Facility type ^a , n (%)					
Small clinic	48 (49.0%)	14 (14.3%)	29 (29.6%)	7 (7.1%)	0.008
Medium clinic	105 (58.3%)	30 (16.7%)	37 (20.6%)	8 (4.4%)	
Large clinic	37 (45.7%)	24 (29.6%)	15 (18.5%)	5 (6.2%)	
Hospital-based clinic	47 (39.5%)	27 (22.7%)	30 (25.2%)	15 (12.6%)	
ART integration ^b , n (%)					
Non-integrated	145 (45.5%)	64 (20.1%)	85 (26.6%)	25 (7.8%)	0.037
Integrated	92 (57.9%)	31 (19.5%)	26 (16.4%)	10 (26.6%)	
Client:provider ratio ^c , median (IQR)	276 (184–517)	276 (176–517)	328 (223–605)	421 (223–605)	0.27

Note: Percentages are calculated across rows to represent the distribution of latent class across client, provider, interaction and facility characteristics.

^aSmall clinic: 0–2500 clients; Medium clinic: 2500–10,000 clients; Large clinic: >10,000 clients; Hospital-based clinic: Outpatient clinic based at facility that also provided inpatient hospital services.

^bNon-integrated: ART services provided during standalone clinic session; Integrated: ART services integrated with other primary care services.

^cNumber of clients in a facility clinic population over number of providers offering ART services at that facility, averaged quarterly.

Abbreviations: ART, antiretroviral therapy; PCC, person-centred communication; IQR, interquartile range; WHO, World Health Organization

Moreover, increased use of shared decision-making and discretionary power—such as identifying convenient return dates and medication refill durations—could allow care delivery to more flexibly meet clients where they are at and avoid precipitating future care lapses [20–23]. This substudy was nested within the larger PCPH study—which sought to assess a multi-component implementation strategy comprised of training and mentoring on principals of person-centred care, systematic audit-and-feedback of the patient experience and a small facility-level incentive for improvements. Although the increase in PCC behaviours over time could have been related to this implementation strategy, this substudy is not able to isolate the cause of these changes away from secular trends due to COVID-19 or a changing healthcare environment. Nevertheless, these skills will be critical in aiding public health

HIV care delivery in Africa to mature beyond often protocolized and algorithmic care to more personalized approaches to public health [15, 17, 52, 53]. Furthermore, linking provider skills training with systematic measurement and feedback of relevant experience metrics (e.g. client-reported outcomes and observed communication behaviours) will also provide more robust guidance on what strategies are needed to better the pivotal interactions between clients and their providers.

There are several limitations of our study. First, these profiles of client–provider communication were generated using a data-driven approach and only provide a descriptive perspective on communication. Although model diagnostics indicated a very good fit, further efforts to validate these profiles against other measures of communication, particularly clients' own assessments of communication, are needed.

Nevertheless, our findings do align with previous research on this topic [10, 11, 21, 25, 31, 32, 34, 35, 40, 42, 43, 45], and generate contextual insights—such as the frequency of different behaviours and provider speaking dominance—that are not commonly captured. Second, differences in communication profiles may be explained by important elements in the interaction outside of what were able to capture (e.g. reason for visit and facility culture). Still, we did not identify substantial differences across measured client, provider, interaction and facility characteristics. Third, we did not assess interactions as clients were triaged or in the waiting room and the RIAS coding system may not have captured all the relevant dimensions of communication during consultations (even though specifically captured PCC behaviours identified as relevant during formative work [e.g. discretionary power, assessing barriers to HIV care and shared decision-making]). Thus, measures may have been limited in their abilities to quantitatively capture the relationship between communication and missing the subsequent visit in exploratory analyses. Fourth, HCW or client behaviour may have been affected by knowing they were being observed (i.e. Hawthorne effect). We did, however, seek to minimize this bias as much as possible by consenting providers far beforehand and using remote-controlled audio-recorders. Fifth, we were unable to link some of the clients and visits to the EHR. Lastly, our sample size may have been too small to identify more nuanced differences, particularly given the known heterogeneity across facilities. Still, the variability in our sample was representative of HIV care in Zambia.

5 | CONCLUSIONS

We used novel methods to quantitatively parse and characterize distinctive patterns of provider communication behaviours in public HIV clinics in Zambia. We identified four unique interaction profiles that varied in the degree to which they integrated PCC behaviours and were distributed across HCW cadres. These findings provide a nuanced characterization of the frequency and typologies of client–provider communication in the Zambian settings and highlight behaviours (e.g. use of shared decision-making and discretionary power, reducing provider speech dominance) that may be strengthened to improve the client experience, care quality and long-term engagement in public health HIV programmes.

AUTHORS' AFFILIATIONS

¹Centre for Infectious Disease Research in Zambia, Lusaka, Zambia; ²University of Washington St. Louis, St. Louis, Missouri, USA; ³Department of Health, Behaviour and Society, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, USA; ⁴Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, USA; ⁵California Department of Public Health, Richmond, California, USA; ⁶Department of Medicine, University of California San Francisco, San Francisco, California, USA; ⁷Centre for Global Health and Quality, Georgetown University Medical Center, Washington, DC, USA; ⁸Department of Medicine, University of California San Francisco, San Francisco, California, USA

COMPETING INTERESTS

All the authors declare that they have no competing interests.

AUTHORS' CONTRIBUTIONS

AM and EHG conceived the study. NM, AM, SR, AS, LKB, HN, MF, KL and CM conducted the analysis and interpretation of data. NM coordinated the data collection. NM and AM wrote the first draft of the manuscript. AS, SR, LKB, DLR, CM, KC, IS, CB-M, CBH and EHG provided critical feedback to enhance the intellectual content of the manuscript. All authors read and approved the final manuscript.

ACKNOWLEDGEMENTS

The authors would like to recognize and thank the participants who willingly gave their time to this study, the Zambian Ministry of Health for supporting the study, and the data collection and study management teams.

FUNDING

This study was funded by the Bill & Melinda Gates Foundation (Grant number INV-010563) and the National Institutes of Health (KL2 TRO02346 to AM and K24 AI134413 to EHG). The funders had no role in study design, data collection, data analysis, data interpretation or writing of the report.

DISCLAIMER

The authors alone are responsible for the views expressed in this publication and these do not necessarily represent the decision or stated policy of the Centre for Infectious Disease Research in Zambia (CIDRZ). The content is solely the responsibility of the authors and does not necessarily represent the official views of the Bill & Melinda Gates Foundation or the National Institutes of Health.

DATA AVAILABILITY STATEMENT

The transcripts and datasets generated and/or analysed during this qualitative study are not publicly available due to privacy provisions but are available from the corresponding author on approval from the authorizing institutional review board.

REFERENCES

1. Mwamba C, Sharma A, Mukamba N, Beres L, Geng E, Holmes CB, et al. 'They care rudely!': resourcing and relational health system factors that influence retention in care for people living with HIV in Zambia. *BMJ Glob Health*. 2018;3(5):e001007.
2. Ware NC, Wyatt MA, Geng EH, Kaaya SF, Agbaji OO, Muyindike WR, et al. Toward an understanding of disengagement from HIV treatment and care in sub-Saharan Africa: a qualitative study. *PLoS Med*. 2013;10(1):e1001369.
3. Eshun-Wilson I, Rohwer A, Hendricks L, Oliver S, Garner P. Being HIV positive and staying on antiretroviral therapy in Africa: a qualitative systematic review and theoretical model. *PLoS One*. 2019;14(1):e0210408.
4. Zanolini A, Sikombe K, Sikazwe I, Eshun-Wilson I, Somwe P, Bolton Moore C, et al. Understanding preferences for HIV care and treatment in Zambia: evidence from a discrete choice experiment among patients who have been lost to follow-up. *PLoS Med*. 2018;15(8):e1002636.
5. Topp SM, Mwamba C, Sharma A, Mukamba N, Beres LK, Geng E, et al. Rethinking retention: mapping interactions between multiple factors that influence long-term engagement in HIV care. *PLoS One*. 2018;13(3):e0193641.
6. Layer EH, Brahmabhatt H, Beckham SW, Ntogwisangu J, Mwampashi A, Davis WW, et al. "I pray that they accept me without scolding:" experiences with disengagement and re-engagement in HIV care and treatment services in Tanzania. *AIDS Patient Care STDs*. 2014;28(9):483–8.
7. Hurley EA, Harvey SA, Winch PJ, Keita M, Roter DL, Doumbia S, et al. The role of patient–provider communication in engagement and re-engagement in HIV treatment in Bamako, Mali: a qualitative study. *J Health Commun*. 2018;23(2):129–43.
8. Mody A, Sikombe K, Beres LK, Simbeza S, Mukamba N, Eshun-Wilson I, et al. Profiles of HIV care disruptions among adult patients lost to follow-up in Zambia: a latent class analysis. *J Acquir Immune Defic Syndr*. 2021;86(1):62–72.
9. Sikazwe I, Eshun-Wilson I, Sikombe K, Beres LK, Somwe P, Mody A, et al. Patient-reported reasons for stopping care or switching clinics in Zambia: a multi-site, regionally representative estimate using a multi-stage sampling-based approach in Zambia. *Clin Infect Dis*. 2020;73(7):e2294–e2302.
10. Wachira J, Middlestadt S, Reece M, Peng CY, Braitstein P. Physician communication behaviors from the perspective of adult HIV patients in Kenya. *Int J Qual Health Care*. 2014;26(2):190–7.

