



Marlène Bras, International AIDS Society, Switzerland

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



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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 Janamnuysook

Supplement Editors: Karoline Soerensen



**With support
from:**



Acknowledgement of contributors



This supplement was guest edited by:

- Rena Janamnuaysook, Institute of HIV Research and Innovation, Thailand
- Jeffrey V. Lazarus, Barcelona Institute for Global Health, Spain
- Georgina Caswell, Global Network of People Living with HIV, South Africa

With thanks to the JIAS Editorial Team and the IAS person-centred care programme



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Moderators



Jeffrey V. Lazarus,
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Rena Janamnuaysook,
Institute of HIV Research
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Rena Janamnuaysook, Institute of HIV Research and Innovation, Thailand
Person-centred approaches to address the health needs of people living with HIV and co-infections and co-morbidities

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



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Conflict of interest disclosure



Gilead Sciences and ViiV Healthcare: Speaker's bureau

The potential effects of relevant financial relationships with ineligible companies have been mitigated. Any clinical recommendations are based on evidence and are free of commercial bias.

Background



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- Despite advances made by health systems to improve the care of people living with HIV, “a higher burden of multi-morbidity and poorer health-related quality of life are reported by many people living with HIV in comparison to people without HIV” [1]
- WHO’s Consolidated HIV Guidelines includes guidance on task-sharing, integration and decentralization of services “to promote the highest quality, person-centred delivery of care for people living with and affected by HIV” [2]
- Gaps in implementation science evidence to support this guidance exist

1. Lazarus, J.V. et.al. *Nat Commun* **12**, 4450 (2021).

2.WHO, Consolidated guidelines on HIV prevention, testing, treatment, service delivery and monitoring, July 2021

Objective of the supplement



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1. Spotlight the latest evidence, best practices and community perspectives from around the world related to person-centred care approaches
2. Enable research groups to share developments around implementing the components of person-centred care in their unique settings

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

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10 publications launched on
6 July 2023 including:

- 1 editorial
- 5 research articles
- 2 viewpoints
- 1 short report
- 1 commentary



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"People-centred health systems are programmes of care that provide individuals, families and communities with humanistic, holistic and trusted healthcare that must be acceptable and responsive to the needs, rights and preferences of people living with HIV and key populations."

IAS supplement editorial



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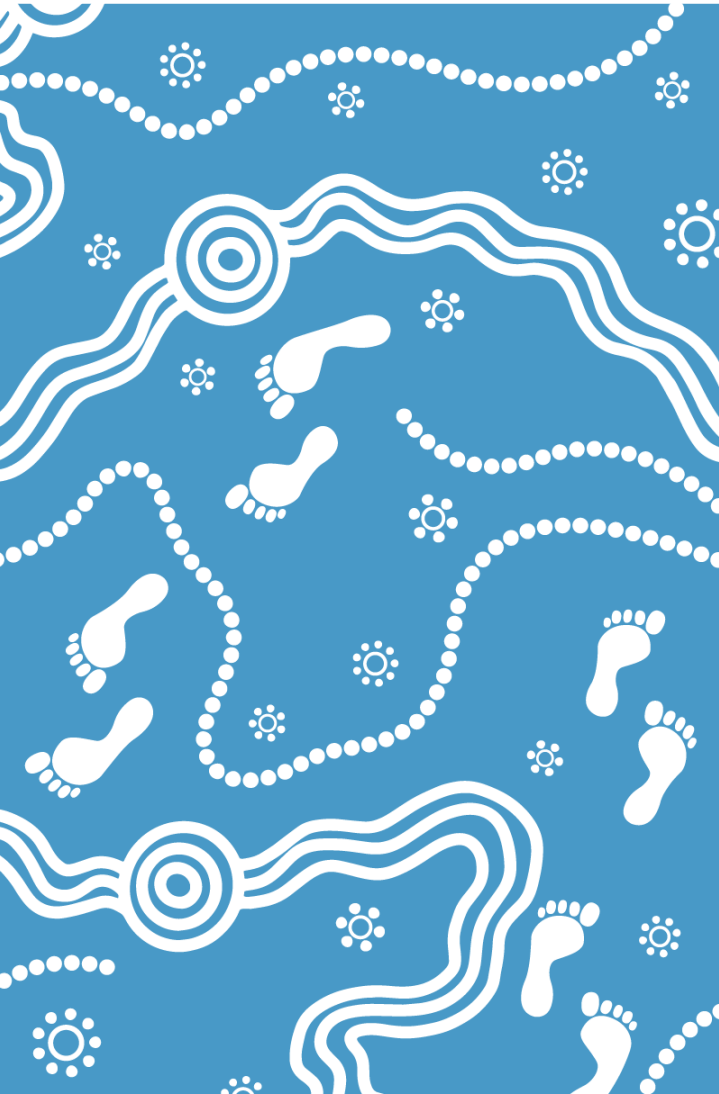
Key takeaways

1. Meaningful and sustained engagement
2. Proven to enhance outcomes
3. Implementation barriers exist
4. Now need to champion wellbeing





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"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 person-centred health systems globally."

IAS supplement editorial

HIV updates: Strategies for long-term success

Prof. Jeffrey V. Lazarus [Jeffrey.Lazarus@ISGlobal.org]

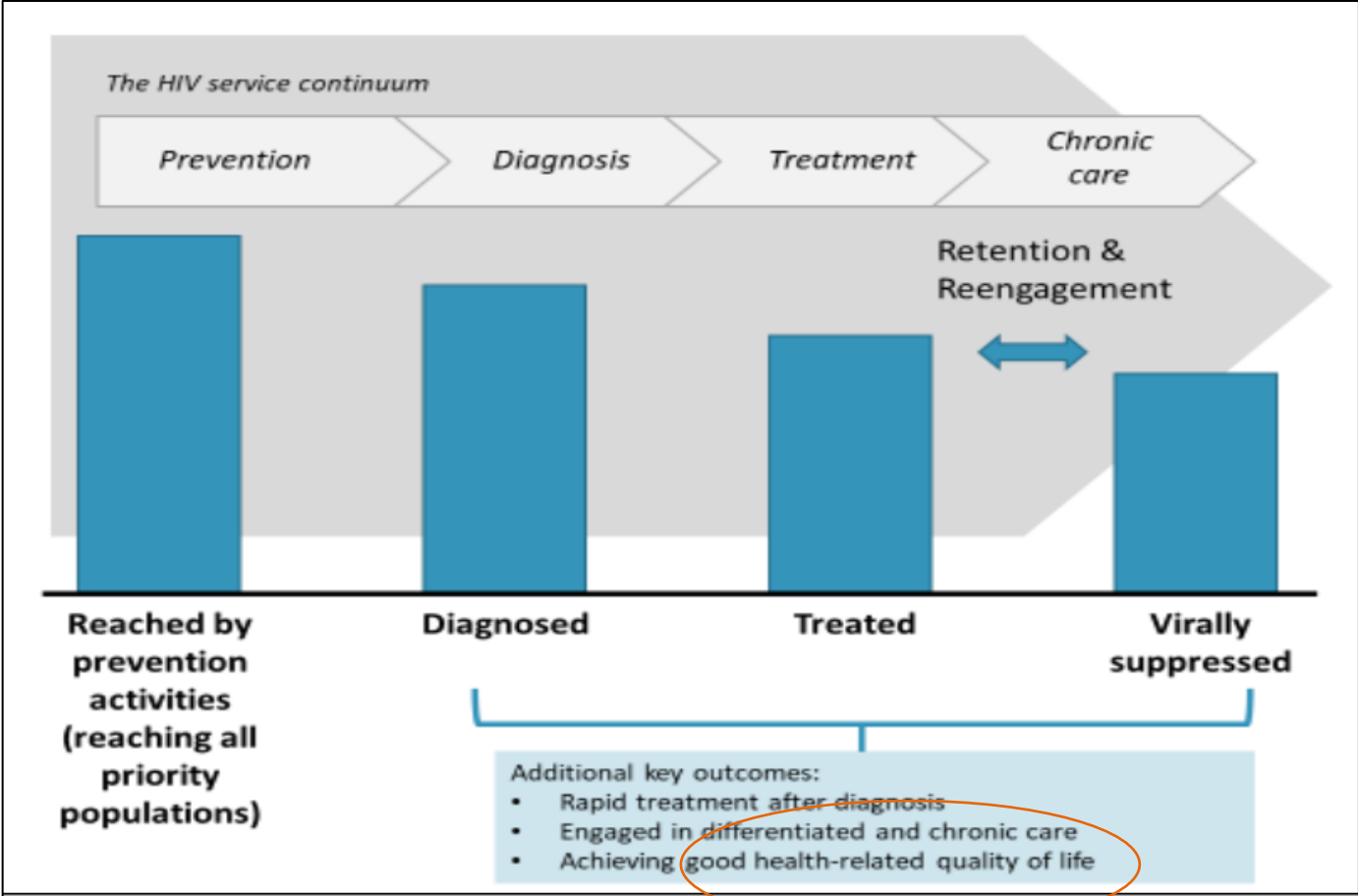
Professor, CUNY Graduate School of Public Health and Health Policy
Associate Research Professor, ISGlobal, Hospital Clínic, Barcelona, Spain
Associate Professor, Faculty of Medicine, University of Barcelona
Member, Policy and Public Health Committee, EASL

WHO Global health sector strategy on HIV for the period 2022–2030

- The WHO strategy calls for a more precise **focus to reach the most affected and at-risk of HIV and AIDS** to address inequities, as they prevent the world from ending the HIV and AIDS epidemic
- An opportunity to go beyond ART and viral suppression: **a more holistic, people-centred HIV care approach focused on long-term well-being** addressing HRQoL, multimorbidity in people living with HIV (NCDs, mental health, etc.) and stigma and discrimination



HRQoL in the WHO GHSS 2022-2030



Source: WHO Global health sector strategy on HIV for the period 2022–2030

HRQoL is not addressed as a quantitative target on the WHO's 2022–2030 global health sector strategies on HIV



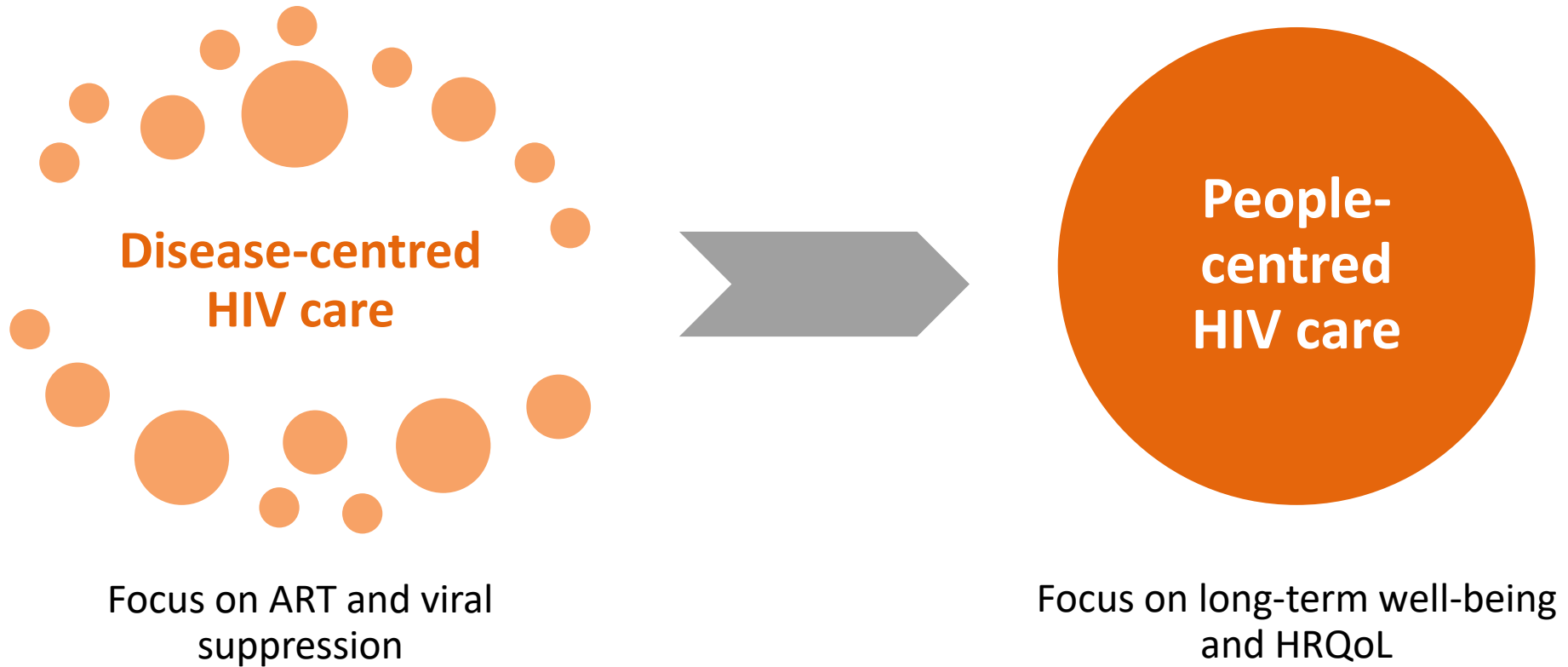
The strategy falls short of making a commitment to monitoring global progress toward improving HRQoL outcomes in people living with HIV and assessing impact and service coverage

- Addressing HRQoL related to people living with HIV can be relatively new for health systems
- Without institutionalised targets, health systems may not recognise the importance of reporting on the HRQoL of people living with HIV

PARADIGM SHIFT: A NEW ERA FOR HIV CARE

THE TRANSITION FROM DISEASE-CENTRED HEALTH SYSTEMS AND HIV CARE TO
HOLISTIC, PEOPLE-CENTRED HIV CARE WITHIN INTEGRATED HEALTH SYSTEMS

Paradigm shift: beyond viral suppression



ART, antiretroviral therapy; HRQoL, health-related quality of life.

Source: Lazarus JV 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.

A global consensus on advancing the long-term well-being of PLHIV



PERSPECTIVE

<https://doi.org/10.1038/s41467-021-24673-w> OPEN



Consensus statement on the role of health systems in advancing the long-term well-being of people living with HIV

Jeffrey V. Lazarus¹, Kelly Safreed-Harmon¹, Adeeba Kamarulzaman^{2,3}, Jane Anderson⁴, Ricardo Baptista Leite⁵, Georg Behrens⁶, Linda-Gail Bekker⁷, Sanjay Bhagani⁸, Darren Brown⁹, Graham Brown¹⁰, Susan Buchbinder¹¹, Carlos Caceres¹², Pedro E. Cahn¹³, Patrizia Carrieri¹⁴, Georgina Caswell¹⁵, Graham S. Cooke¹⁶, Antonella d'Arminio Monforte¹⁷, Nikos Dedes¹⁸, Julia del Amo¹⁹, Richard Elliott²⁰, Wafaa M. El-Sadr²¹, Maria José Fuster-Ruiz de Apodaca^{22,23}, Giovanni Guaraldi²⁴, Tim Hallett¹⁶, Richard Harding²⁵, Margaret Hellard²⁶, Shabbir Jaffar²⁷, Meaghan Kall²⁸, Marina Klein²⁹, Sharon R. Lewin^{30,31,32}, Ken Mayer³³, Jose A. Pérez-Molina³⁴, Doreen Moraa³⁵, Denise Nanche¹, Denis Nash³⁶, Teymur Noori³⁷, Anton Pozniak^{9,38}, Reena Rajasuriar², Peter Reiss³⁹, Nesrine Rizk⁴⁰, Jürgen Rockstroh⁴¹, Diana Romero³⁶, Caroline Sabin⁴², David Serwadda⁴³ & Laura Waters⁴⁴

Health systems have improved their abilities to identify, diagnose, treat and, increasingly, achieve viral suppression among people living with HIV (PLHIV). Despite these advances, a higher burden of multimorbidity and poorer health-related quality of life are reported by many PLHIV in comparison to people without HIV. Stigma and discrimination further exacerbate these poor outcomes. A global multidisciplinary group of HIV experts developed a consensus statement identifying key issues that health systems must address in order to move beyond the HIV field's longtime emphasis on viral suppression to instead deliver integrated, person-centered healthcare for PLHIV throughout their lives.

Steering committee

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A multidisciplinary panel of **44 global HIV experts, including PLHIV, clinicians and researchers**, was convened to identify **key issues that health systems must address** to move beyond their focus on viral suppression and advance the long-term wellbeing of PLHIV from a patient-centred perspective.

Key next steps from the consensus on advancing the long-term well-being of PLHIV

PERSPECTIVE

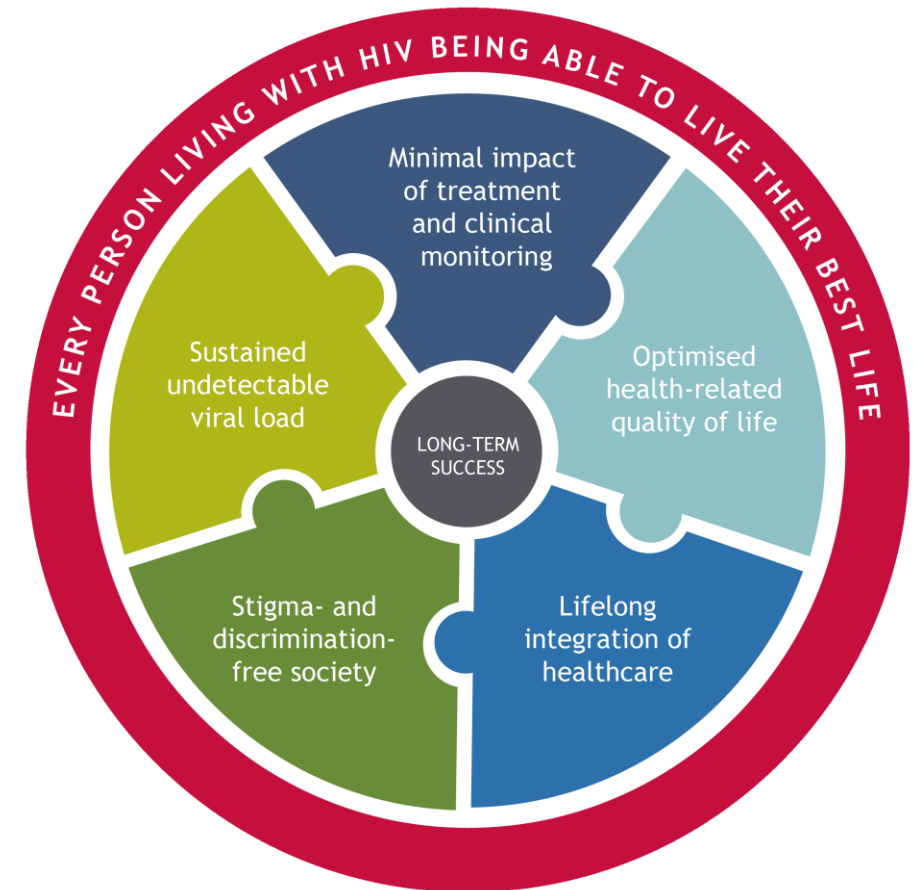
NATURE COMMUNICATIONS | <https://doi.org/10.1038/s41467-021-24673-w>

Box 3 | Key next steps for health systems to advance the long-term well-being of people living with HIV

1. Incorporate the **monitoring of comorbidities** in electronic health records, where feasible, for use in integrated clinical care and international multimorbidity monitoring.
2. Develop and pilot models of care that employ **frameworks for healthy aging, frailty, functional ability**, and other dimensions of health that are relevant to PLHIV, using HRQoL as a key outcome measure. Meaningfully involve PLHIV in these efforts.
3. Expand integrated HIV and primary care outreach services to locations and times that **reduce access barriers for marginalized and vulnerable groups**. Pilot integrated models of care for these groups that link them with the formal health system, including community-based health and psychosocial services and peer support programs.
4. Establish annual surveys of PLHIV, conducted at the subnational and/or facility level, to **collect and document data on HRQoL** and on experiences of stigma and discrimination in healthcare settings.
5. Implement interventions to strengthen empathy among healthcare staff and **decrease stigma and discrimination in healthcare settings**. These should be accompanied by interventions involving peers and community members, which can reduce internalized stigma in PLHIV by enhancing the effect of protective factors such as empowerment, social support, resistance, and adaptive coping strategies.

The Long-Term Success (LTS) Framework

- HIV management goals have shifted to meet the evolving needs of people living with HIV.
- Re-defining long-term success (LTS), in light of the new WHO strategy, is necessary to help address these needs.
- An expert panel co-created a framework to help guide clinical practice and establish LTS as a new goal in the HIV management landscape.
- The framework includes five key outcome pillars that, if achieved, would support the LTS vision of **every person living with HIV being able to live their best life**.



ENHANCING LONG-TERM HEALTH AND WELL-BEING AMONG PEOPLE LIVING WITH HIV:

KEY AREA 1:

COMORBIDITY PREVENTION, TREATMENT AND MANAGEMENT

Policy recommendations: Comorbidity prevention, treatment and management

- THE EUROPEAN UNION

Expand the mandate of the Steering Group on Health Promotion, Disease Prevention, and Non-Communicable Diseases (NCDs) management to initiate work programmes on **communicable diseases**, such as HIV, including prevention, diagnosis and coordinated management of comorbidities.

- NATIONAL AND REGIONAL HEALTH AUTHORITIES

Develop/update a monitoring and evaluation **framework for HIV care**, incorporating indicators on comorbidities, leading causes of mortality and hospitalisation, and person-reported outcomes (PROs) including health-related quality of life (HRQoL).

- HIV CLINICS / CARE PROVIDERS

Implement **routine screening for all relevant comorbidities** based on individual characteristics and needs, in line with national and international guidelines, using short, easy to administer, validated screening instruments.