11. Wachira J, Mwangi A, Chemutai D, Nyambura M, Genberg B, Wilson IB. Higher clinician–patient communication is associated with greater satisfaction with HIV care. *J Int Assoc Provid AIDS Care*. **2021**;20:1–7.
12. Mukamba N, Chilyabanyama ON, Beres LK, Simbeza S, Sikombe K, Padian N, et al. Patients' satisfaction with HIV care providers in public health facilities in Lusaka: a study of patients who were lost-to-follow-up from HIV care and treatment. *AIDS Behav*. **2020**;24(4):1151–60.
13. Ondenge K, Renju J, Bonnington O, Moshabela M, Wamoyi J, Nyamukapa C, et al. 'I am treated well if I adhere to my HIV medication': putting patient–provider interactions in context through insights from qualitative research in five sub-Saharan African countries. *Sex Transm Infect*. **2017**;93(Suppl 3):e052973.
14. Lazarus JV, Safreed-Harmon K, Kamarulzaman A, Anderson J, Leite RB, Behrens G, et al. Consensus statement on the role of health systems in advancing the long-term well-being of people living with HIV. *Nat Commun*. **2021**;12(1):4450.
15. De Man J, Mayega RW, Sarkar N, Waweru E, Leys M, Van Olmen J, et al. Patient-centered care and people-centered health systems in sub-Saharan Africa: why so little of something so badly needed? *Int J Pers Cent Med*. **2016**;6(3):162–73.
16. Roy M, Bolton Moore C, Sikazwe I, Holmes CB. A review of differentiated service delivery for HIV treatment: effectiveness, mechanisms, targeting, and scale. *Curr HIV/AIDS Rep*. **2019**;16(4):324–34.
17. Ehrenkranz P, Grimsrud A, Holmes CB, Preko P, Rabkin M. Expanding the vision for differentiated service delivery: a call for more inclusive and truly patient-centered care for people living with HIV. *J Acquir Immune Defic Syndr*. **2021**;86(2):147–52.
18. Duncombe C, Rosenblum S, Hellmann N, Holmes C, Wilkinson L, Biot M, et al. Reframing HIV care: putting people at the centre of antiretroviral delivery. *Trop Med Int Health*. **2015**;20(4):430–47.
19. Scholl I, Zill JM, Härter M, Dirmaier J. An integrative model of patient-centeredness - a systematic review and concept analysis. *PLoS One*. **2014**;9(9):e107828.
20. Gogovor A, Fakhfakh M, Asmaou Bouba D, Acakpo O, Ayivi-Vinz G, Musabyimana A, et al. Shared decision-making and person-centred care approaches in three African regions. *Z Evid Fortbild Qual Gesundheitsw*. **2022**;171:6–10.
21. Mwamba C, Mukamba N, Sharma A, Lumbo K, Foloko M, Nyirenda H, et al. Provider discretionary power practices to support implementation of patient-centered HIV care in Lusaka, Zambia. *Front Health Serv*. **2022**;2:918874.
22. Gilson L, Schneider H, Orgill M. Practice and power: a review and interpretive synthesis focused on the exercise of discretionary power in policy implementation by front-line providers and managers. *Health Policy Plan*. **2014**;29(Suppl 3):iii51–69.
23. Camara BS, Belaid L, Manet H, Kolie D, Guillard E, Bigirimana T, et al. What do we know about patient–provider interactions in sub-Saharan Africa? A scoping review. *Pan Afr Med J*. **2020**;37:88.
24. Tanenbaum SJ. What is patient-centered care? A typology of models and missions. *Health Care Anal*. **2015**;23(3):272–87.
25. Lau SR, Christensen ST, Andreasen JT. Patients' preferences for patient-centered communication: a survey from an outpatient department in rural Sierra Leone. *Patient Educ Couns*. **2013**;93(2):312–8.
26. Wachira J, Middlestadt S, Reece M, Peng CY, Braitstein P. Psychometric assessment of a physician–patient communication behaviors scale: the perspective of adult HIV patients in Kenya. *AIDS Res Treat*. **2013**;2013:706191.
27. Beach MC, Keruly J, Moore RD. Is the quality of the patient–provider relationship associated with better adherence and health outcomes for patients with HIV? *J Gen Intern Med*. **2006**;21(6):661–5.
28. Flickinger TE, Saha S, Moore RD, Beach MC. Higher quality communication and relationships are associated with improved patient engagement in HIV care. *J Acquir Immune Defic Syndr*. **2013**;63(3):362–6.
29. Beach MC, Roter DL, Saha S, Korthuis PT, Eggly S, Cohn J, et al. Impact of a brief patient and provider intervention to improve the quality of communication about medication adherence among HIV patients. *Patient Educ Couns*. **2015**;98(9):1078–83.
30. Lewin SA, Skea ZC, Entwistle V, Zwarenstein M, Dick J. Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database Syst Rev*. **2001**;4:CD003267. <https://doi.org/10.1002/14651858.CD003267>
31. Wachira J, Genberg B, Kafu C, Koeh B, Akinyi J, Owino RK, et al. The perspective of HIV providers in western Kenya on provider–patient relationships. *J Health Commun*. **2018**;23(6):591–6.
32. Hurley EA, Harvey SA, Keita M, Kennedy CE, Roter D, Dao S, et al. Patient–provider communication styles in HIV treatment programs in Bamako, Mali: a mixed-methods study to define dimensions and measure patient preferences. *SSM Popul Health*. **2017**;3:539–48.
33. Maclachlan EW, Shepard-Perry MG, Ingo P, Uusiku J, Mushimba R, Simwanza R, et al. Evaluating the effectiveness of patient education and empowerment to improve patient–provider interactions in antiretroviral therapy clinics in Namibia. *AIDS Care*. **2016**;28(5):620–7.
34. Hurley EA, Doumbia S, Kennedy CE, Winch PJ, Roter DL, Murray SM, et al. Patient-centred attitudes among medical students in Mali, West Africa: a cross-sectional study. *BMJ Open*. **2018**;8(1):e019224.
35. Abiola T, Udofia O, Abdullahi AT. Patient–doctor relationship: the practice orientation of doctors in Kano, Niger. *J Clin Pract*. **2014**;17(2):241–7.
36. Kwame A, Petruca PM. Communication in nurse–patient interaction in healthcare settings in sub-Saharan Africa: a scoping review. *Int J Afr Nurs Sci*. **2020**;12:100198.
37. Genberg B, Wachira J, Kafu C, Wilson I, Koeh B, Kamene R, et al. Health system factors constrain HIV care providers in delivering high-quality care: perceptions from a qualitative study of providers in western Kenya. *J Int Assoc Provid AIDS Care*. **2019**;18:1–10.
38. Mbindyo P, Blaauw D, English M. The role of clinical officers in the Kenyan health system: a question of perspective. *Hum Resour Health*. **2013**;11:32.
39. Labhardt ND, Aboa SM, Manga E, Bensing JM, Langewitz W. Bridging the gap: how traditional healers interact with their patients. A comparative study in Cameroon. *Trop Med Int Health*. **2010**;15(9):1099–108.
40. Roter D, Larson S. The Roter interaction analysis system (RIAS): utility and flexibility for analysis of medical interactions. *Patient Educ Couns*. **2002**;46(4):243–51.
41. Roter DL, Stewart M, Putnam SM, Lipkin M, jr Stiles W, Inui TS. Communication patterns of primary care physicians. *JAMA*. **1997**;277(4):350–6.
42. Roter D, Ellington L, Erby LH, Larson S, Dudley W. The Genetic Counseling Video Project (GCVP): models of practice. *Am J Med Genet C Semin Med Genet*. **2006**;142c(4):209–20.
43. Jenson A, Roter DL, Mkocho H, Munoz B, West S. Patient-centered communication of community treatment assistants in Tanzania predicts coverage of future mass drug administration for trachoma. *Patient Educ Couns*. **2018**;101(6):1075–81.
44. Ruben MA, Stosic MD, Roter DL. Emotion dialogue in the medical encounter: when and how often does it happen? In: Schwartz R, Hall JA, Osterberg LG, editors. *Emotion in the clinical encounter*. New York: McGraw Hill; **2021**:83–100.
45. Bensing JM, Roter DL, Hulsman RL. Communication patterns of primary care physicians in the United States and the Netherlands. *J Gen Intern Med*. **2003**;18(5):335–42.
46. Pry JM, Sikombe K, Mody A, Iyer S, Mutale J, Vlahakis N, et al. Mitigating the effects of COVID-19 on HIV treatment and care in Lusaka, Zambia: a before-after cohort study using mixed effects regression. *BMJ Glob Health*. **2022**;7(1):e007312.
47. Mukamba N, Sharma A, Mwamba C, Nyirenda H, Foloko M, Lumbo K, et al. HIV care experiences and health priorities during the first wave of COVID-19: clients' perspectives - a qualitative study in Lusaka, Zambia. *BMC Public Health*. **2022**;22(1):2238.
48. Collins LM, Lanza ST. *Latent class and latent transition analysis: with applications in the social behavioral, and health sciences*. Hoboken, NJ: Wiley; **2010**.
49. Bray BC, Lanza ST, Tan X. Eliminating bias in classify-analyze approaches for latent class analysis. *Struct Equ Modeling*. **2015**;22(1):1–11.
50. Beres LK, Simbeza S, Holmes CB, Mwamba C, Mukamba N, Sharma A, et al. Human-centered design lessons for implementation science: improving the implementation of a patient-centered care intervention. *J Acquir Immune Defic Syndr*. **2019**;82(Suppl 3):S230–43.
51. Wouters E, Heunis C, van Rensburg D, Meulemans H. Patient satisfaction with antiretroviral services at primary health-care facilities in the Free State, South Africa—a two-year study using four waves of cross-sectional data. *BMC Health Serv Res*. **2008**;8:210.
52. Geng EH, Holmes CB, Moshabela M, Sikazwe I, Petersen ML. Personalized public health: an implementation research agenda for the HIV response and beyond. *PLoS Med*. **2019**;16(12):e1003020.
53. Geng EH. Doctor as street-level bureaucrat. *N Engl J Med*. **2021**;384(2):101–3.









SUPPORTING INFORMATION

Additional information may be found under the Supporting Information tab for this article:

Supplementary Information: Sensitivity and Exploratory Analyses and Tables S1 to S7

RESEARCH ARTICLE

Provider perspectives on patient-centredness: participatory formative research and rapid analysis methods to inform the design and implementation of a facility-based HIV care improvement intervention in Zambia

Chanda Mwamba^{1,§,#} , Laura K. Beres^{2,#}, Njekwa Mukamba¹ , Lazarus Jere¹, Marksman Foloko¹, Kasapo Lumbo¹, Kombatende Sikombe¹ , Sandra Simbeza¹, Aaloke Mody³ , Jake M. Pry^{1,4} , Charles B. Holmes⁵ , Izukanji Sikazwe¹, Carolyn Bolton Moore^{1,6} , Katerina Christopoulos⁷, Anjali Sharma¹ and Elvin H. Geng³ 

[§]**Corresponding author:** Chanda Mwamba, Centre for Infectious Disease Research in Zambia, Lusaka 10101, Zambia. (Chandaruta84@gmail.com)

[#]These authors have contributed equally to the work.

Abstract

Introduction: Implementation of patient-centred care (PCC) practices in HIV treatment depends on healthcare workers' (HCWs) perceptions of the acceptability, appropriateness and feasibility of such practices (e.g. use of intentional, metric-driven activities to improve patient experiences).

Methods: We applied rapid, rigorous formative research methods to refine a PCC intervention for future trial. In 2018, we conducted focus group discussions (FGDs) with 46 HCWs purposefully selected from two pilot sites. We elicited HCW perceptions of HIV service delivery, HCW motivation and perceived value of patient experience measures intended to improve PCC. FGDs utilized participatory methods to understand HCW responses to patient-reported care engagement challenges and Scholl's PCC Framework principles (e.g. seeing a patient as a unique person), enablers (e.g. care coordination) and activities (e.g. patient involvement). Our rapid analysis used analytic memos, thematic analysis, research team debriefs and HCW feedback to inform time-sensitive trial implementation.

Results: While HCWs nearly universally identified with and supported principles of PCC in both facilities, they raised practical barriers given the practice environment. HCWs described motivation to help patients, attached value to seeing positive health outcomes and the importance of teamwork. However, HCWs reported challenges with enablers needed to deliver PCC. HCWs cited a work culture characterized by differential power dynamics between cadres and departments restricting HCW autonomy and resource access. Barriers included inflexibility in accommodating individual patient needs due to high patient volumes, limited human resources, laboratory capacity, infrastructure and skills translating patient perspectives into practice. HCW motivation was negatively influenced by encounters with "difficult patients," and feeling "unappreciated" by management, resulting in cognitive dissonance between HCW beliefs and behaviours. However, the enactment of PCC values also occurred. Results suggested that PCC interventions should reduce practice barriers, highlighting the value of mentors who could help HCWs dynamically engage with health system constraints, to facilitate PCC.

Conclusions: While HCWs perceived PCC principles as acceptable, they did not think it universally appropriate or feasible given the practice environment. Participatory and rapid methods provided timely insight that PCC interventions must provide clear and effective systems enabling PCC activities by measuring and mitigating relational and organizational constraints amenable to change such as inter-cadre coordination.

Keywords: ART; formative research; HIV; patient-centred care; rapid qualitative analysis; Zambia

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

Received 31 October 2022; Accepted 11 May 2023

Copyright © 2023 The Authors. *Journal of the International AIDS Society* published by John Wiley & Sons Ltd on behalf of the International AIDS Society.

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

1 | INTRODUCTION

In both healthcare and public health, which traditionally prioritize scale and standardization, attention to patient or person-centredness as a strategy for improving effectiveness is rising. While still evolving, the concept of patient-centredness generally implies a collaborative, respectful approach that seeks patient perspectives and accommodates patient concerns; prioritizes communication and shared decision-making; and takes a bio-social perspective on the health of both individuals and communities [1, 2]. Patient-centred approaches have been examined in numerous experimental (e.g. cluster randomized) and observational studies; positively associated with improvements in patient satisfaction, provider satisfaction and clinical patient outcomes across a range of conditions from diabetes to mental health [3–5].

Poor patient–provider interactions contribute to sub-optimal retention in global HIV treatment services; improved patient-centred care (PCC) may offer a needed approach to improve effectiveness [6–9]. How to implement PCC, however, remains an open question in real-world public health services often beset by staffing shortages, inadequate infrastructure and uneven management. How healthcare workers (HCWs) and health leadership perceive the acceptability, appropriateness and feasibility of PCC approaches [10] remains under-studied. Yet, as implementers of PCC, their buy-in and actions are paramount to successful uptake and sustained PCC practice. Research on implementation outcomes is a challenge, in part, because PCC is a complex construct that does not have a single definition and is composed of numerous perspectives and practices [1], complicating efforts to understand how it fits into complex and varied health systems environments. Attempts to make practice more patient-centred may need to act at micro, mezzo and macro levels of a health system to succeed [11, 12], but the evidence is scarce. Further, much extant evidence on PCC draws from high-income settings [2], therefore, is of attenuated relevance in low- and middle-income countries (LMICs).

Formative research is an important tool in developing a contextually relevant, best-fit intervention [13]. While qualitative research methods are ideal to identify perceptions and context to effectively design and tailor interventions pre-implementation, traditional qualitative approaches to data collection and analysis, including recording, transcription and line-by-line coding, often take too long to influence intervention implementation within a short programmatic or funding cycle timeline [14–16]. The field of rapid, rigorous analysis of qualitative approaches continues to grow, particularly in implementation science, yet there is limited development and application from southern Africa documented in extant literature [14, 17–19].

We utilized formative research methods to tailor a multi-component intervention to enhance patient-centred practices for HIV services in Zambia prior to testing the intervention in a cluster randomized trial. The intervention design was multiphase and participatory [20]. Here, we report findings from one formative research phase with HCWs to understand their: (1) beliefs and attitudes about PCC principles,

enablers and activities; (2) perceptions of ongoing HIV service delivery and the patient experience; (3) motivation for improved practice. Understanding how HCWs in high-volume, public sector, government-operated health facilities interpret PCC and perceive the operational landscape can provide critical insights on the role of PCC in public health and how PCC can be improved. We also sought to advance the conceptualization of qualitative formative research in implementation science through the application of rapid, participatory methods to generate timely but rigorous insights.

2 | METHODS

2.1 | Study background

The “Person-Centred Public Health for HIV Treatment in Zambia” (PCPH) trial was implemented by the Centre for Infectious Disease Research in Zambia (CIDRZ) across 24 government-run, public health facilities in Lusaka, Zambia from 2019 to 2021. The trial sought to improve HIV service delivery and patient retention by improving the overall patient experience of care, with the aim of improving patient clinical outcomes, including viral suppression [21]. Prior research by the study team in Zambia showed care and treatment engagement among persons living with HIV was influenced by their perceived experience of care, affected not only by service delivery structures, but also by the perceived quality of patient–provider relations [6, 8, 9, 22]. Researchers envisioned a multi-component intervention, including training and mentoring HCWs on principals of PCC, systematic audit-and-feedback of the patient experience. Prior to implementation, the trial conducted a 6-month pilot study in two facilities, one urban and one rural in Lusaka Province, Zambia, purposefully selected [23] as having characteristics similar to expected trial sites (e.g. medium-large volume, HIV services alongside in-patient and outpatient departments) [24]. The pilot aims included utilizing formative research to better understand the PCC landscape, context, opportunities and challenges from the perspective of HCWs to tailor the intervention design, content and implementation strategies pre-trial. Our study’s conceptualization of PCC built from the integrative Scholl Framework of PCC principles (e.g. seeing a patient as a unique person), enablers (e.g. care coordination) and activities (e.g. patient involvement) (Appendix S1) [1].

The Zambian public health system, the primary provider of healthcare country-wide, has three main levels: Level 1 includes district hospitals, health centres and health posts; Level 2 has provincial or general hospitals; and Level 3 includes referral hospitals [25]. Data from 2020 show a patient-doctor ratio of 1:12,000, and a patient-nurse ratio of 1:14,960, nearly double and 21 times the World Health Organisation (WHO)-recommended ratios, respectively [26]. Zambia, an LMIC, has a generalized HIV epidemic with an estimated adult HIV prevalence of 11.3%, the eighth highest in the world [27], and an annual adult HIV incidence of 0.61% [28]. HIV testing, treatment and associated services are available free-of-charge to patients in public facilities [26].

2.2 | Participants and procedures

2.2.1 | Sampling and recruitment

We purposefully [23] recruited HCWs, seeking variation in representation from the three cadres of HCW in each pilot site as their varying perspectives and roles may differentially influence the implementation of PCC: facility management teams, professional HCWs and lay HCWs. Management are qualified medical practitioners who oversee day-to-day health facility operations, including staff, finances and resources. Professional HCWs have completed medical education and perform different roles within their departments (e.g. nurse, doctor and pharmacist), whereas lay HCWs lack formal medical training but provide specific services for which they have received targeted training, such as HIV counselling and testing. We aimed to conduct one focus group discussion (FGD) of up to eight participants for each cadre at each facility, including HCWs who worked primarily in HIV (e.g. antiretroviral therapy (ART) or voluntary counseling and testing departments) and those not primarily in HIV (e.g. tuberculosis and environmental health), as the planned intervention intended to improve the patient experience facility-wide. HCWs were invited for (FGDs) by study staff during facility staff meetings and those interested provided written informed consent to participate in discussions and be recorded until FGD enrolments were full. The formative research was done after study ethical approval was received but before introducing the details of the trial to health facility representatives (e.g. sensitization around research question, procedures, etc.) to avoid study definitions of PCC influencing formative findings.

2.2.2 | Rapid formative approach

Guided by best practices in rapid qualitative research [15, 29] and pragmatism [23], we undertook a phased, rapid research approach (Table 1) with participatory, interactive FGDs. Over the course of 6 weeks (September–October 2018), the formative research included data collection and analysis to meet the goals of the study, produce information to comprehend the context and generate suggestions to refine the intervention to improve acceptability, appropriateness and feasibility.

2.3 | Data collection

Five Zambians with varying participatory, qualitative data collection and analysis expertise (two masters-level senior social science researchers, three bachelor-level juniors; three males, two females) collected the data after being trained in the study data collection methods by two of the study co-investigators (American, MPH and Indian, PhD, both with more than 5 years' experience working in Zambia) over a 2-week period. During training, the interview guide was reviewed and reflexivity activities were conducted to identify researcher perspectives of PCC to promote data quality [30]. The team also received practical training in memo writing and compiling field notes.

The study enrolled 46 HCWs (Table 2) with FGDs separated by cadre to allow each group to speak freely among themselves ($N = 6$ total FGDs). Ten management-level HCWs at one site sought study enrolment. We accommodated this

Table 1. The PCPH study formative research process to inform and refine the patient-centred care intervention

Step 1: Study introduction

- Visit the health facility in-charge (local term for health facility managers) to introduce the formative study
- Facility in-charge invites departmental heads and introduces them to the study team as contact persons for study activities

Step 2: Participant recruitment

- Departmental heads invite study team staff to a facility team meeting to explain formative activities and recruit interested participants

Step 3: Focus group discussions (FGDs)

- Conduct FGDs applying participatory activities with participants

Step 4: Rapid analysis

- Note-taker writes field notes within 48 hours after data collection
- Moderator writes analytic memos highlighting key points for each section within 48 hours after data collection, listening to audio recording as necessary to confirm findings
- Joint review of analytic memo by moderator and note-taker
- Weekly review of memos and field notes by data collection teams and two study qualitative co-investigators to finalize memos
- Thematic analysis of memos and field notes by the two moderators

Step 5: Study team debriefs

- Review and finalization of key thematic analysis findings through dialogue between moderators and two qualitative co-investigators
- Presentation of key findings to full study team (moderators, note-takers, qualitative co-investigators, principal investigators and implementation team) for clarification and review of interpretation

Step 6: Proposals for tailoring content and implementation strategies

- Systematic review of all key findings and propose ways to tailor study implementation to address findings by full study team

Step 7: Member checking

- Share insights and findings to make conclusions with management and facility staff from pilot sites for feedback

by, in addition to the FGD ($n = 8$ participants), conducting one dyad ($n = 2$ participants) and one interview ($n = 1$ participant) of leadership using the same semi-structured guides to enable participation within busy HCW schedules.

FGDs were conducted using two overlapping semi-structured guides, including open-ended discussion questions

Table 2. Number of participants by cadre and facility

Participant type ^a	Facility 1	Facility 2	Total (N = 46)
Lay HCWs	7	8	15
Professional HCWs	9	7	16
Management Role	5	10	15
Lay counsellors	7	8	15
Pharmacist	2	0	2
Lab technologists	1	2	3
Environmental technologists	0	1	1
Nurses	6	4	10
Head of departments	5	10	15
Years of service			
< 5 years	17	13	30
5–15 years	2	9	11
> 15 years	2	3	5

Note: Heads of departments laboratory, pharmacy, outpatient services, tuberculosis, environmental health, registry, nursing service, clinical services.

^aDiversity sought in purposeful sampling including facility management teams, professional and lay HCWs.

Abbreviation: HCW, health care worker.

and interactive, participatory activities, differentiated to allow for an in-depth discussion in a limited timeframe. Guide A, used with professional and lay cadres, included the interactive 10 PCC principles and interactive questions designed to measure the patient experience. Guide B, used with management, professional and lay cadres, included the facility context for HIV care and treatment services, interactive feedback on patient reasons for disengaging from care, differentiated service delivery models for HIV care, HCW motivation, suggestions for patient retention and the proposed PCPH intervention approach.

The guides used traditional FGD open-ended questions [31] and interactive, participatory exercises that shared relevant concepts visually and probed participant feedback on information shared. “Ten PCC Principles”: researchers posted 10 flipchart pages around the FGD room, each with a pre-written statement derived from the Scholl framework of PCC principles, enablers and activities [1] (Appendix S2) with a strongly disagree to strongly agree Likert scale underneath (Appendix S3). Participants were asked to anonymously rate each statement on a scale from strongly disagree to strongly agree by placing a sticky note on their Likert answer choice for each statement, lasting approximately 15 minutes. Facilitators used open-ended reflection questions during group review of the sticky-note ranking results to explore and elaborate on participants’ opinions and experiences about PCC and their contexts. “Patient reasons for disengagement”: researchers posted a list of patient-articulated reasons for disengagement from HIV care in Zambia from our past research [6–8, 32] for HCW discussion and reflection. “Patient experience measures”: researchers posted example questions intended to

measure the patient experience at the facility in the PCPH study to receive real-time feedback on HCW perceived value of the data (Appendix S4).

The two researchers managed the FGDs with one as a moderator (senior researcher) and another as the note-taker (junior researcher), both previously unknown to participants. The moderator provided structure to the FGDs and allowed participants to explore the topics sharing their opinions and experiences, while the note-taker documented the discussion proceedings for each section of the FGD guide, capturing key points, the intensity of the conversation and points of consensus or disagreement. The data collection lasted 2 weeks. The FGDs were conducted primarily in English with some local language use (e.g. Nyanja and Bemba), held in private, available rooms within the health facilities, lasted between 2 and 3 hours and were audio-recorded. All products of the participatory activities (e.g. paper voting charts) were photographed. We followed Consolidated criteria for reporting qualitative research (COREQ) [33] in our manuscript writing.

2.4 | Rapid data analysis

2.4.1 | Memos and synthesis

To provide timely results for intervention design, we undertook a rapid analysis approach [15, 29]. Within 48 hours of each collection activity, the moderator wrote a structured analytic memo based on field notes from the note-taker and their own notes referencing interactive exercise outputs and audio recordings, as necessary. Our memos were structured using the questions in the FGD guides as deductive themes (categorized under: (1) beliefs and attitudes about PCC principles, enablers and activities; (2) perceptions of ongoing HIV service delivery and the patient experience; (3) motivation for improved practice) and included synthesized key concepts from the study interaction for each question, with higher-level themes and additional information summarized at the end. The note-taker read these memos, discussed the interpretations with the moderator and added any clarifications. Inconsistencies in data interpretation were resolved through dialogue, including review of notes listening to audio recordings as needed. Once consensus was reached, findings were shared with the qualitative co-investigators for further dialogue and interpretation. Thereafter, the moderators analysed the finalized memos and field notes thematically using NVivo analysis software. The analysis involved identifying themes and sub-themes that were synthesized into summaries. The key findings from the thematic analysis were reviewed and discussed with the qualitative co-investigators.

2.5 | Study team debriefs

The full study team (principal investigators, qualitative co-investigators, moderators, note-takers and implementation team) had iterative dialogues to review and interpret the formative findings. Sub-teams within the research group, particularly study team members responsible for pilot study HCW training and mentoring interventions, read the memos and field notes, writing out discussion points for meetings with the data collection and the full study team.

2.6 | Tailoring of content and implementation strategies and member-checking

The moderators created a final summary of key findings. Through the iterative data reviews and discussions between the data collection team and the full study team, we systematically reviewed each of the key findings and identified suggestions for revisions to the proposed intervention design, content and implementation strategies. Following that, member checking [34] was done by the data collection team and other study implementation team members who shared findings at the pilot sites for feedback and further insights to inform the intervention.

2.7 | Ethical approval

The research was approved by the Zambian National Health Research Ethics Board, the University of Zambia Biomedical Research Ethics Committee and the University of Alabama at Birmingham Institutional Review Board. All participants gave written informed consent.