ENHANCING LONG-TERM HEALTH AND WELL-BEING AMONG PEOPLE LIVING WITH HIV:

KEY AREA 2:
AGEING WITH HIV

Policy recommendations: Ageing with HIV

- THE 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 with HIV, using HRQoL as a key outcome measure. People with HIV should be meaningfully involved in these efforts.

- NATIONAL AND REGIONAL HEALTH AUTHORITIES

Develop and implement **training programmes for carers**, in particular those working in retirement homes, focused on the specific health and well-being needs of older people with HIV – including mental health.

- HIV CLINICS / CARE PROVIDERS

Provide **specialised, integrated healthcare services** focused on the needs of older adults with HIV, including frailty and other geriatric syndromes, disability, age-related comorbidities, and mental health (e.g. depression).

ENHANCING LONG-TERM HEALTH AND WELL-BEING AMONG PEOPLE LIVING WITH HIV:

KEY AREA 3:

MEASUREMENT OF PROS AND MONITORING OF HRQOL

Policy recommendations: Measurement of PROs and monitoring of HRQoL

- THE EUROPEAN UNION

Allocate funding for the inclusion of HIV within the **OECD Paris Initiative** to provide standardised, comparable data on PROs and experiences across countries.

- NATIONAL AND REGIONAL HEALTH AUTHORITIES

Establish **annual surveys of people with HIV** to collect and document data on HRQoL and on experiences of **stigma and discrimination** in healthcare settings.

- HIV CLINICS / CARE PROVIDERS

Integrate person-reported outcomes measurement (PROMs) into clinical practice, which can then be used for shared decision-making with those living with HIV, to tailor interventions to individual needs and preferences, and for monitoring of health outcomes.

ENHANCING LONG-TERM HEALTH AND WELL-BEING AMONG PEOPLE LIVING WITH HIV:

KEY AREA 4:
COMBATTING STIGMA AND DISCRIMINATION

Policy recommendations: Combatting stigma and discrimination

- THE EUROPEAN UNION

Given the negative impact of stigma and discrimination on mental health, ensure that any future EU mental health strategy includes a focus on reducing stigma and discrimination among groups at risk, including people with HIV.

- NATIONAL AND REGIONAL HEALTH AUTHORITIES

Design and implement interventions that can strengthen empathy towards people with HIV among healthcare staff and decrease stigma and discrimination in healthcare settings. Monitor and regularly review the effectiveness of these interventions.

- HIV CLINICS / CARE PROVIDERS

Offer peer-to-peer and community-based interventions to address stigma and discrimination experienced by people with HIV, including a focus on the fact that an undetectable viral load means untransmissible virus.

Priority areas moving forward



Integrate patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) into clinical practice



People-centred, integrated health service delivery models



Availability of digital health technologies and tools



Recognising the importance of social determinants of health and inequity, stigma and discrimination, mental health, disability and life rehabilitation

Acknowledgements

***Everyone** who has contributed to the cited slides, the WHO Global Health Sector Strategy on HIV team.*

***And everyone** who continues to fight to for people living with HIV and communities at risk.— we can end this persistent public health threat.*

The ISGlobal Health Systems Research team

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Partner in the following 4 multi-country EU-funded projects: **BOOST, CATALYSE, META-Trial and SEMID**





Jane Kabami

Infectious Diseases Research collaboration, Uganda

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

Person-centred dynamic choice prevention in rural Kenya and Uganda: SEARCH SAPPHIRE study



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Conflict of interest disclosure



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Objective



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- To evaluate the uptake of a person-centred, Dynamic Choice Prevention (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).



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Client-centered care in all situations of provider-client interaction in the SAPPHIRE study refers the following:

- Respect
- Warmth and genuine concern
- Responsiveness to client's preferences, values and needs
- Active collaboration and shared decision making between client and provider
- Physical and emotional comfort

THE SEARCH COLLABORATION

Background



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- 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
- Using the PRECEDE framework, we developed a person-centred, dynamic choice HIV prevention (DCP) delivery model that offers
 - Structured choices in product
 - HIV test modality
 - Location of service delivery,
 - Together with person-centred staffing, service provision and client support.

Person at the centre



Methodology



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- Population: Adults aged ≥ 15 years, HIV-negative, at risk of HIV
- Settings and designs
 1. Antenatal Clinics (ANC)- Individually randomized
 2. Outpatient Department (OPD) - Individually randomized
 3. Community (delivery by community health workers or VHT) – Cluster randomized
- Primary Outcome: Biomedical Covered Time (“Coverage”)
 - Proportion of participants selecting each DCP option at each scheduled visit
 - % of follow-up time for which a participant reported use of PrEP or PEP
 - Assessed over 24 weeks
 - Secondary: % of follow-up time at risk of HIV for which a participant reported use of PrEP or PEP

Person-centred, Dynamic Choice Prevention (DCP) Delivery Model



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Intervention	Population and frequency of delivery	Purpose
Education, case studies and discussion on concept of a patient centred, dynamic Choice Prevention (DCP) model	Health centre leadership and staff, clinicians, provided the initial and ongoing training and education to the study participants	Predisposing
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 (CHW) visits. Reproductive health and gender-based violence services, 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 CHWs 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 one 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 24hrs/7days per week. Staff contact all participants who initiate PrEP or PEP by phone every 2weeks in the first month, and monthly thereafter.	Reinforcing