3 | RESULTS

3.1 | PCC principles, enablers and activities

There was broad agreement on and support for principles of PCC, such as clinicians treating patients with respect, the value of partnership between patients and providers, that each patient is an individual, and that social, emotional and physical health are important to patients' wellbeing. HCWs expressed the importance of empathy by discussing the value of "putting yourself in a patient's position." However, in the practical service delivery setting, HCWs agreed they prioritize physical health over any emotional concerns. The terms "umuyo" (life) and "pa tupi" (on the body) were used interchangeably to refer to one's physical health. Further, while agreeing each patient is unique, HCWs expressed concern that a diversity of approaches at the patient level could risk patient confidence because patients discuss their care with each other and inconsistency in messaging or approaches could cause patients to question the quality of care.

While valued in principle, a variety of barriers to the practice of PCC manifested during the discussion of the principles. HCWs stated that the provision of individualized care, improved access (e.g. reduced wait times), patient or family involvement and tailored information provision were challenging due to high patient volumes, insufficient health personnel and limited infrastructure (e.g. laboratory capacity, counselling space and electricity back-up), all of which limit duration and quality of the provider–patient interaction. A professional HCW shared, "sometimes, you find that you have nine or six clients waiting by the time you finish counselling [one client]."

There was nearly universal agreement that the enablers, "teamwork" and "care coordination" were critical to care delivery. However, there were notable differences in the discussions of the operationalization of these enablers among the lay HCWs, professional HCWs and the facility management teams. Some reflected on different HCWs performing differ-

ent but necessary tasks (e.g. screening, counselling, prescribing, etc.), while one mentioned consulting each other when unsure. HCWs expressed that differential power dynamics between cadres affected their service provision and inhibited cooperation among co-workers and between management and other cadres. For example, lay HCWs described how they often feel undervalued by professional HCWs and excluded from the care team. They gave examples of how professional HCWs would ask them to move from rooms while they are counselling a patient if the professional HCW needed that space. A lack of management appreciation of their work was voiced by both professional and lay HCWs. Further, at one facility, the professional HCWs reported a lack of inter-departmental cooperation, while the management discussed it as well-functioning.

There was also variation in knowledge of differentiated models of service delivery (DSD) in the health facilities, (e.g. ART collection at private chemists and group-based rotational ART collection), which are opportunities to extend patient access to care through more convenient, less-frequent health system interactions. Compared to HCWs at the urban facility, HCWs from the rural facility expressed better awareness of available models at their facility, including how they operate and perceived benefits, such as reduced facility congestion. The management teams from both facilities had greater knowledge of DSDs and their related benefits than the professional and lay HCWs.

Particularly noted by the management level, but also echoed by other cadres, a lack of sufficient knowledge of rapidly evolving ART guidelines and skill in efficiently using electronic medical record systems presented barriers to practicing individualized care, and to providing efficient, high-quality care that supports patient retention and employs PCC practices.

3.2 | HCW perspectives and motivation

Understanding HCW intrinsic motivation can inform opportunities for the PCC trial intervention to facilitate the adoption of PCC behaviours, while linking motivation to PCC principles, activities and enablers or outcomes may improve PCC practices. Many participants described seeing positive health outcomes from patients as highly motivating in their work, an evidence-based outcome of PCC practices. Some HCWs discussed being motivated by the co-operation they shared with their co-workers, related to the enabler "teamwork" [1]. Lay HCWs highlighted being motivated by positive interactions with professional HCWs who respect them. Professional HCWs reported being motivated by supportive management. When asked about preferred extrinsic motivations or rewards that may be included in the intervention, they noted training opportunities, performance certificates, recognition including "being heard by" and receiving appreciation from management, and, among lay HCWs, remuneration, supplies and formal uniforms or badges to demonstrate their official role in the health system.

HCW motivation and ability to implement PCC practices, however, was negatively affected by the lack of resources in their facilities inhibiting their work coupled with feeling that their work was sometimes unappreciated and taken for

granted by both patients and management. Other participants re-evoked the challenge of management dynamics that make it difficult for them to bring forth suggestions for ways to improve patient care at their facilities. HCWs discussed encounters with “difficult patients” who added challenge to their work premised on the notion that “a patient is always right.” This included examples of patients who were demanding, yelling or intoxicated.

HCWs had mixed reactions to reasons for patient disengagement from care derived from patient interviews in Zambia that highlighted failures of PCC, such as long wait times (reducing access) and rude providers (the antithesis of clinician–patient empathy and respect). For example, while some HCWs accepted long wait times as a problem, others explained that patients’ perception of the situation may differ from HCWs’. While patients may think the long wait is caused by HCW late arrival, HCWs see patients arriving prior to facility opening times and not understanding that HCWs must prepare their stations prior to patient interaction. Some HCWs acknowledged HCW attitude and behaviour towards patients as a problem stating, “we treat patients as cases not as human beings.” More lay than professional HCWs acknowledged that they are sometimes rude to patients, with professional HCWs highlighting their professional and ethical treatment of patients as precluding rudeness. Professional and lay HCWs stated that the behaviour of “difficult patients” and other difficulties in their work environments shaped their responses which could be considered rude. Importantly, the challenges of being an HCW arose:

Being a HCW is an extremely difficult thing, you have to be strong! You need to have a neutral heart, but sometimes when some [patients] go far, your temper may raise and you respond, you ma’am, you should have manners, go and sit down you came late!’ and you, go outside and we won’t talk to each other again. (Lay HCW)

3.3 | Data and feedback supporting PCC

When presented with possible patient experience survey questions that could collect data and feedback information to the HCWs during the proposed PCC intervention (Appendix S4), participants discussed which questions may be most useful. HCWs seemed more favourable to questions related to overall satisfaction, lost lab results or if the provider allowed the patient to discuss their reasons for coming. They expounded that lab results were an ongoing challenge, which patient data would support advocacy for change, and that a provider should allow a patient to express themselves, something under their locus of control. Less interest arose for the question on wait time, for example, stating they knew the response would be “long” and described the many factors leading to long wait times outside of their control. Some HCWs explained that they not only need to know what a patient thinks, but why (i.e. more specifics on what led to a good or bad experience rating). Overall, professional and lay HCWs expressed challenges understanding data usefulness for many reasons, including concern about the relevance of some questions, lack of involvement in data review meetings,

lack of skills to translate information from survey results into practice and lack of ownership of facility-level data, demonstrating the need for an intervention to address data use in addition to data provision. Conversely, the facility management teams were able to describe how results from the survey questions could inform the facilities and lead to necessary actions drawing from their experience with a review of other facility-level data.

3.4 | Intervention tailoring

Data from the participatory interviews and FGDs led to multiple suggestions to inform the PCPH Trial, with examples listed in Table 3.

3.5 | Participatory and rapid analysis methods

The participatory methods and rapid analysis methods produced rich data with conclusions derived by research team members and reviewed by HCW participants within a 3-month period (Appendix S5).

4 | DISCUSSION

Our formative research offered clear insights about HCW perceptions of PCC, providing useful information that directly informed the intervention’s design (e.g. working across departments and cadres), content (e.g. training topics and data the intervention will feedback to clinics) and implementation strategies (e.g. the intervention led by flexible mentoring approach). In this study, HCWs generally accepted and supported principles of PCC; however, the practice of PCC involves complexities that made PCC less appropriate and feasible in their operational context. HCWs gave examples of practical barriers that created dissonance between PCC ideas and persistent health system constraints. The findings suggest that recognizing the challenges of the HCWs as implementers is critical for the appropriate and feasible translation of PCC principles into action.

Our findings fundamentally relocate the problem of improving PCC as one of the organizational functions rather than deficiencies in provider attitude or capability. The shift in thinking about this issue is significant and moves away from methodological individualism, which has been a barrier to achieving meaningful change. While the organizational and structural levels of the health system have long been recognized as relevant to improving patient-centredness in conceptual models [1, 2, 12], the prevailing intervention approaches in low- and middle-income settings prioritize individual-level targets [5, 35]. Considering the implementation of PCC practices through the lens of Normalization Process Theory [36], our FGDs demonstrate that the necessary work of sense-making around the value of PCC comes naturally to HCWs (they endorse PCC concepts), while the relational work of cognitive participation may be interrupted by challenging power dynamics between cadres and that operationalization of PCC through collective action is challenged by organizational and structural barriers. During our FGDs, HCWs both endorsed patient-reported challenges with HIV service delivery that led to patient disengagement (e.g. long wait times

Table 3. Example findings and associated intervention tailoring suggestions

HCW perceptions	Intervention implications
PCC principles, enablers and activities	
<ul style="list-style-type: none"> • HCWs value patient-centred care practices but are challenged by system constraints • Teamwork considered important, however: <ul style="list-style-type: none"> ◦ Lay HCWs felt disrespected ◦ Lay and professional HCWs felt undervalued by management ◦ Power dynamics disrupted care coordination • Health was seen as including physical, social and emotional; however, physical is prioritized 	<ul style="list-style-type: none"> • On-site mentorship by PCC study could support a flexible approach to implementing PCC, looking for flexibility amidst human resource and infrastructure constraints • Mentors will need to relate differently with different cadres and prioritize different skills and learning • Mentors should focus on work culture, team-based approach and address power dynamics • Mentors can build on inductive terms, such as “putting yourself in the patient’s position”
HCW perspectives and motivation	
<ul style="list-style-type: none"> • HCWs had mixed reactions to patient-generated reasons for disengagement, offering their own perspectives on the challenges that HCWs experience that influence the patient experience • HCWs feel motivated by patients doing well 	<ul style="list-style-type: none"> • Mentors will need to acknowledge that HCWs work under difficult conditions • HCWs must be able to express themselves and be listened to/feel heard • Mentors will need to: <ul style="list-style-type: none"> ◦ create the coaching materials and deliver coaching in a way that builds on the current reality at the clinic ◦ Identify the best ways of handling patients considered to be challenging (use examples in FGDs) • Mentors will need to: celebrate positive patient outcomes
Data and feedback supporting PCC	
<ul style="list-style-type: none"> • Management cadre more comfortable with data and application • Professional and lay HCWs were interested in many questions but also unsure of how to apply data 	<ul style="list-style-type: none"> • Work with facility ART in-charge and medical superintendent to provide objective information that can support HCW supervision and support • Feedback of data should include mentor support for data interpretation and use, including support for quality improvement initiatives • Questions in survey should consider “actionability” of data from HCW perspective

Abbreviations: PCC, patient-centred care; HCW, healthcare workers; FDG, focus group discussions.

and rude providers) and displayed defensiveness around those same challenges. This defensiveness manifested in HCWs’ tone during the discussion and their explanations of factors outside of HCW control that led to those negative patient experiences. They demonstrated how their interactions with patients (which can be interpreted as provider attitude) are fundamentally shaped by the circumstances in which HCWs work. Importantly, however, other research with this population identified examples of HCWs practising patient-centredness even within challenging system constraints [20]. Unfortunately, the constraints noted by the HCWs in 2018 persist at present [26]. This, then, is a call to action for PCC interventions to identify flexibility within constrained systems to enable improved PCC instead of dismissing PCC as impossible within constrained systems or placing the burden of enacting PCC solely on the shoulders of the individual HCWs.

Furthermore, our data revealed variation in PCC operationalization at the facility and cadre levels. For example, we discovered differences in DSD awareness and application between the two pilot facilities and between cadres, highlighting the importance of intervention approaches that are responsive to the facility and HCW-level variation [27, 28].

In the implementation of PCC, patient-centredness and provider-centredness are inseparable. Consistent with principles of person-centredness, interventions requiring HCWs to do more or to increase their cognitive load by doing things differently to improve patient-centredness must begin by acknowledging the load HCWs carry, and the innovation and effort they apply to deliver patient services within extant constraints [37]. It is also critical for interventions to consider how institutional-level priorities, often influenced by external actors and funding agencies, and interpersonal hierarchies

between cadres constrain HCW–patient interactions [38]. In the FGDs, HCWs were clear about valuing “being heard,” “appreciated” and recognized by supervisors and colleagues. Consistent with principles of person-centredness, intervention designs should recognize and appreciate intervention implementers. While many PCC approaches in the HIV space target HCW knowledge and skills [39–41], those that begin with understanding the HCW context will both position the HCW to adopt new practices by recognizing their existing efforts, and identify relational and organizational intervention targets that will enable individual-level HCW change, supporting intervention appropriateness. Similarly, while our FGDs supported that providing information to HCWs to improve PCC [42–44] is acceptable, specific HCW responses demonstrate that the perceived relevance of the questions asked and the ability to identify HCW recourse to action in response to the information shared influences information appropriateness. Data use and actionability may be important intervention targets, particularly among non-management-level HCWs.

The participatory and rapid analysis methods employed served the interests of our implementation research agenda. The participatory methods were highly engaging, leading to an animated discussion that brought out rich insights into HCW lived experiences, and not only their synthesized reflections. Offering statements and anonymous means of sharing an opinion using sticky notes on a Likert scale facilitated contributions from each participant, and supported HCWs to feel free to discuss topics that may have been uncomfortable (e.g. HCW rudeness) by removing direct blame or personalization. Offering example patient experience questions allowed for immediate feedback on question utility and rapid revision of survey question inclusion, consistent with a prototyping approach [45]. While the analysis approach remained time and labour-intensive, it achieved synthesis more rapidly than traditional methods. The participatory and rapid methods enhanced methodological rigour through credibility and transparency by involving data collectors in analysis, allowing for close iterative engagements with the raw data and confirmability through participatory methods with participants and team debriefs. Member-checking endorsed the recommendations (Table 3). The study took the work into a specified human-centred design workshop to further develop the findings [20]. The lessons from our application of rapid analysis methods are important in the current dispensation, as rapid methods are gaining increased attention to inform interventions through “collaborative, inclusive qualitative health research” [46] within streamlined timelines and budgets when compared to traditional qualitative methods that require more time and resources.

4.1 | Limitations

By their nature, our data are formative and derived from a small, non-generalizable sample. However, our use of participatory, qualitative methods yield rich, authentic information from this small sample, and would be transferable to settings with similar health facility structures, resources, patient population and workplace norms [30]. The HIV practice setting has changed since data collection in 2018, limiting the applicability of specific knowledge and practice targets. However, the

findings of this study provide valuable insights into the knowledge and practice targets that can still be used as a reference point for future research and to help develop interventions and policies to address the changing landscape of HIV care.

5 | CONCLUSIONS

Our research found that the concept of PCC is widely resonant with HCWs, but the practicalities are seen as a major barrier; therefore, implementation efforts have a strong foundation, but must understand and resolve practice-based challenges. Consequently, provider-centredness is an important complementary concept to understand in the context of PCC. Positive HCW attitude and actions, often construed as an individual-level attribute, are shaped by the health system environment. This wider approach can identify areas beyond the individual HCW level that may impact their ability to deliver PCC, such as organizational policies, facility culture and power dynamics. Participatory and rapid methods provided timely insights demonstrating a rigorous approach for teams seeking to inform intervention implementation.

AUTHORS' AFFILIATIONS

¹Centre for Infectious Disease Research in Zambia, Lusaka, Zambia; ²Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, USA; ³University of Washington, St. Louis, Missouri, USA; ⁴School of Medicine, University of California, Davis, Davis, California, USA; ⁵Georgetown University, Washington, DC, USA; ⁶Department of Infectious Diseases, University of Alabama at Birmingham, Birmingham, Alabama, USA; ⁷University of California, San Francisco, San Francisco, California, USA

COMPETING INTERESTS

The authors declare no competing interests.

AUTHORS' CONTRIBUTIONS

CM, LKB, NM, EG, AS, AM, JMP and KC supported conceptualization. CM, NM, KL, MF, LJ, SS and KS supported data collection. CM, LKB, NM, CK, KL, MF, LJ and AS conducted formal analysis. CM, LKB, AS, NM, EG, AM, JMP, IS and CBM contributed to data interpretation. IS, CBM, CH and EG acquired study funding. AS, KS, CH, IS, CBM, AM, EG, JMP and LKB were study investigators. CM, LKB, AS, NM, AM and EG designed the methodology. SS, KS and CBM conducted project administration. CM and LKB wrote the original manuscript draft. All co-authors reviewed and edited the final draft.

ACKNOWLEDGEMENTS

We are grateful to the participants and research team associated with the “Person-Centred Public Health for HIV Treatment in Zambia” (PCPH) study and the Zambian Ministry of Health.

FUNDING

This research was supported by the Bill and Melinda Gates Foundation grant number INV-010563. Dr. Beres' contributions were also supported by the National Institutes of Health, 1K01MH130244-01.

DATA AVAILABILITY STATEMENT

The Government of Zambia allows data sharing when applicable local conditions are satisfied. To request data access, contact the Secretary to the CIDRZ Ethics and Compliance Committee /Head of Research Operations, Ms. Hope Mwanyungwi (Hope.Mwanyungwi@cidrz.org), mentioning the intended use for the data.

REFERENCES

1. Scholl I, Zill JM, Härter M, Dirmaier J. An integrative model of patient-centeredness - a systematic review and concept analysis. *PLoS One*. 2014;9(9):e107828.
2. De Man J, Van Olmen J, Criel B. Patient-centered care and people-centered health systems in sub-Saharan Africa: why so little of something so badly needed? *Int J Pers Cent Med*. 2016;6(3):162–73.
3. Kuipers SJ, Cramm JM, Nieboer AP. The importance of patient-centered care and co-creation of care for satisfaction with care and physical and social well-being of patients with multi-morbidity in the primary care setting. *BMC Health Serv Res*. 2019;19(1):13.
4. Stewart M, Brown JB, Donner A, McWhinney IR, Oates J, Weston WW, et al. The impact of patient-centered care on outcomes. *J Fam Pract*. 2000;49(9):796–804.
5. Updated recommendations on service delivery for the treatment and care of people living with HIV. Geneva: World Health Organization; 2021.
6. Mwamba C, Sharma A, Mukamba N, Beres L, Geng E, Holmes CB, et al. 'They care rudely!': resourcing and relational health system factors that influence retention in care for people living with HIV in Zambia. *BMJ Glob Health*. 2018;3(5):e001007.
7. Topp SM, Mwamba C, Sharma A, Mukamba N, Beres LK, Geng E, et al. Rethinking retention: mapping interactions between multiple factors that influence long-term engagement in HIV care. *PLoS One*. 2018 Mar 14;13(3):e0193641.
8. Zanolini A, Sikombe K, Sikazwe I, Eshun-Wilson I, Somwe P, Bolton Moore C, et al. Understanding preferences for HIV care and treatment in Zambia: evidence from a discrete choice experiment among patients who have been lost to follow-up. *PLoS Med*. 2018;15(8):e1002636.
9. Sikazwe I, Eshun-Wilson I, Sikombe K, Beres LK, Somwe P, Mody A, et al. Patient-reported reasons for stopping care or switching clinics in Zambia: a multisite, regionally representative estimate using a multistage sampling-based approach in Zambia. *Clin Infect Dis*. 2021;73(7):e2294–302.
10. Proctor EK, Powell BJ, McMillen JC. Implementation strategies: recommendations for specifying and reporting. *Implement Sci*. 2013;8:139.
11. Barry MJ, Edgman-Levitan S. Shared decision making—pinnacle of patient-centered care. *N Engl J Med*. 2012;366(9):780–1.
12. Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med*. 2000;51(7):1087–110.
13. Bentley ME, Johnson SL, Wasser H, Creed-Kanashiro H, Shroff M, Fernandez Rao S, et al. Formative research methods for designing culturally appropriate, integrated child nutrition and development interventions: an overview. *Ann N Y Acad Sci*. 2014;1308:54–67.
14. Vindrola-Padros C, Johnson GA. Rapid techniques in qualitative research: a critical review of the literature. *Qual Health Res*. 2020;30(10):1596–604.
15. Hamilton A. Qualitative methods in rapid turn-around health services research. US Department of Veteran Affairs Health Services Research and Development Service; 2013.
16. Lewinski AA, Crowley MJ, Miller C, Bosworth HB, Jackson GL, Steinhauer K, et al. Applied rapid qualitative analysis to develop a contextually appropriate intervention and increase the likelihood of uptake. *Med Care*. 2021 Jun;59(6 Suppl 3):S242.
17. Nevedal AL, Reardon CM, Opra Widerquist MA, Jackson GL, Cutrona SL, White BS, et al. Rapid versus traditional qualitative analysis using the consolidated framework for implementation research (CFIR). *Implement Sci*. 2021;16(1):67.
18. Gale RC, Wu J, Erhardt T, Bounthavong M, Reardon CM, Damschroder LJ, et al. Comparison of rapid vs in-depth qualitative analytic methods from a process evaluation of academic detailing in the Veterans Health Administration. *Implement Sci*. 2019;14(1):11.
19. Taylor B, Henshall C, Kenyon S, Litchfield I, Greenfield S. Can rapid approaches to qualitative analysis deliver timely, valid findings to clinical leaders? A mixed methods study comparing rapid and thematic analysis. *BMJ Open*. 2018;8(10):e019993.
20. Beres LK, Simbeza S, Holmes CB, Mwamba C, Mukamba N, Sharma A, et al. Human centered design lessons for implementation science: improving the implementation of a patient-centered care intervention. *J Acquir Immune Defic Syndr*. 2019 Dec;82(3):S230.
21. Sikombe K, Mody A, Goss C, Eshun-Wilson I, Simbeza S, Sharma A, et al. The impact of patient centred care on HIV treatment in Zambia, a stepped-wedge trial. Conference on Retroviruses and Opportunistic Infections; February; Seattle, Washington, USA. 2023.
22. Topp SM, Mwamba C, Sharma A, Mukamba N, Beres LK, Geng E, et al. Rethinking retention: mapping interactions between multiple factors that influence long-term engagement in HIV care. *PLoS One*. 2018;13(3):e0193641.
23. Patton MQ. *Qualitative research & evaluation methods*. 3rd ed. Thousand Oaks, CA: Sage Publications, Inc.; 2002.
24. Topp SM, Chipukuma JM, Chiko MM, Matongo E, Bolton-Moore C, Reid SE. Integrating HIV treatment with primary care outpatient services: opportunities and challenges from a scaled-up model in Zambia. *Health Policy Plan*. 2013;28(4):347–57.
25. Songiso M, Pinder LF, Munalula J, Cabanes A, Rayne S, Kapambwe S, et al. Minimizing delays in the breast cancer pathway by integrating breast specialty care services at the primary health care level in Zambia. *JCO Glob Oncol*. 2020;6:859–65.
26. Zambia MoH. 2022–2026 National Health Strategic Plan: "Towards Attainment of Quality Universal Health Coverage Through Decentralisation". Lusaka, Zambia: Government of the Republic of Zambia; 2022.
27. UNAIDS. Zambia HIV and AIDS Estimates 2018. Available from: <http://www.unaids.org/en/regionscountries/countries/Zambia>. Accessed April 02, 2023.
28. Ministry of Health Zambia. Zambia Population-based HIV Impact Assessment (ZAMPHIA) 2016: Final Report. Lusaka, Zambia: Ministry of Health; 2019.
29. Koenig CJ, Abraham T, Zamora KA, Hill C, Kelly PA, Uddo M, et al. Pre-implementation strategies to adapt and implement a veteran peer coaching intervention to improve mental health treatment engagement among rural veterans. *J Rural Health*. 2016;32(4):418–28.
30. Tobin GA, Begley CM. Methodological rigour within a qualitative framework. *J Adv Nurs*. 2004;48(4):388–96.
31. Hennink M. *International focus group research*. Cambridge University Press; 2007.
32. Sikazwe I, Eshun-Wilson I, Sikombe K, Czaicki N, Somwe P, Mody A, et al. Retention and viral suppression in a cohort of HIV patients on antiretroviral therapy in Zambia: regionally representative estimates using a multistage-sampling-based approach. *PLoS Med*. 2019;16(5):e1002811.
33. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349–57.
34. Waweru E, Sarkar ND, Ssengooba F, Gruénais ME, Broerse J, Criel B. Stakeholder perceptions on patient-centered care at primary health care level in rural eastern Uganda: a qualitative inquiry. *PLoS One*. 2019;14(8):e0221649.
35. Nakkeeran N, Sacks E, P NS, Juneja A, Gaitonde R, Garimella S, et al. Beyond behaviour as individual choice: a call to expand understandings around social science in health research. *Wellcome Open Res*. 2021;6:212.
36. May CR, Cummings A, Girling M, Bracher M, Mair FS, May CM, et al. Using normalization process theory in feasibility studies and process evaluations of complex healthcare interventions: a systematic review. *Implement Sci*. 2018;13(1):80.
37. McCormack B. A conceptual framework for person-centred practice with older people. *Int J Nurs Pract*. 2003;9(3):202–9.
38. Sheikh K, Gilson L, Agyepong IA, Hanson K, Ssengooba F, Bennett S. Building the field of health policy and systems research: framing the questions. *PLoS Med*. 2011;8(8):e1001073.
39. Erb S, Letang E, Glass TR, Natamatungiro A, Mnzava D, Mapesi H, et al. Health care provider communication training in rural Tanzania empowers HIV-infected patients on antiretroviral therapy to discuss adherence problems. *HIV Med*. 2017;18(9):623–34.
40. Maclachlan EW, Shepard-Perry MG, Ingo P, Uusiku J, Mushimba R, Simwanza R, et al. Evaluating the effectiveness of patient education and empowerment to improve patient-provider interactions in antiretroviral therapy clinics in Namibia. *AIDS Care*. 2016;28(5):620–7.
41. Jones DL, Sued O, Cecchini D, Bofill L, Cook R, Lucas M, et al. Improving adherence to care among "Hard to Reach" HIV-infected patients in Argentina. *AIDS Behav*. 2016;20(5):987–97.
42. Ikeda DJ, Nyblade L, Srihanaviboonchai K, Agins BD. A quality improvement approach to the reduction of HIV-related stigma and discrimination in healthcare settings. *BMJ Glob Health*. 2019;4(3):e001587.
43. Teasdale CA, Geller A, Shongwe S, Mafukidze A, Choy M, Magaula B, et al. Patient feedback surveys among pregnant women in Eswatini to improve antenatal care retention. *PLoS One*. 2021 Mar 24;16(3):e0248685.
44. Kays M, Woelk G, Callahan T, Katirayi L, Montandon M, Chauwa F, et al. Evaluating the effect of a community score card among pregnant and breast-feeding women living with HIV in two districts in Malawi. *PLoS One*. 2021 Aug 11;16(8):e0255788.
45. Lyon AR, Munson SA, Renn BN, Atkins DC, Pullmann MD, Friedman E, et al. Use of human-centered design to improve implementation of evidence-based