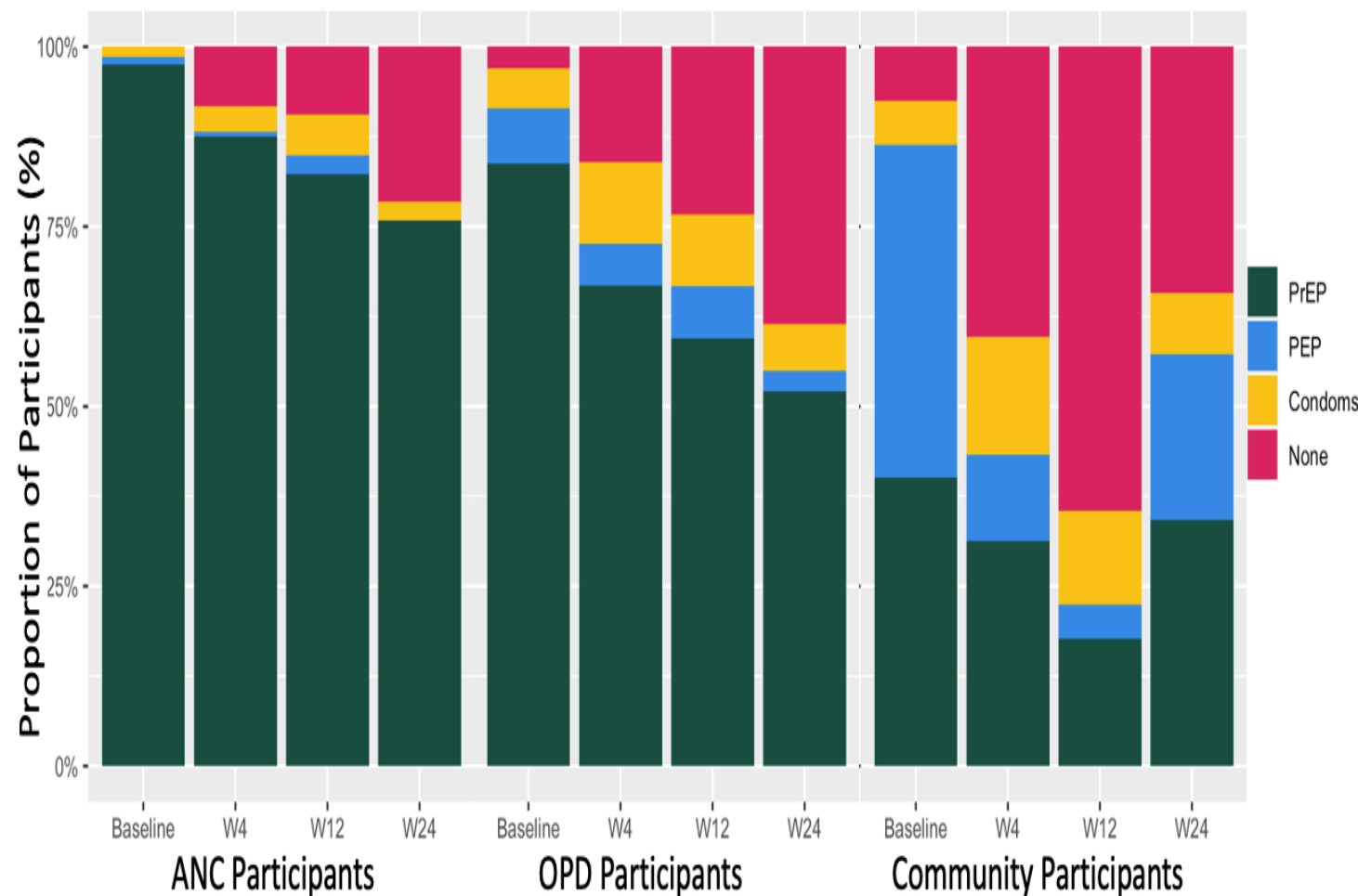
Results



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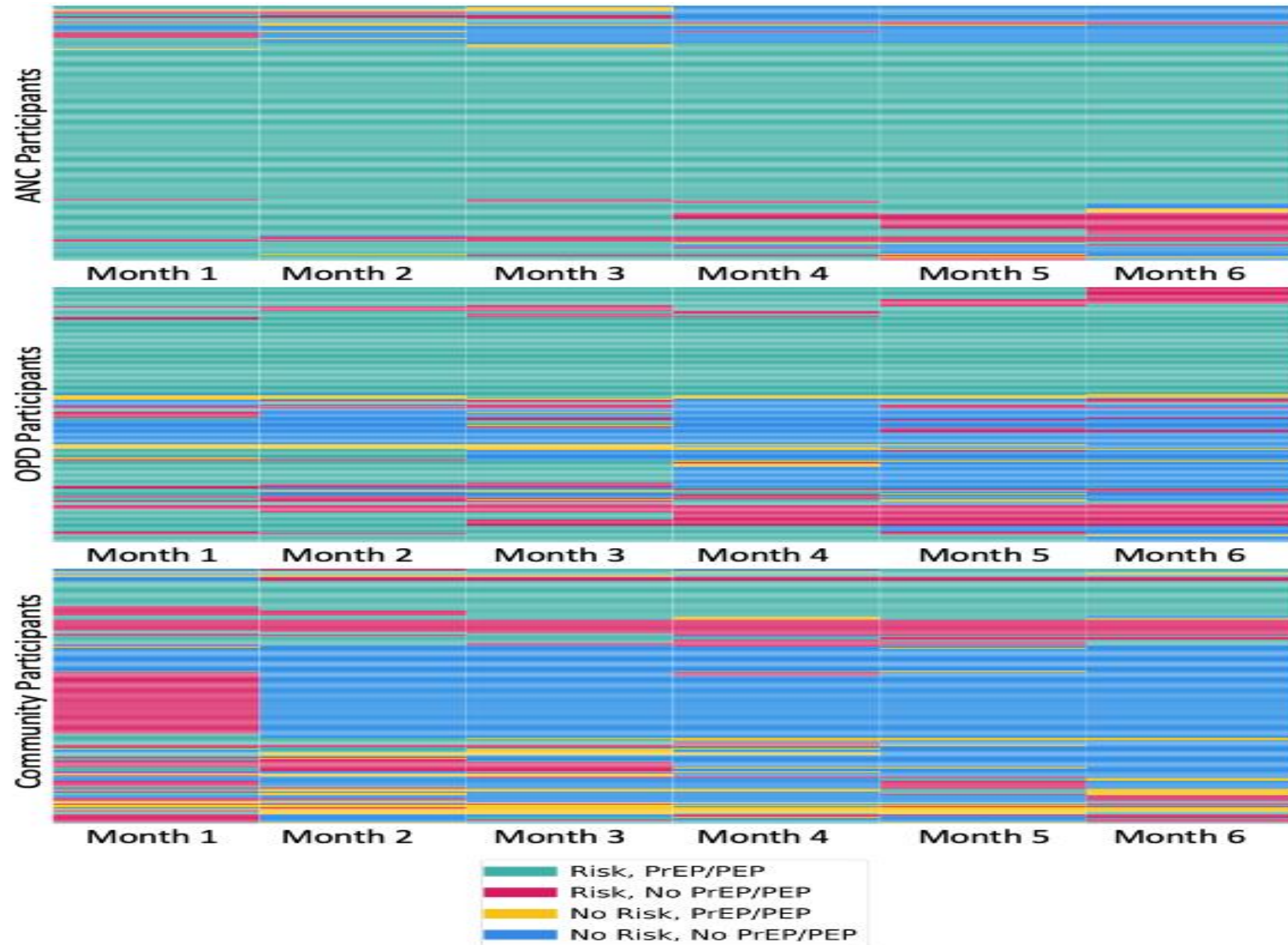
- A total of 612 (203 ANC, 197 OPD, 212 community) participants were randomized to the person-centred DCP intervention.
- We delivered the DCP intervention in all three diverse settings
 - **ANC: 39% pregnant; median age: 24 years**
 - **OPD: 39% male, median age 27 years**
 - **Community: 42% male, median age: 29 years**
- 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).

Choice of prevention options



Self-reported use of biomedical prevention by HIV risk

- Mean biomedical covered time was 80%(ANC), 60%(OPD) and 32% Community
- Average follow-up time at risk covered by PrEP or PEP was 88% (ANC) 75%(OPD) and 42% Community



Dynamic Prevention Choice Model increased self-reported biomedical HIV prevention coverage at week 48



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Setting	N	Intervention coverage	Control coverage	Increase
Antenatal	400	69.6%	29.4%	40.2%
OPD	403	47.5%	18.3%	29.2%
Community	429	28.0%	0.5%	27.5%

Conclusions



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- A person-centred model incorporating structured choice in biomedical prevention and care delivery options in diverse settings was responsive to varying personal preferences over time in HIV prevention programs.
- This interim analysis demonstrated the intervention was successfully delivered in settings that are entry points for HIV prevention and can be adapted as new prevention options such as CAB LA become available.

Antenatal clinic



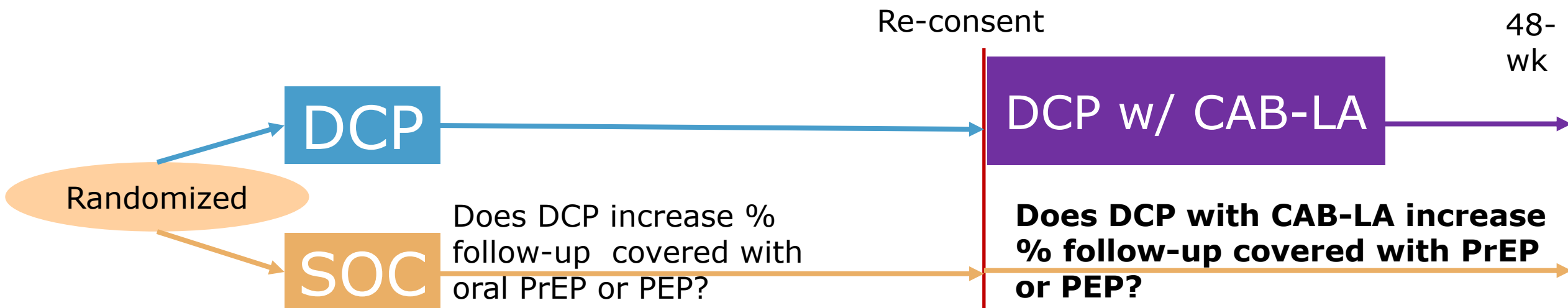
Community



Outpatient department

CAB-LA extension to the 3 ongoing trials: Antenatal, OPD, and community

- **Primary objective:** Evaluate the effect of DCP with CAB-LA as prevention option on biomedical coverage, as compared to the SOC
 - Rigorous evaluation through 48-wk extension of 3 randomized trials
- **Secondary objective:** Optimize implementation in real-world settings
 - Rigorous evaluation through the RE-AIM framework





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Acknowledgements



Study Participants and Communities

Republic of Kenya Ministry of Health, Republic of Uganda
Ministry of Health

Diane Havlir, Moses Kamya, Maya Petersen – **Co-PIs**

SEARCH study team

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Gabriel Chamie, MD

National Institute of Allergies and Infectious Diseases

Melanie Bacon

Funding: U.S. NIH/NIAID/NHLBI/NIMH (U01AI150510); NIAID- Melanie Bacon, Joana Roe, Carl Dieffenbach





Leveraging person-centred public health for HIV treatment in Zambia (PCPH)

Njekwa Mukamba

Centre for Infectious Disease Research in Zambia (CIDRZ)



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

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- I have no relevant financial relationships with ineligible companies to disclose.



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Presentation Outline

- Provider perspectives on person-centredness
- Patterns of person-centred communications in public HIV clinics



Study Setting: Lusaka, Zambia





PCPH Trial

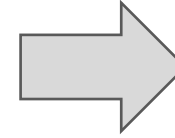
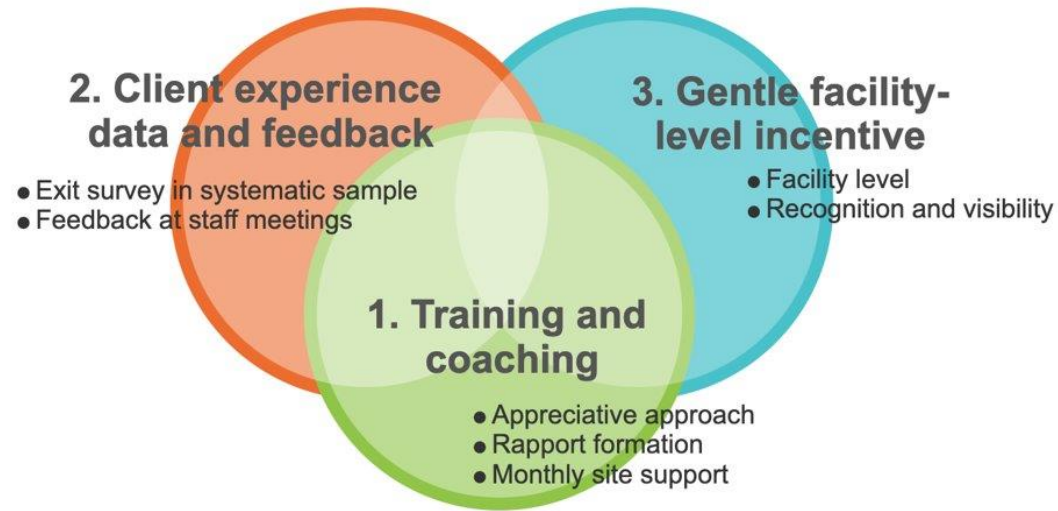
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Formative Phase



- **Theory of change**
- **Qualitative work**
- **Human-centred design**

Trialed Intervention



Outcomes

Service delivery

Client experience

Client retention

Client clinical outcomes

Provider experience

Summary Trial Results:

- 70% reduction in HIV care visits with a bad experience and 56,000 visits with bad experience averted during the intervention period
- Qualitatively improved inter-personal dynamics between clients and providers



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“Person-centred care (PCC) is about treating people who use health and social services as equal partners in planning, developing and monitoring care to make sure care services meet their needs.”

Royal College of Nursing, UK



Provider perspectives on person-centredness:

Participatory formative research and rapid analysis to inform a HIV Care improvement intervention in Zambia

Chanda Mwamba*, Laura K. Beres*, Njekwa Mukamba, Lazarus Jere, Marksman Foloko, Kasapo Lumbo, Kombatende Sikombe, Sandra Simbeza, Aaloke Mody, Charles Holmes, Izukanji Sikazwe, Carolyn Bolton, Katerina Christopoulos, Anjali Sharma, Elvin Geng

***equal contributors**



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RESEARCH ARTICLE | Open Access |

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 , 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, Elvin H. Geng ... [See fewer authors](#) ^

First published: 06 July 2023 | <https://doi.org/10.1002/jia2.26114> | Citations: 1

Background



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- Healthcare workers' perception of the **acceptability, appropriateness, and feasibility** of PCC practices – key to **successful implementation**.
- **Evidence on effective implementation** of PCC practices in the real world, and **provider views** in low-middle-income countries **is limited**.
- We **sought to understand healthcare workers'**:
 - 1) beliefs and attitudes about PCC principles, enablers, and activities,
 - 2) perceptions of ongoing HIV service delivery and the client experience,
 - 3) motivation for improved practiceto tailor intervention content and implementation pre-trial.

Methods



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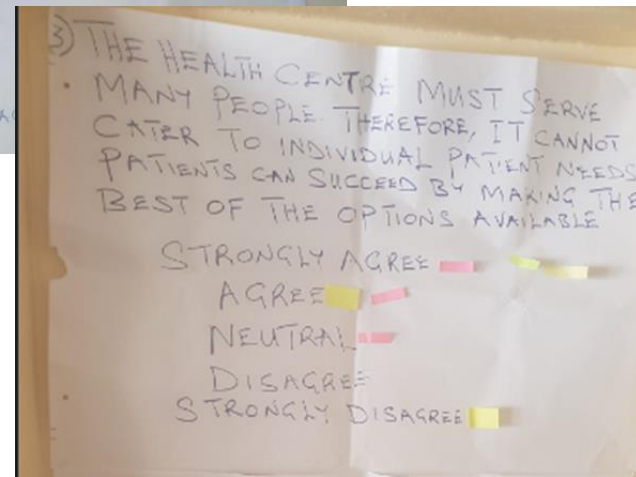
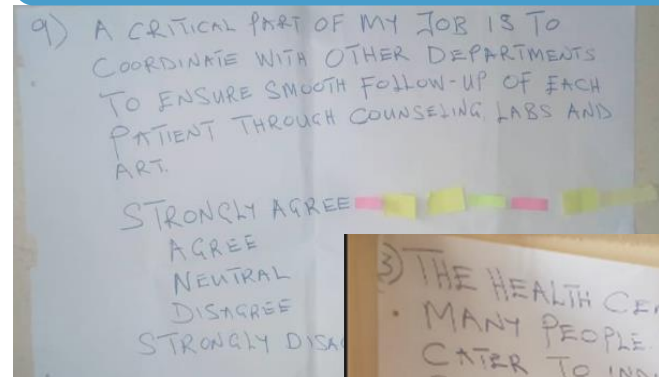
- 8 participatory focus group discussions
- Purposeful sampling of n=46 healthcare workers (HCW) across three cadres: health facility management teams, professional HCWs and lay HCWs
- Rapid data analysis: Analytic memos, study team debriefs, summarized implications for PCC intervention, member checking with HCWs

FGD Topics covered:

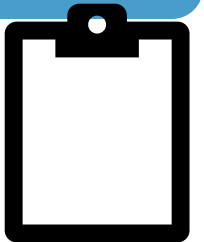
Open-ended discussion of:

- facility context for HIV services
- HCW motivation
- DSD models
- suggestions to improve client retention

Interactive prioritisation of 10 PCC statements derived from Scholl et al¹



Critique of proposed study client experience measures



Reflection on reasons for HIV care disengagement given by clients



Results: PCC Principles, Enablers, Activities



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**Facilitators
of PCC
practices**

**Barriers to
PCC
practices**

**Intervention
implementation
opportunities**

Person-centered care acceptable:

HCWs valued and endorsed PCC concepts e.g., respectful communication, shared decision making, provision of emotional & social support.