psychotherapies in low-resource communities: protocol for studies applying a framework to assess usability. *JMIR Res Protocols*. 2019;8(10):e14990.
46. Flicker S, Nixon SA. The DEPICT model for participatory qualitative health promotion research analysis piloted in Canada, Zambia and South Africa. *Health Promot Int*. 2015;30(3):616–24.

SUPPORTING INFORMATION

Additional information may be found under the Supporting Information tab for this article:

Supporting Information 1: Dimensions of patient-centeredness and integrative model of patient-centredness (reproduced from Scholl et al. 2014 [1]).

Supporting Information 2: PCC Statements, adapted from the Scholl Framework

Supporting Information 3: Example Scholl-derived statement photos from FGDs

Supporting Information 4: Example patient experience survey questions used in participatory activity

Supporting Information 5: Rapid Analysis Steps and Timeline

VIEWPOINT

Person-centred care: shifting the power dynamic in the delivery of adolescent and youth-friendly health services

Lynn Phillips^{1, #} , Heleen Soeters^{1, #}, Maximina Jokonya², Allen Kyendikuwa² and Luann Hatane^{1, §}

§ **Corresponding author:** Luann Hatane, Building 20, Suite 5A, Waverley Business Park, Wyecroft Road, Mowbray, Cape Town 8000, South Africa. (Luann@teampata.org)

These authors have contributed equally to the work.

Received 13 October 2022; Accepted 11 May 2023

Copyright © 2023 The Authors. *Journal of the International AIDS Society* published by John Wiley & Sons Ltd on behalf of the International AIDS Society.

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

The provision of healthcare has evolved from applying a traditional, paternalistic, provider-driven and disease-focused approach towards one of person-centred care (PCC), that engages the client in decision-making, develops client knowledge and fosters self-care behaviour. Supporting participation along with greater emphasis on a more engaged, equal and beneficial health partnership between healthcare providers and service users is now recognized as one of the pillars of quality healthcare, and a growing body of evidence underpins the beneficial effects of PCC in provider, caregiver and client satisfaction, client health behaviour, quality of life and better healthcare outcomes [1–3].

The importance of shifting power to the client is only heightened in the long-term management of chronic diseases [4], prevention and care services of sexually transmitted infections and when delivering services to adolescents and young people living with HIV (AYPLHIV) in their diversity, and other stigmatized, vulnerable and excluded key populations. The principles and strategies of PCC—building trust, being compassionate and respectful of client preferences, needs, values, environment and cultural background—help to address the inequality of AYPLHIV health service experience, support their active involvement, foster autonomy and trust in their healthcare journey.

PCC is not a new concept, yet there is considerable variability in the definition of PCC, with different frameworks and measurements described in the literature [5]. Although there is some consensus on the most important elements (i.e. client as a unique person, client involvement in care, client information, client–clinician communication and client empowerment), PCC conceptualization is blurry, with few practical strategies, hampering its successful implementation, particularly in low-income African countries. We still meet healthcare providers who think they are already doing PCC when this may not be the case. Stigma, unfriendliness and judgemental provider attitudes remain a reality on the ground, resulting in a reluctance to access sexual reproductive health rights and HIV services, stay in care or adhere to treatment [6].

The long-standing partnership of Paediatric-Adolescent Treatment Africa (PATA), an action network of frontline

healthcare providers, together with the Global Network of Young People Living with HIV (Y+ Global), provides an opportunity to harness mutual understanding, and build on the combined expertise and insight on successful and practical strategies on how to positively influence the power imbalance inherent in the health provider–AYPLHIV relationship. Our practical recommendations are informed by the regional joint programme implementation of PATA/Y+ Global, and align with the three key domains identified in a recent systematic review of PCC within the context of HIV treatment settings in southern Africa: staffing, service delivery standards and direct client support services [7].

More investment will be needed both for staff capacity-building and staff composition. In most African countries, healthcare provider educational systems still favour a paternalistic provider patient relationship, shaping the future attitude of caregivers to prioritize biomedical aspects over client preferences and needs. Multiple, ongoing and layered sensitization strategies are required to equip health providers to deliver adolescent-friendly health services that are person-centred. Tools that prove to be successful include (1) values clarification training supporting health providers to reflect upon and re-define their own values; (2) relationship-building practice sessions for health providers on how to engage more meaningfully; and (3) the identification of PCC champions who lead the process of shifting power and changing entrenched mindsets.

AYPLHIV have first-hand experience of service gaps and age-related challenges, and are ideally placed to understand and respond to the needs of their peers and communities. Engaging AYPLHIV as peer supporters working in partnership with the healthcare team has the potential to facilitate a fundamental shift in power structures. Enlisting AYPLHIV whom the system is supposed to serve in the delivery of those services breaks down inequalities, with the potential to challenge often ingrained practices and beliefs. Through the provision of individual or group psychosocial support, counselling and health promotion in the form of teen clubs and adolescent-friendly safe spaces, peer support has shown to improve retention in care and viral suppression [8]. Effective

peer support rests on successful integration into the clinic team, mutually agreed upon divisions of roles and responsibilities that may vary according to local context and healthcare provider appreciation of the value of peer support.

The quality of service delivery can be positively affected through community-led monitoring assisting health facilities, providers and users in identifying service delivery challenges and developing quality improvement plans that promote a person-centred standard of care. Again, AYPLHIV have a vital role to play as change agents, and must be included in the design of tools and their application. The PATA/Y+ quality improvement plan process starts with a gap analysis based on PATA's client satisfaction scorecard [9], which provides AYPLHIV and other key populations with the opportunity to assess the perceived quality and accessibility of a range of services, in a self-reported, anonymous and voluntary manner, and identify potential areas for improvement. Both health facilities and clients are then engaged to jointly review feedback against a matrix of acceptable and comprehensive standards of care, in a productive, collaborative and respectful manner and decide on a matrix of interventions for action.

Client-centred health system strengthening is possible, but will require institutional commitment and careful implementation across designated roles. An enabling work environment with available resources, including equipment, medication and infrastructure to respond to client needs, will go a long way to increase caregivers' intrinsic motivation and attitude towards providing nurturing PCC.

AUTHORS' AFFILIATIONS

¹Paediatric-Adolescent Treatment Africa (PATA), Cape Town, South Africa; ²Global Network of Young People Living with HIV (Y+ Global), Kampala, Uganda

COMPETING INTERESTS

The authors declare that they have no competing interests.

AUTHORS' CONTRIBUTIONS

Wrote the paper: LP and LH. Contributed to the writing of the manuscript: HS and MJ. Reviewed the paper: AK. All authors have read and approved the final manuscript.

ACKNOWLEDGEMENTS

Since this viewpoint seeks to make a contribution based on practical experience and work in the field, we wish to thank the networks and/or organizations that enabled both PATA and Y+ Global to gain this expertise and thus make this contribution in the journal. We also gratefully acknowledge the contributions made by Mary Caesar and Barbara Engelsmann in providing guidance in finalizing this manuscript.

REFERENCES

1. Rathert C, Wyrwich MD, Boren SA. Patient-centred care and outcomes: a systematic review of the literature. *Med Care Res Rev*. 2013;70(4):351–79. <https://doi.org/10.1177/1077558712465774>
2. Cramm JM. The benefits of person centered care for professional, patients and informal caregivers. *Int J Integr Care*. 21(S1):p.99. <https://doi.org/10.5334/ijic.ICIC203>
3. Kuipers SJ, Cramm JM, Nieboer AP. The importance of patient centred care and co-creation of care for satisfaction with care and physical and social well-being of patients with multi-morbidity in the primary care setting. *BMC Health Serv Res*. 2019;13. <https://doi.org/10.1186/s12913-018-3818-y>
4. World Health Organization. Innovative care for chronic conditions: building blocks for action: global report. 1st ed. Geneva: World Health Organization; 2002.
5. Nolte E, Merkur S, Anell A. Achieving person-centred health systems. Cambridge University Press; 2020.
6. Ninsiima LR, Chiumia IK, Ndejjo R. Factors influencing access to and utilization of youth-friendly sexual and reproductive health services in sub-Saharan Africa: a systematic review. *Reprod Health*. 2021;18:135.
7. Duffy M, Madevu-Matson C, Posner J, Zwick H, Sharer M, Powell A. Systematic review: development of a person-centred care framework within the context of HIV treatment settings in sub-Saharan Africa. *Trop Med Int Health*. 2022;27(5):479–93. <https://doi.org/10.1111/tmi.13746>
8. Mavhu W, Willis N, Mufuka J, Bernays S, Tshuma M, Mangenah C, et al. Effect of a differentiated service delivery model on virological failure in adolescents with HIV in Zimbabwe (Zvandiri): a cluster-randomised controlled trial. *Lancet Glob Health*. 2020;8(2):e264–27.
9. Paediatric AIDS Treatments for Africa (PATA). Pata standardised scorecard. Available from: <https://teampata.org/wp-content/uploads/2023/05/PATA-standardised-scorecard-2.pdf> [09 May 2023].

VIEWPOINT

A person-centred approach to enhance the long-term health and wellbeing of people living with HIV in Europe

Jeffrey V. Lazarus^{1,2,3,§} , Mario Cascio⁴, Jane Anderson⁵, Sini Pasanen⁶ and Richard Harding⁷

§Corresponding author: Jeffrey V. Lazarus, Calle del Rosellón, 171, ENT-2, Barcelona ES-08036, Spain. Tel: +34 608 70 35 73. (jeffrey.lazarus@sph.cuny.edu)

Received 2 November 2022; Accepted 12 May 2023

Copyright © 2023 The Authors. *Journal of the International AIDS Society* published by John Wiley & Sons Ltd on behalf of the International AIDS Society.

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

Person-centred care is a critical attribute of high-quality healthcare, promoting quality of life, improving an individual's interaction with the health system and valuing people's social networks [1]. Lifesaving antiretroviral therapy is now increasingly widely available around the world, although not all countries have reached their coverage targets related to prevention, diagnosis and linkage to care. As a consequence of the enormous progress made, most people living with HIV are able to grow older rather than dying prematurely [2]. Therefore, it is essential that health systems respond to the changing needs of an ageing population living with HIV, who have comparatively higher multimorbidity (both physical and mental) and experience persistent stigma [3, 4].

To achieve this, person-centred care services for people living with HIV must focus on long-term wellbeing by monitoring and managing multimorbidity, health-related quality of life (HRQoL), stigma and discrimination [5]. In line with WHO's global strategy on HIV for 2022–2030 [2] and UNAIDS' targets set in 2021 [6], a people-centred approach is essential to allow for this transformation of health systems. Health services must offer an integrated response to the evolving health needs and choices of people living with HIV—and this is still not the case in most settings, including high-income countries in Europe [7].

The crisis with health systems during 2020 and the worsening of health outcomes during the COVID-19 pandemic [8] demonstrated the importance of coordination among European countries to protect population health across national borders, especially among the most vulnerable. Against the backdrop of the pandemic, in 2020, the European Union put forward a proposal for a European Health Union [9]. Ambitious policy opportunities were identified, from a proposal for a European Health Data Space, to reinforcing the European Centre for Disease Prevention and Control mandate and pushing forward the European Care Strategy [10]. Person-centricity is at the core of these health system initiatives, paving the way for personalized healthcare delivery. These initiatives are of particular relevance for people living with HIV and their healthcare services given their multidimensional health and social care needs.

A people-centred health system is organized around what is important to people living with HIV, their needs and

choices, rather than focusing on individual diseases [5, 11]; it “consciously adopts the perspectives of individuals, families and communities (...), sees them as participants and beneficiaries of trusted health systems that respond (...) in humane and holistic ways” and “acknowledges the experiences and perspectives of health-care providers that may enable or prevent the delivery of [these health services]” [12]. In the context of HIV, people living with HIV must be empowered and supported to make decisions about the degree of self-management that they are capable of and willing to assume in line with their age, gender, socio-economic status and support network.

A key objective of a people-centred approach is to ensure that the views, needs and wellbeing of people living with HIV are represented in policy initiatives by prioritizing the enhancement of their long-term health, HRQoL and overall wellbeing, from diagnosis until the end of life [5]. With this goal in mind, in 2021 and 2022, over 60 multidisciplinary HIV organizations and experts from the HIV Outcomes initiative co-developed a set of 27 policy asks and recommendations for European health systems and authorities [13]. Qualitative input was collected with a representation of people living with HIV, clinicians, academics, public health professionals, policymakers and industry representatives. Expert interviews were conducted via a questionnaire and at seven workshops. Entitled “Enhancing long-term health and wellbeing among people living with HIV,” the policy asks were grouped into four areas where policy action is most urgent to improve wellbeing: (1) comorbidity prevention, treatment and management-including mental health; (2) ageing with HIV; (3) patient-reported outcomes measures and national monitoring of HRQoL; and (4) combatting stigma and discrimination. For each area, specific, implementable and translatable recommendations were made for HIV clinics/care providers, national and regional authorities and European Union health policymakers. Priority recommendations are highlighted in Table 1 [13].

Although focusing on monitoring HRQoL may be challenging for countries or health systems with fewer resources available, people living with HIV experience a greater overall burden of multimorbidity in comparison with the general population and reduced HRQoL across all domains. Therefore, actions that can benefit both individual wellbeing and health

Table 1. Summary of policy recommendations for each area of action in the European context

Areas of action	Priority recommendations	
Comorbidity prevention, treatment and management	HIV clinics/care providers	<ul style="list-style-type: none"> Implement routine screening for all relevant comorbidities based on individual characteristics and needs, in line with national and international guidelines, using short, easy-to-answer and validated screening instruments. Capture relevant data using electronic health records as a tool to support integrated, personalized care. Inclusion of management and referral protocols for the range of person-centred problems identified. Involve peers or community members to support with prevention, screening, treatment and management of comorbidities.
	National and regional authorities	<ul style="list-style-type: none"> Develop or update a monitoring and evaluation framework for HIV care, incorporating indicators on comorbidities, leading causes of mortality and hospitalization and patient-reported outcomes, including HRQoL. Integrate the framework into the national HIV strategy and ensure funding for its implementation. Include other communicable diseases and HRQoL as core elements of national HIV strategies.
	European Union	<ul style="list-style-type: none"> Expand the mandate of the European Commission's Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases to initiate work programmes on communicable diseases, such as HIV, including prevention, diagnosis and coordinated management of comorbidities. Ensure sustainable funding for cohort studies to provide information on the long-term health of people living with HIV, including comorbidities and HRQoL.
Ageing with HIV	HIV clinics/care providers	Deliver specialized, integrated healthcare and social services focused on the needs of older adults living with HIV: frailty and other geriatric syndromes, disability, age-related comorbidities, as well as mental and sexual health and active ageing.
	National and regional authorities	Develop and implement training programmes for carers, in particular those working in retirement homes, focused on the specific health and wellbeing needs of older adults living with HIV, including mental and sexual health and active ageing.
	European Union	Provide funding for pilot studies on models of HIV care that employ or develop frameworks for healthy ageing, frailty, functional ability and other dimensions of health that are relevant to people living with HIV, using HRQoL as a key outcome measure.
PROMs and HRQoL	HIV clinics/care providers	Integrate PROMs into clinical practice, which can then be used for shared decision-making with those living with HIV, to tailor interventions to meet the needs and preferences of individuals and for monitoring of health outcomes.
	National and regional authorities	Implement methodologically robust annual surveys of people living with HIV to collect and document data on HRQoL and on experiences of stigma and discrimination in healthcare settings.
	European Union	Allocate funding for the inclusion of HIV within the OECD Paris Initiative to provide standardized, comparable data on person-reported outcomes and person-reported experiences across countries.
Stigma and discrimination	HIV clinics/care providers	Offer peer-to-peer and community-based interventions that address stigma and discrimination experienced by people living with HIV, including a focus on the fact that an undetectable viral load means an untransmissible virus.
	National and regional authorities	Design and implement interventions that can strengthen empathy towards people living with HIV among healthcare staff, disseminating the U = U message in order to decrease stigma and discrimination in and outside of healthcare settings.
	European Union	Ensure that any future EU mental health strategy includes a focus on people experiencing stigma and discrimination, including people living with HIV specifically.

Abbreviations: EU, European Union; HRQoL, health-related quality of life; OECD, Organization for Economic Cooperation and Development; PROMs, patient-reported outcome measures; U = U, Undetectable = Untransmittable.

system costs need to be adopted. This should be in tandem with efforts to increase the numbers of people diagnosed, linked to care and virally suppressed [14]. A particular focus should be placed on reaching people who are diagnosed late as they are at high risk of clinical progression and poor outcomes. Currently, 53% of people newly diagnosed with HIV in the WHO European region are diagnosed late, of whom 51% are aged >50 [15]. We encourage the adoption of these measures by all European Union member states by the end of 2023. The aforementioned policy recommendations are tailored to tackle the shortcomings in healthcare settings for people living with HIV in Europe. Different priority areas of action also may be considered for other regions of the world.

AUTHORS' AFFILIATIONS

¹Barcelona Institute for Global Health (ISGlobal), Hospital Clínic, University of Barcelona, Barcelona, Spain; ²CUNY Graduate School of Public Health and Health Policy (CUNY SPH), New York, New York, USA; ³Faculty of Medicine and Health Sciences, University of Barcelona, Barcelona, Spain; ⁴European AIDS Treatment Group, Brussels, Belgium (E-mail: marcascio@gmail.com); ⁵Homerton Healthcare NHS Foundation Trust London, London, UK; ⁶Positiiviset HivFinland and AIDS Action Europe, Helsinki, Finland; ⁷Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, Cicely Saunders Institute, King's College London, London, UK

COMPETING INTERESTS

JVL reports grants and speaker fees from AbbVie, Gilead Sciences, MSD and Roche Diagnostics to his institution, speaker fees from Intercept, Janssen, Novo Nordisk and ViiV and consulting fees from Novavax, outside of the submitted work. JA reports consultancy and speaker fees from Gilead Sciences and speaker fees from ViiV Healthcare, outside of the submitted work. MC, SP and RH have no competing interest to declare.

AUTHORS' CONTRIBUTIONS

JVL conceived of the paper. MC, JA, SP and RH reviewed the first full draft of the article. All authors were involved in subsequent revisions and approved the final version for submission.

ACKNOWLEDGEMENTS

The authors are members of the HIV Outcomes initiative (<https://hivoutcomes.eu/about-us/team-members/>). JVL acknowledges support to ISGlobal from the grant CEX2018-000806-S funded by MCIN/AEI/10.13039/501100011033 and the 'Generalitat de Catalunya' through the CERCA Programme, outside of the submitted work. The Policy Asks were developed in collaboration with European multidisciplinary experts and members of the HIV Outcomes Initiative, including researchers, HIV clinicians, people living with HIV, patient group representatives and industry. Thank you to everyone at HIV Outcomes. HIV Outcomes, a multi-stakeholder European initiative, was created in 2016 to advance the health-related quality of life of people living with HIV—beyond viral suppression.

HIV Outcomes members: HIV Outcomes Steering Group Members: Antonella d'Arminio Monforte: University of Milan; AIDS Action Europe: represented by Sini Pasanen; Children's HIV Association (CHIVA): represented by Amanda Ely and Amanda Williams; European AIDS Treatment Group (EATG): represented by Mario Cascio; Jane Anderson: Homerton University Hospital NHS Foundation Trust, London (Steering Group Co-Chair); National AIDS Trust (NAT): represented by Cheryl Gowar; Nikos Dedes: Positive Voice (Greek association for people living with HIV) (Steering Group Co-Chair); Richard Harding: King's College London; Jeffrey Lazarus: Barcelona Institute for Global Health (ISGlobal), Hospital Clínic, University of Barcelona (Steering Group Co-Chair); Stéphan Vernhes: AIDES & Coalition PLUS; and Industry represented by: Andrea Zangaglio (Gilead Sciences) and Rhon Reynolds (ViiV Healthcare).

HIV Outcomes general members: Adhara Asociación VIH/SIDA (ADHARA): represented by Diego Garcia and Alejandro Bertó Morán; AFEW International: represented by Yulia Komo; Correlation—European Harm Reduction Network [C-EHRN]: represented by Roberto Pérez-Gayo; Dr Casper Rokx; Erasmus MC; Dr Diana Barger: University of Bordeaux; Dr Patrizia Carrieri: French Institute of Health and Medical Research (INSERM); East Europe & Central Asia Union

of PLWH (ECUO): represented by Vladimir Zhovtyak; GAMIAN-Europe: represented by Nigel Olisa; Georg Behrens: Hannover Medical School; Grupo de Ativistas em Tratamentos (GAT Portugal): represented by Luis Mendão; Igor Gordon: Eurasian Harm Reduction Association; Maryam Said; National HIV Nurses Association (NHVNA): represented by Shaun Watson; Prof Alan Winston—Okeefe: Imperial College London; Prof Anna Mia Ekström: Karolinska Institutet; Prof Caroline Sabin: University College London; Prof Giovanni Guaraldi: University of Modena and Reggio Emilia (UNIMORE); Prof Kyriakos Souliotis: University of Peloponnese & Health Policy Institute; Prof Lars E Eriksson: Karolinska Institutet; Sociedad Española Interdisciplinaria del SIDA (SEISIDA): represented by Dr María José Fuster-Ruiz de Apodaca; Supporting Women with HIV Information Network (SWIFT Network): represented by Yvonne Gilleece; SKUK-Magnus: represented by Miran Solinc; and Terrence Higgins Trust (THT): represented by Richard Angell.

HIV Outcomes Observer members: European Centre for Disease Prevention and Control (ECDC); Joint United Nations Programme on HIV/AIDS (UNAIDS); European AIDS Clinical Society (EACS); Fast Track Cities Europe; and UNITE Global Parliamentarians Network (UNITE).

HIV Outcomes in-country initiatives: HIV Outcomes Germany; HIV Outcomes Italy; HIV Outcomes Spain; HIV Outcomes Romania; and HIV Outcomes UK.