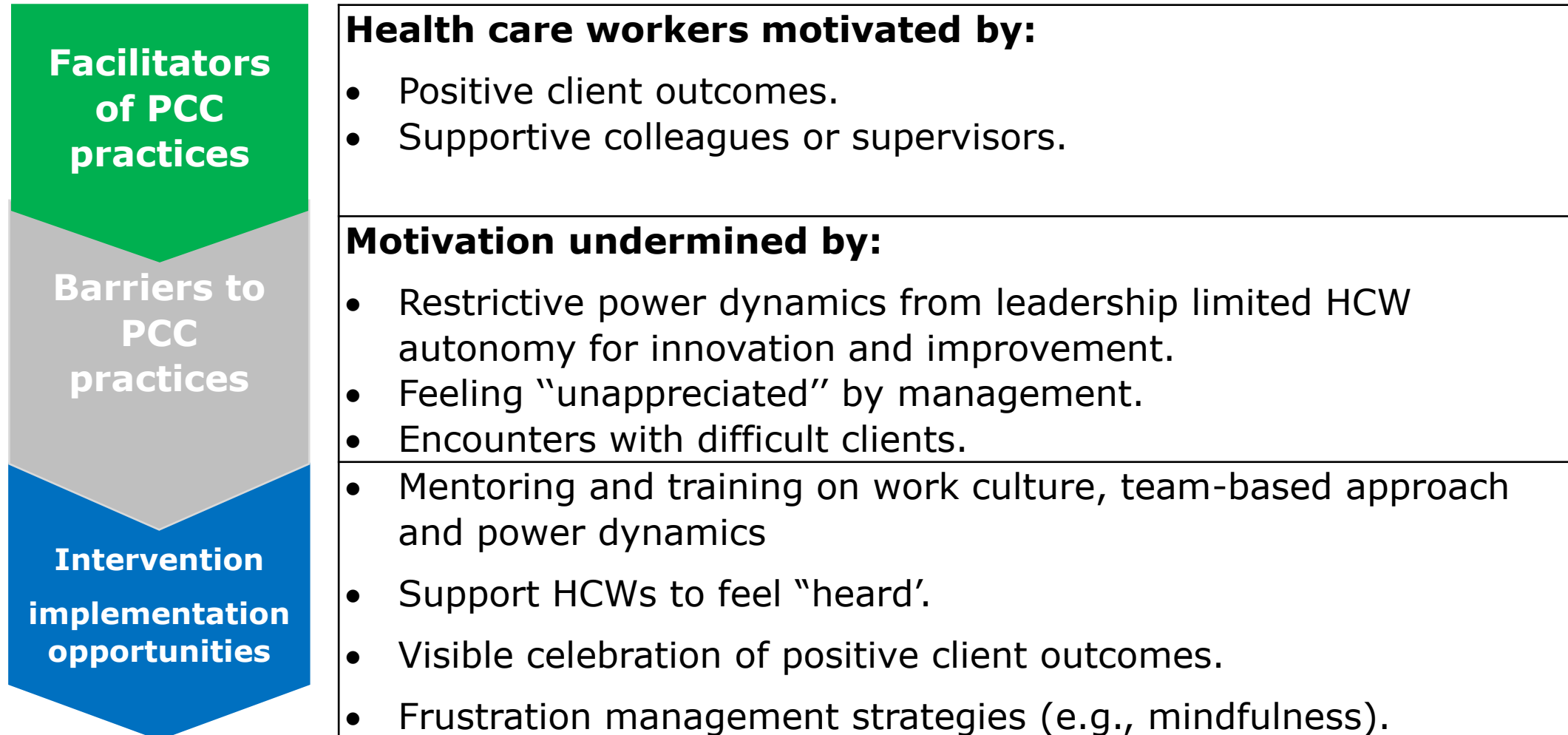
Perceive appropriateness and feasibility limited by practice environment:

- Workflows focused on physical health.
 - Limited organizational and infrastructure (human resource, space, etc.)
 - Clash of value of PCC with inability to implement led to HCW moral injury and defensiveness.
-
- Mentors can build on the endorsement of PCC principles.
 - On-site mentorship by PCC study could support a flexible PCC implementation approach amidst resource constraints.
 - Mentors to acknowledge that HCWs work under difficult conditions

Results: HCW perspectives and motivation



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Results: Data and feedback supporting PCC



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**Facilitators
of PCC
practices**

**Barriers to
PCC
practices**

**Intervention
implementation
opportunities**

Health care workers interest in monitoring:

- Valued client satisfaction survey question: leadership preferred summaries, other HCWs preferred specifics (e.g. lost lab results)

Limited application opportunities undercut coherence:

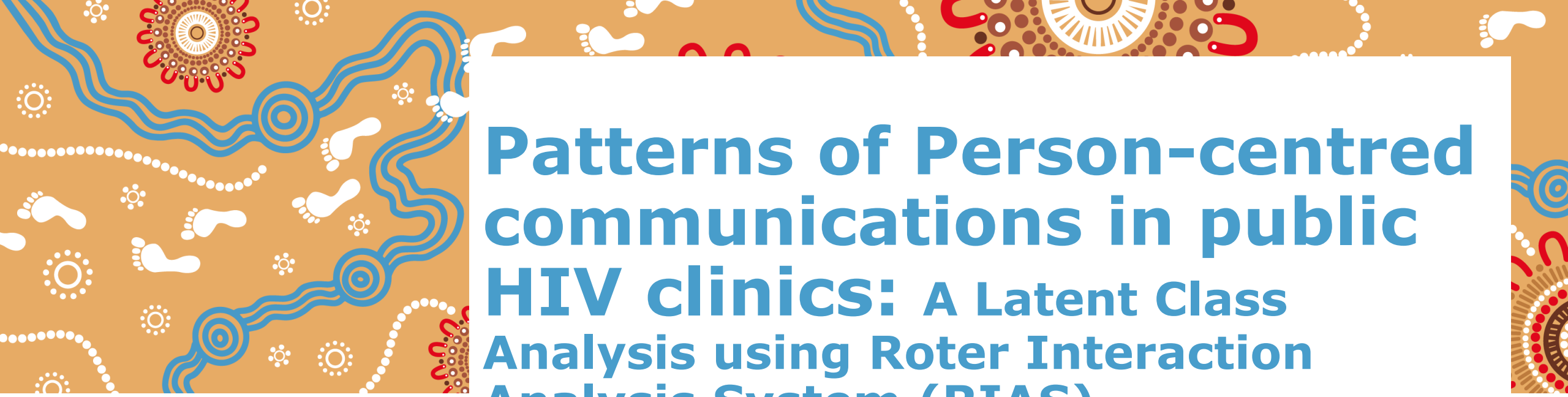
- Lack of data analysis skills and opportunities to participate in data review meetings.
- Facility leadership teams key to provide objective information from client experience measurements.
- Feedback of data should include mentor support for data interpretation and use.

Calls to Action – Provider Perspectives



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- Interventions should target organisational and structural barriers that inhibit PCC practices.
- Improved PCC must include both clients and providers.



Patterns of Person-centred communications in public HIV clinics: A Latent Class Analysis using Roter Interaction Analysis System (RIAS)

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, Aaloke Mody



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RESEARCH ARTICLE | Open Access |

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

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, Aaloke Mody ... [See fewer authors](#) ^

First published: 06 July 2023 | <https://doi.org/10.1002/jia2.26119> | Citations: 1

Background



RIAS 2023

- 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.
- Roter Interaction Analysis System (RIAS) is a well-validated method to parse out and quantify patient and provider communication that has been used across diverse settings
- We used RIAS to quantitatively parse and characterize patterns of person-centered communication (PCC) behaviors in Zambia.

Methodology



- **We enrolled pairs of people living with HIV (≥ 18 yrs) making a routine HIV follow-up visit and their providers** and audio-recorded client-provider encounters at the 24 parent study clinics.
- **Trained staff coded encounters using RIAS schema** (high levels of intercoder reliability - Pearson correlation 0.8).
- **RIAS coding schema classifies each client and provider utterance into one of 37 mutually exclusive categories.** Examples include:
 - question types (open vs. close ended, question topics)
 - types of information giving (medical, psychosocial)
 - statement types (encouragement, empathy, criticism,)
- **After coding, we performed latent class analysis (LCA)** to identify interactions with distinctive patterns of provider PCC behaviors.