REFERENCES

- Giusti A, Nkhoma K, Petrus R, Petersen I, Gwyther L, Farrant L, et al. The empirical evidence underpinning the concept and practice of person-centred care for serious illness: a systematic review. *BMJ Glob Health*. 2020;5(12):e003330.
- World Health Organization. Global health sector strategies on, respectively, HIV, viral hepatitis and sexually transmitted infections for the period 2022–2030. Geneva: World Health Organization; 2022.
- Abboah-Offei M, Bristowe K, Koffman J, Vanderpuye-Donton NA, Ansa G, Abas M, et al. How can we achieve person-centred care for people living with HIV/AIDS? A qualitative interview study with healthcare professionals and patients in Ghana. *AIDS Care*. 2019;32(12):1479–88.
- Bristowe K, Clift P, James R, Josh J, Platt M, Whetham J, et al. Towards person-centred care for people living with HIV: what core outcomes matter, and how might we assess them? A cross-national multi-centre qualitative study with key stakeholders. *HIV Med*. 2019;20(8):542–54.
- Lazarus JV, Saftreed-Harmon K, Kamarulzaman A, Anderson J, Leite RB, Behrens G, et al. Consensus statement on the role of health systems in advancing the long-term well-being of people living with HIV. *Nature Commun*. 2021;12(1):4450.
- UNAIDS. End Inequalities. End AIDS. Global AIDS Strategy 2021–2026. UNAIDS; 2021.
- Van Hout M, Bachmann M, Lazarus JV, Shayo EH, Bukenya D, Picchio CA, et al. Strengthening integration of chronic care in Africa: protocol for the qualitative process evaluation of integrated HIV, diabetes and hypertension care in a cluster randomised controlled trial in Tanzania and Uganda. *BMJ Open*. 2020;10:e039237.
- Parisi CE, Varma DS, Wang Y, Vaddiparti K, Ibañez GE, Cruz L, et al. Changes in mental health among people with HIV during the COVID-19 pandemic: qualitative and quantitative perspectives. *AIDS Behav*. 2022;26(6):1980–91.
- European Health Union. European Commission [Internet]. [Cited 2022 Aug 19]. Available from: https://ec.europa.eu/info/strategy/priorities-2019-2024/promoting-our-european-way-life/european-health-union_en
- European Care Strategy. European Commission [Internet]. [Cited 2022 Aug 17]. Available from: https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/13298-European-care-strategy_en.
- PEPFAR 2022 Country and Regional Operational Plan (COP/ROP) Guidance for all PEPFAR-Supported Countries. 2022.
- World Health Organization. Consolidated guidelines on HIV prevention, testing, treatment, service delivery and monitoring: recommendations for a public health approach. World Health Organization; 2021.
- Enhancing long-term health and wellbeing among people living with HIV. Launch of HIV Outcomes Policy Asks. HIV Outcomes [Internet]. [Cited 2022 Oct 21]. Available from: <https://hivoutcomes.eu/event/enhancing-long-term-health-and-wellbeing-among-people-living-with-hiv-launch-of-hiv-outcomes-policy-asks/>
- Lazarus JV, Wohl DA, Cascio M, Guaraldi G, Rockstroh J, Hodson M, et al. Long-term success for people living with HIV: a framework to guide practice. *HIV Med*. 2023;24(Suppl. 2):8–19.
- European Centre for Disease Prevention and Control. ECDC and WHO call for improved HIV testing in Europe [Internet]. [Cited 2022 Sep 18]. <https://www.ecdc.europa.eu/en/news-events/ecdc-and-who-call-improved-hiv-testing-europe>

AUTHOR INDEX

A	H	N
Amanyeibe, U. 31	Harding, R. 64	Nishimoto, L. 12
Anderson, J. 64	Hatane, L. 62	Nyabuti, M. 23
Ayieko, J. 23	Havlir, D.V. 23	Nyirenda, H. 39
	Herbeck, J.T. 4	
	Holmes, C.B. 39, 52	
B	J	O
Bailey, L. 31	Janamnuaysook, R. 1	Osi, K. 12
Balzer, L.B. 23	Jere, L. 52	
Bateganya, M. 12	Jokonya, M. 62	
Beres, L.K. 39, 52		
Bolton-Moore, C. 39		
Bukusi, E.A. 23		
	K	P
C	Kabami, J. 23	Pasanen, S. 64
Calnan, J. 31	Kadama, H. 31	Patel, D. 31
Camlin, C.S. 23	Kakande, E. 23	Patel, K. 31
Canagasabey, D.S. 18	Kambale, H. 12	Petersen, M.L. 23
Cascio, M. 64	Kamya, M.R. 23	Phillips, L. 62
Caswell, G. 1	Karamagi Nkolo, E.K. 31	Pry, J.M. 39, 52
Chamie, G. 23	Kasongo, P. 18	
Christopoulos, K. 39, 52	Kerani, R.P. 4	
	Kiluba, J.-C. 18	
	Kisyeri, N. 12	
	Koss, C.A. 23	
	Kyendikuwa, A. 62	
D	L	S
Ddumba, I. 31	Lazarus, J.V. 1, 64	Sensalire, S. 31
Dessie, M. 31	Lieke, O. 18	Sharma, A. 39, 52
Diur, B. 18	Lumbo, K. 39, 52	Shook, A. 4
		Sikazwe, I. 39, 52
E		Sikombe, K. 39, 52
Ejike, J.C. 31		Simbeza, S. 39, 52
		Soeters, H. 62
		Srikanth, K. 31
		Ssali, J.N. 31
F	M	T
Foloko, M. 39, 52	Maina, N. 31	Tendo-Bugondo, C. 18
Ford, N. 12	Milenge, P.K. 18	Thior, I. 18
	Minalga, B. 4	Tordoff, D.M. 4
	Minior, T. 12, 31	Trejo, A. 4
	Mody, A. 39, 52	
	Moore, C.B. 52	
	Mukamba, N. 39, 52	
	Mulabe, M. 39	
	Munsamy, M. 12	
G	Mwamba, C. 39, 52	
Geng, E.H. 39, 52		
Goldstein, D. 12		
Gonzalez, C. 31		

Journal Information

About the journal

The *Journal of the International AIDS Society*, the official journal of the Society, provides a peer-reviewed, open access forum for essential and innovative HIV research, across all disciplines. All articles published by the *Journal of the International AIDS Society* are freely accessible online. The editorial decisions are made independently by the journal's Editors-in-Chief.

Website: www.jiasociety.org

eISSN: 1758-2652

Contact details

Editorial office:

Avenue de France, 23
CH-1202 Geneva
Switzerland

Email: editorial@jiasociety.org

Tel: +41 (0) 22 710 0800

Publisher

The *Journal of the International AIDS Society* is published by John Wiley & Sons Ltd on behalf of the IAS - International AIDS Society

John Wiley & Sons Ltd
9600 Garsington Road
Oxford, OX4 2DQ UK

Telephone: +44 1865 776868

Email: customer@wiley.com

Production Editor

Geethu RS (rgeethu@wiley.com)

Abstracting and Indexing Services

The *Journal of the International AIDS Society* is indexed in a variety of databases including PubMed, PubMed Central, MEDLINE, Science Citation Index Expanded and Google Scholar. The 2022 Journal Impact Factor is 6.0, Journal Citation Reports (Clarivate Analytics, 2023).

Advertising, sponsorship and donations

Please contact the editorial office if you are interested in advertising on our journal's website. We also gladly receive inquiries on sponsorship and donations to support open access publications from authors in low- and middle-income countries.

Supplements

The *Journal of the International AIDS Society* publishes supplements and thematic series on its own initiative or based on proposals by external organisations or authors. Inquiries can be sent to the editorial office at editorial@jiasociety.org.

All articles submitted for publication in supplements are subject to peer review. Published supplements are freely accessible online and can also be produced in print.

Disclaimer

The Publisher, IAS - the International AIDS Society and Editors cannot be held responsible for errors or any consequences arising from the use of information contained in this journal; the views and opinions expressed do not necessarily reflect those of the Publisher, IAS and Editors, neither does the publication of advertisements constitute any endorsement by the Publisher, IAS and Editors of the products advertised.

Copyright and Copying

The content in this supplement is published under the Creative Commons Attribution license ("CC-BY"). The license allows third parties to share the published work (copy, distribute, transmit) and to adapt it under the condition that the authors are given credit, and that in the event of reuse or distribution, the terms of this license are made clear. Authors retain the copyright of their articles, with first publication rights granted to the *Journal of the International AIDS Society*.

Wiley's Corporate Citizenship Initiative

Wiley's Corporate Citizenship Initiative seeks to address the environmental, social, economic, and ethical challenges faced in our business and which are important to our diverse stakeholder groups. Since launching the initiative, we have focused on sharing our content with those in need, enhancing community philanthropy, reducing our carbon impact, creating global guidelines and best practices for paper use, establishing a vendor code of ethics, and engaging our colleagues and other stakeholders in our efforts. Follow our progress at www.wiley.com/go/citizenship.

Research4Life

Wiley is a founding member of the UN-backed HINARI, AGORA, and OARE initiatives. They are now collectively known as Research4Life, making online scientific content available free or at nominal cost to researchers in developing countries.

Please visit Wiley's Content Access – Corporate Citizenship site: www.wiley.com/WileyCDA/Section/id-390082.html

Editorial Board

Editors-in-Chief

Prof. Kenneth H. Mayer (United States)
Dr. Annette Sohn (Thailand)

Executive Editor

Dr. Marlène Bras (Switzerland)

Managing Editor

Dr. Alberto Rossi (Switzerland)

Editorial Assistants

Christina Boger (Switzerland)
Chloé Zufferey (Switzerland)

Deputy Editors

Dr. Jenny Anderson (Australia)
Dr. Kim Anderson (South Africa)
Dr. Benjamin Bavinton (Australia)
Dr. Cheryl Baxter (South Africa)
Dr. Kristin Beima-Sofie (United States)
Prof. Carol Camlin (United States)
Dr. Morna Cornell (South Africa)
Dr. Claudia Cortés (Chile)
Dr. Trevor Crowell (United States)
Dr. Halima Dawood (South Africa)
Dr. Jeffrey Eaton (United States)
Prof. Matthew Fox (United States)
Dr. Kimberly Green (Vietnam)
Dr. Anna Grimsrud (South Africa)
Prof. Renee Heffron (United States)
Prof. Martin Holt (Australia)
Prof. Mina Hosseinipour (Malawi)
Dr. Dvora Joseph Davey (South Africa)
Prof. John Joska (South Africa)
Prof. Rami Kantor (United States)
Dr. Sherrie Kelly (Australia)
Prof. Carmen Logie (Canada)
Neetha Morar (South Africa)
Dr. Kenneth Ngure (Kenya)
Dr. Brooke Nichols (the Netherlands)
Dr. Sophie Pascoe (South Africa)
Dr. Nittaya Phanuphak (Thailand)
Dr. Arjee Restar (United States)
Jeremy Ross (Thailand)
Prof. Steven Safran (United States)
Dr. Colette Smith (United Kingdom)
Prof. Sunil Solomon (United States)
Dr. Rayner Kay Jin Tan (Singapore)
Dr. Junko Tanuma (Japan)
Dr. Elona Toska (South Africa)
Dr. Jennifer Vellozo (United States)
Dr. Lara Vojnov (Switzerland)
Dr. Dan Wu (China)
Dr. Fan Yang (China)
Dr. Iryna Zablotska (Australia)

Editorial Board

Dr. Allison Agwu (United States)
Dr. Joseph Amon (United States)
Dr. Judith Auerbach (United States)
Prof. Linda-Gail Bekker (South Africa)
Dr. Sarah Bernays (Australia)
Prof. Chris Beyrer (United States)
Dr. Susan Buchbinder (United States)
Prof. Carlos Caceres (Peru)
Dr. Hiam Chemaitelly (Qatar)
Dr. Andrea Ciaranello (United States)
Prof. Elizabeth Connick (United States)
Dr. Victor DeGruttola (United States)
Dr. Nathan Ford (Switzerland)
Dr. Elvin Geng (United States)
Dr. Beatriz Grinsztejn (Brazil)
Dr. Diane Havlir (United States)
Dr. Leigh Johnson (South Africa)
Prof. Amy Justice (United States)
Dr. Adeeba Kamarulzaman (Malaysia)
Prof. Rami Kantor (United States)
Prof. Marina Klein (Canada)
Dr. Nagalingeswaran Kumarasamy (India)
Prof. Sharon Lewin (Australia)
Dr. Mathias Lichterfeld (United States)
Dr. Grace CY Lui (China)
Dr. Kathleen MacQueen (United States)
Dr. Landon Myer (South Africa)
Prof. Denis Nash (United States)
Dr. Praphan Phanuphak (Thailand)
Dr. Tonia Potat (United States)
Dr. Anton Pozniak (United Kingdom)
Dr. Robert Remien (United States)
Dr. Sean Rourke (Canada)
Dr. Gabriella Scarlatti (Italy)
Prof. Lorraine Sherr (United Kingdom)
Dr. Izukanji Sikazwe (Zambia)
Dr. Colette Smith (United Kingdom)
Dr. Bruno Spire (France)
Dr. Tim Spelman (Australia)
Dr. Omar Sued (Argentina)
Dr. Wataru Sugiura (Japan)
Dr. Darrell Tan (Canada)
Prof. Francois Venter (South Africa)
Dr. Sten Vermund (United States)
Prof. Iryna Zablotska (Australia)

Ethics Committee

Dr. Joseph Amon (United States)
Dr. Nathan Ford (Switzerland)
Dr. Kathleen MacQueen (United States)