Results

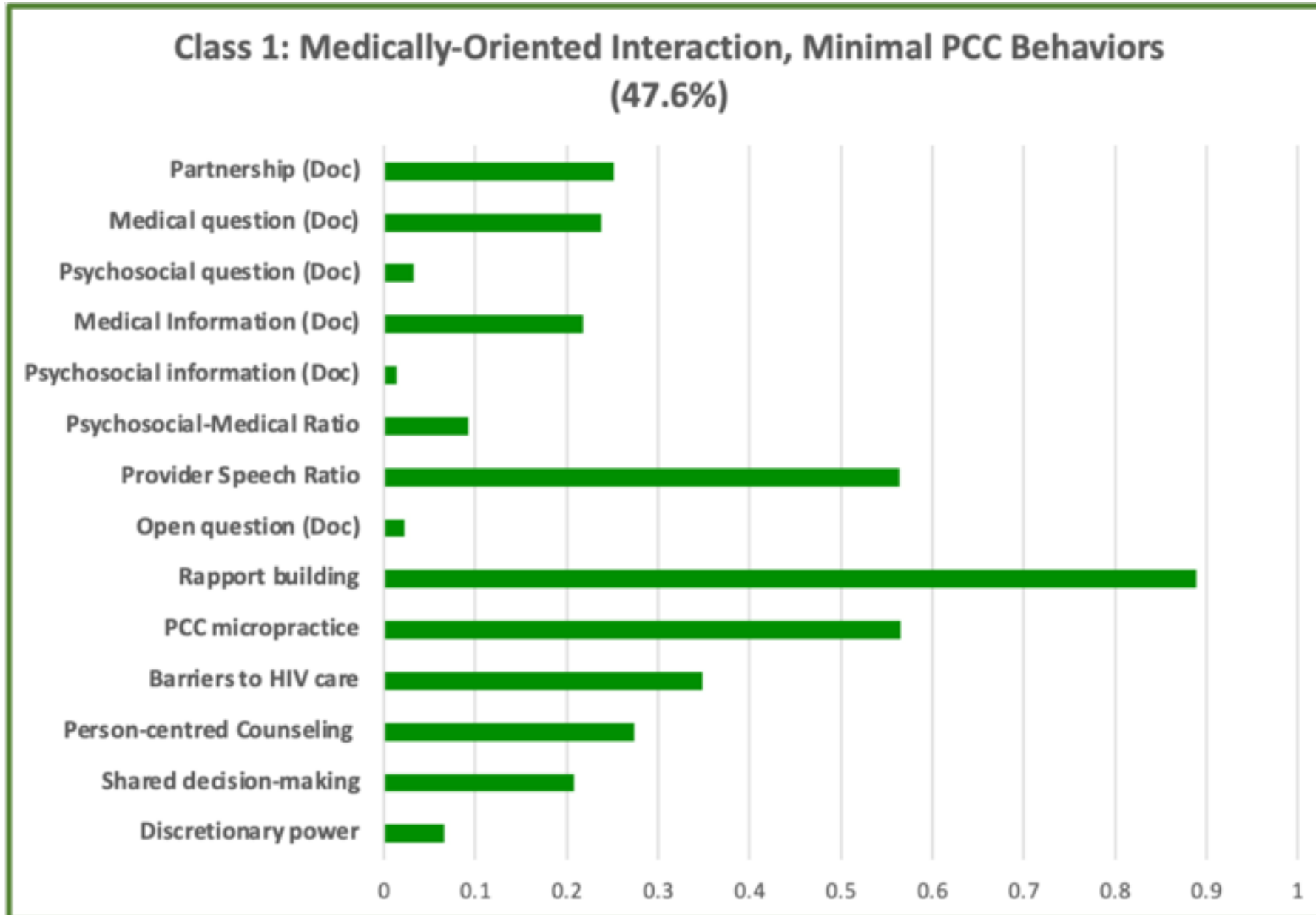
Table 1. Client, Provider, Interaction, and Facility Characteristics (n = 478)

Client	Overall (n = 478)	Nurse (n = 67)	Clinical Officer (n = 352)	Medical Officer (n = 59)	p-value
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%)	
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%)	-	-	-	
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%)	

Results



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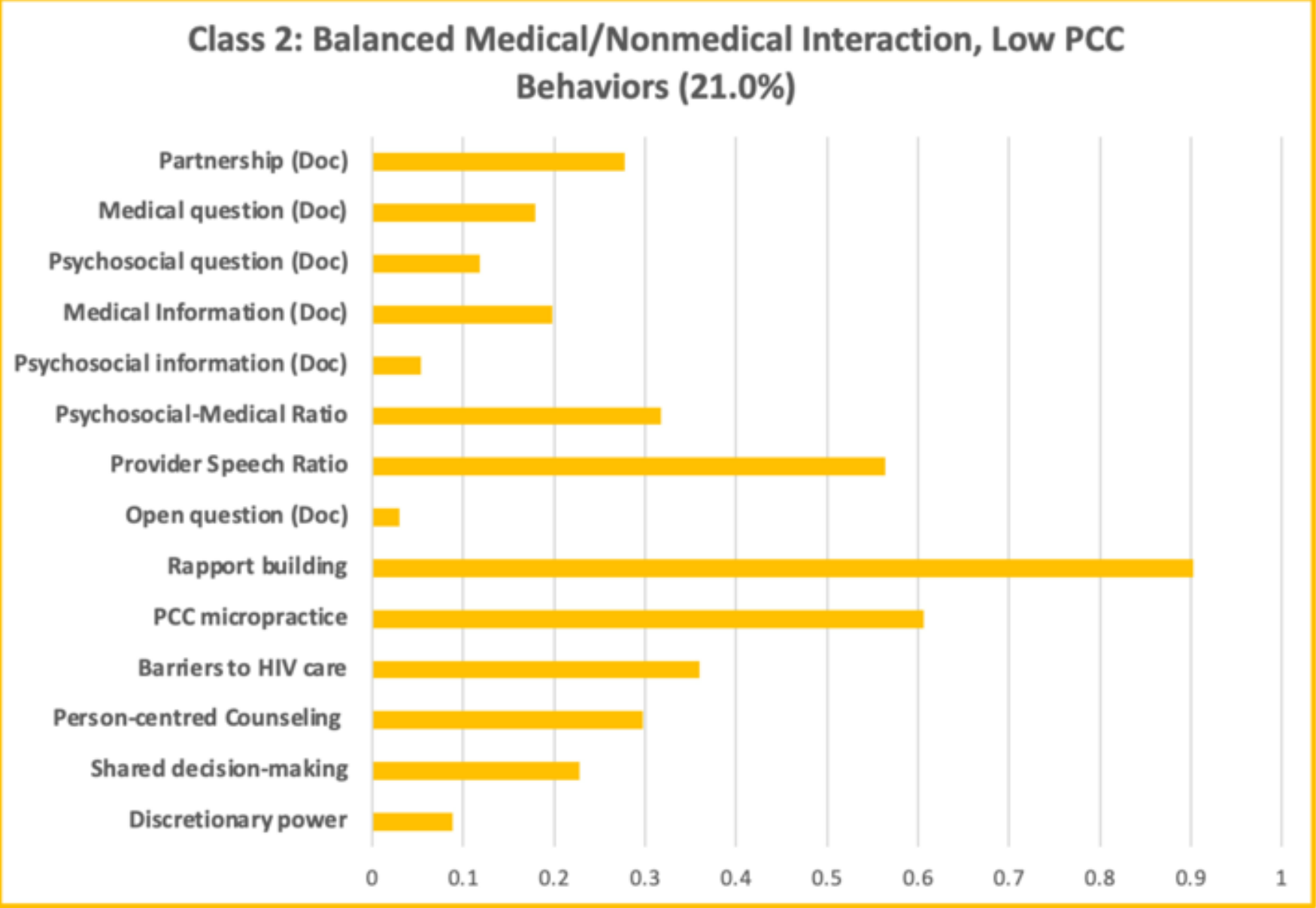


47.6% of interactions were characterized by discussion predominately around medical topics only.

Results



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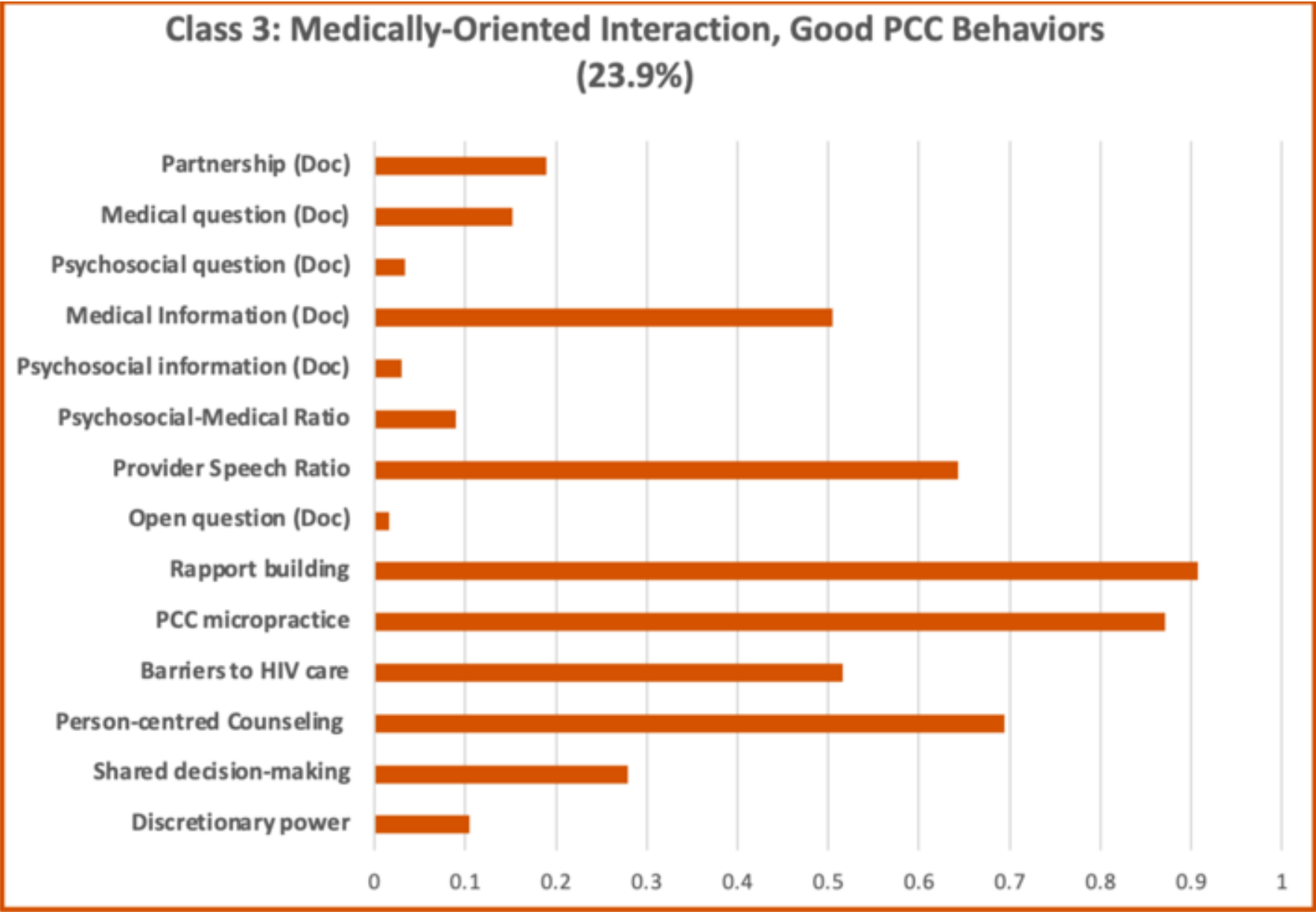


21.0% of interactions was characterized by more balance between medical and psychosocial topics, but still low use of PCC behaviors.

Results



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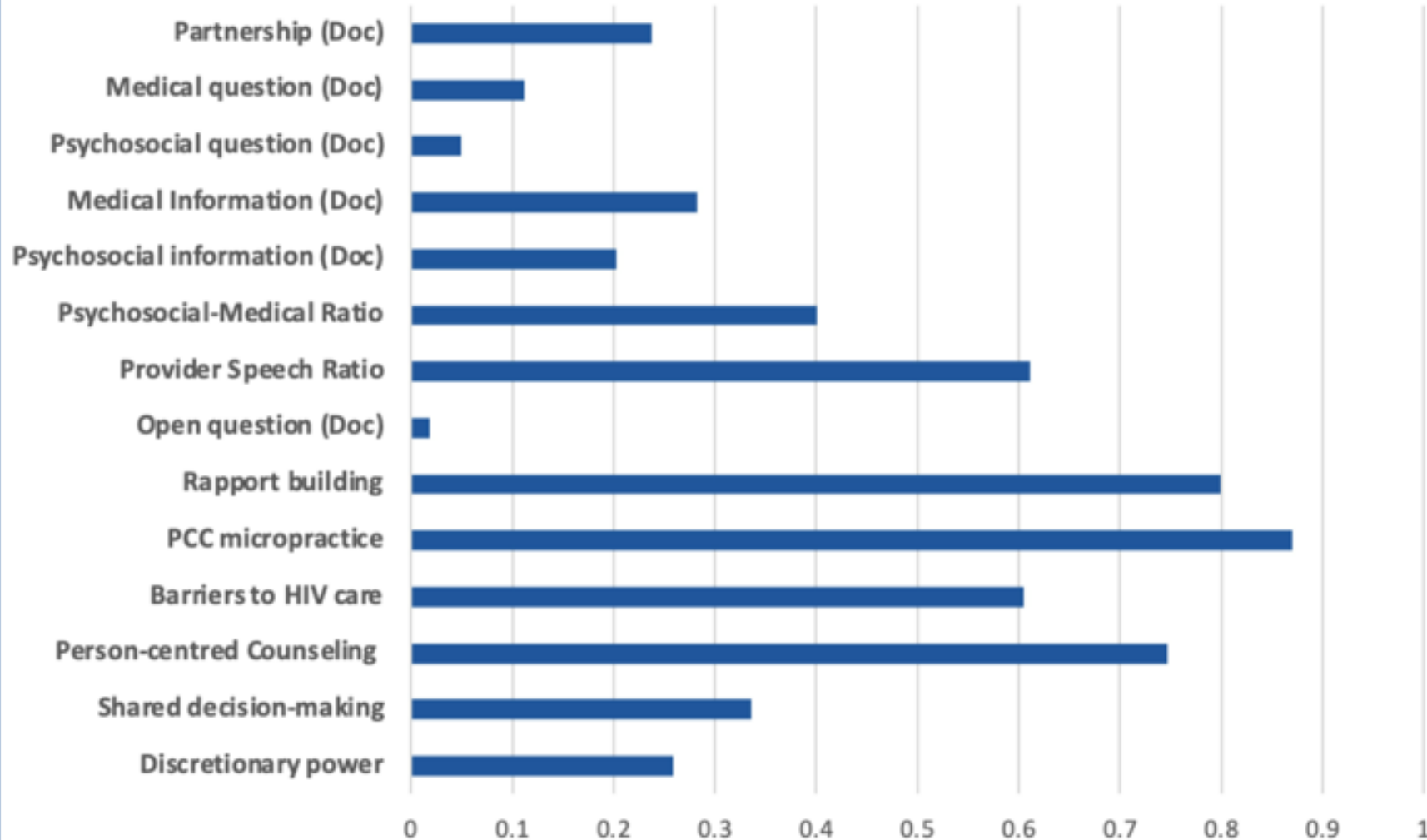
23.9% of interactions was characterized again by predominately medically-oriented discussion, but greater use of PCC behaviors.

Results



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Class 4: Highly Person-centred Interaction (7.5%)



7.5% of interactions was characterized by discussion of both medical and psychosocial topics and the highest of use of PCC behaviors.

Results



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Table 2: Interaction by Health Provider Type

Position of Health Provider	Latent Classes			
	Medically-Oriented Interaction, Minimal PCC behaviour	Balanced Medical/Non Medical Interaction, Low PCC Behaviour	Medically-Oriented Interaction, Good PCC Behaviour	Highly Person-Centred Interaction
Medical Officer	37.3%	28.8%	23.7%	10.5%
Clinical Officer	53.7%	19.0%	21.0%	6.3%
Nurse	38.8%	16.4%	34.3%	10.5%

Conclusions



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- Majority of client-provider communication focused only on medical aspects of clients living with HIV.
- Person-centred communication still possible within the public health HIV setting. Improvements still needed.
- Integration of PCC behaviours varied across the profiles & health care worker cadre.
- PCC behaviours - key in improving client experience and long-term engagement in HIV care.

Calls to Action - RIAS



RIAS 2023

- Systems for positive reinforcement of non-medical communication.
- Deliberately train and mentor HCWs in good communication skills.
- Research is needed to understand changes in client-provider communications over time.

Continued operationalization of PCC



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- MoH & CIDRZ Letter of Agreement – signed: training, curriculum & policy intergration.
- Client Satisfaction Tool launched.
- PCC theme for National Quality Improvement Conference.
- Light touch PCC Mentorship in 24 public clinics.
- PCC Trainer of Trainers for HCWs.
- Develop a sustainable PCC activity package – Human-Centred Design workshop.
- Roadmap for PCC Integration.

Acknowledgement of contributors



Ministry of
Health



 Washington
University in St. Louis



BILL & MELINDA
GATES foundation


JOHNS HOPKINS
UNIVERSITY



Georgetown
University

LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE 

Davina Canagasabey | Senior Technical Advisor | PATH

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

Facilitating person-centered care

Integrating an electronic client feedback tool into continuous quality improvement processes to deliver client-responsive HIV services in the Democratic Republic of Congo



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Disclosures



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Conflict of interest: *I have no relevant financial relationships with ineligible companies to disclose.*

Funder acknowledgement and disclaimer: This work was financed by the US President's Emergency Plan for AIDS Relief (PEPFAR) through the United States Agency for International Development (USAID) under the PATH-led Integrated HIV/AIDS Project in Haut-Katanga (IHAP-HK).

The views expressed in this presentation and the contents of our manuscript do not necessarily reflect the views of USAID or the United States government.

Purpose and objectives



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Purpose

To create a digital system for gathering and using client feedback to ensure services are responsive to client needs and to improve perceived client satisfaction with HIV services received.

Where and when

System was designed and tested at eight high-volume facilities in six health zones supported by the USAID/PATH IHAP-HK project from May 2021 through September 2022.

Objective of our analysis

Understand the feasibility and effectiveness of our service quality monitoring system in identifying and addressing quality-of-care gaps not aligned with client needs and preferences.



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"We consider person-centered HIV care to be HIV services that are informed by and respect the expressed preferences of people living with HIV."

IHAP-HK study team

Background and context

“The experience of patients should serve as the fundamental source of the definition of quality.”

-- D. Berwick

- Comprehensive community engagement across the implementation life cycle (design → implementation → monitoring) is needed to deliver high-quality and responsive services that keep clients engaged in care.
 - *Communities and clients need to be at **the core** of person-centered care.*
- Understanding client satisfaction with services provided is critical to ensuring continuity in HIV services.
- IHAP-HK embedded passive tools to collect client feedback as part of continuous quality improvement (CQI) processes.
 - Seeking an active service quality feedback collection mechanism that was feasible to implement and effective at addressing service quality gaps.

Service quality monitoring feedback loop

Issues identification & tool development



IHAP-HK, people living with HIV, and facility providers co-identify exit interview focus areas and questions.

IHAP-HK integrates selected questions into electronic client feedback tool (English and Swahili).

Trained 30 peer educators to administer exit interview with consenting clients and record answers via the KoboToolbox mobile application.



Exit interview administration

Client feedback compilation & analysis



IHAP-HK staff exports client responses and shares with facility quality improvement team and peer educators for analysis to identify quality-of-care gaps (by topic; frequency of occurrence; and severity of issue).

IHAP-HK, facility quality improvement teams, and peer educators jointly identify solutions to quality-of-care gaps.

Findings and identified solutions integrated into monthly remediation plans for implementation and monitoring.



Integration into quality improvement plans

Service quality questionnaire

Feedback gathered and analyzed from **4,917 exit interviews** conducted with clients receiving HIV treatment and care services at the 8 pilot facilities.



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 viral load sample taken in the past six months?

Did you received 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?



Service quality gaps, solutions, and impact over time: *Long wait time*

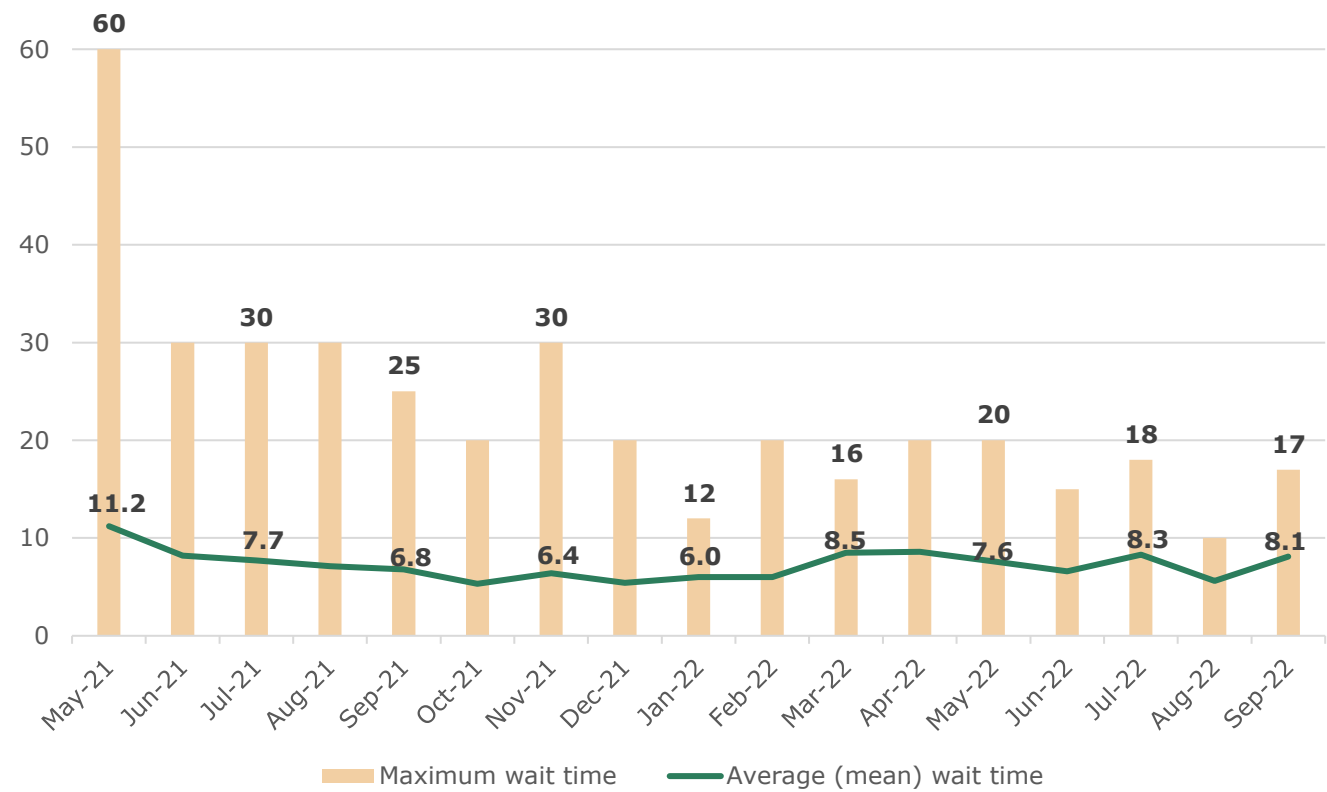
Solutions

- Using peer educators to conduct appointment prep tasks.
- Coaching providers to use appointment agendas to better triage needed services.
- Escorting clients to consultation rooms, pharmacies, and/or laboratories.
- Improving waiting room conditions.

Impact

- **Decrease in wait time range** (min-max):
 - May 2021: 0–60 minutes
 - September 2022: 1–17 minutes.
- **Decrease in mean wait time** from 11.2 minutes to 8.2 minutes. (Figure 1)
- **Increase in reported client satisfaction with wait time** → 76% wait times to be excellent or acceptable (May 2021) compared to 100% (September 2022).

Figure 1: Maximum and average wait time, by month, May 2021–September 2022.



Service quality gaps, solutions, and impact over time: *Stigma and confidentiality*

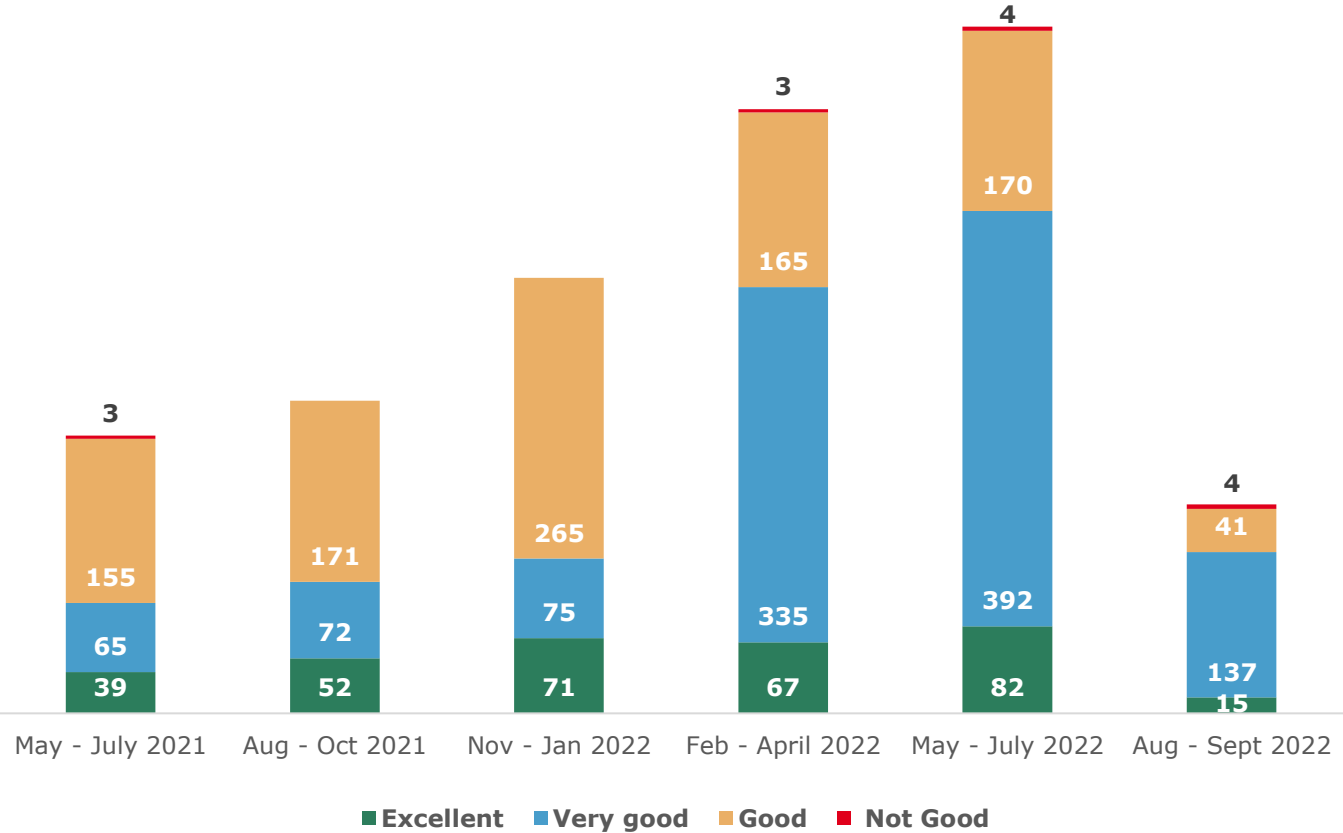
Solutions

- Removing HIV status from access cards used by clients to enter facilities.
- In-service coaching for providers on delivering services in a non-stigmatizing manner.
- Limiting individuals permitted in consultation rooms during client appointments.

Impact

- **Increase in the proportion of clients reporting providers' attitudes to be excellent or very good** (Figure 2).
- **Decrease in percentage of clients reporting cases of stigma** → 5% (May 2021) to 0% (September 2022).
- **Improved perceptions of confidentiality** → 71% (May 2021) to 99% (September 2022).

Figure 2: Client grading of provider attitude, by quarter, May 2021–September 2022.



Service quality gaps, solutions, and impact over time: *Viral load services*

Solutions

- Conducting daily follow-up with referral laboratories to ensure timely analysis of client samples.
- Providing results to clients on multi-month dispensing through text, telephone call, or home visit, based on client preference.

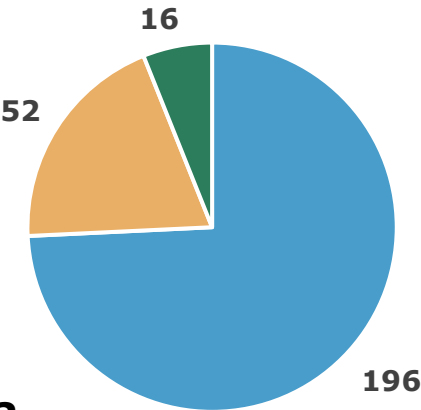
Impact

- **Increase in the number of clients who were informed of their VL results**, from 264 to 318 (Figure 3).
- Increase in the number of VL results returned within one month of sample collection, from 196 to 224 (Figure 3).

Figure 3: Comparison of turnaround time for VL results between May-July 2022 and July-September 2022.

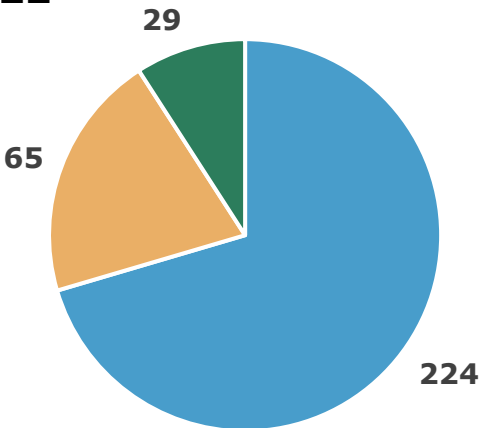
May-July 2021

n=264 VL results



July-September 2022

n=318 VL results



Note: Reagent stock out in June and July 2022 that created backlogs of VL samples to be processed.

Conclusions & next steps



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Use of an electronic client service quality feedback tool as part of a client-driven service quality monitoring system proved to be feasible and effective at rapidly identifying and deploying solutions leading to improved client perception of service quality.

This client feedback collection tool and larger service quality monitoring system is a promising mechanism for advancing client-responsive → recommended next steps are to expand and test use of this system in other provinces.

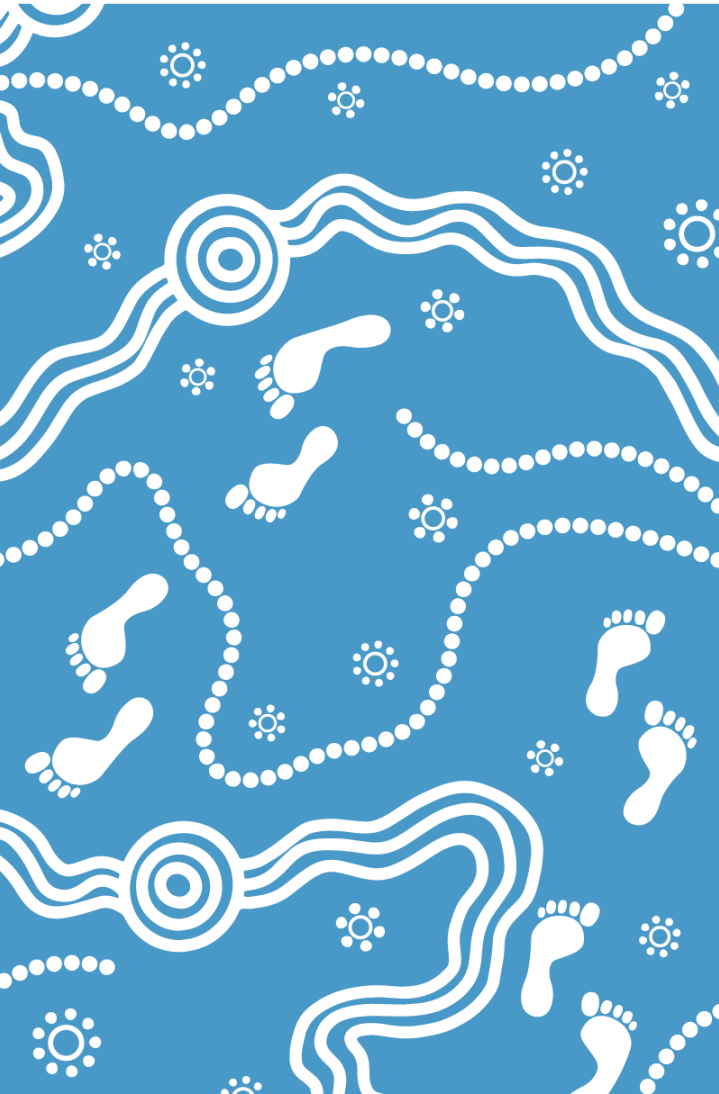


Peer educator administering an exit interview and recording responses on the KoboToolbox mobile application at an IHAP-HK health facility.

Photo: IntraHealth International.



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"The feedback system allowed us to gather clients' complaints...for example, about waiting time, viral load results delay...the [quality improvement] team worked to address [these] issues by preparing drug packages prior to each appointment to reduce time duration of each client refill. Then these complaints have drastically decreased."

Lylian Masengo

Peer educator | Clinique Universitaire Lubumbashi



IHAP PROJET
INTÉGRÉ
DE VIH/SIDA
HAUT KATANGA

PATH
10A001120

Acknowledgements



IAS 2023

- Programme National de Lutte contre le Sida
- Programme Multisectoral Nationale de Lutte contre le SIDA
- Health care providers and quality improvement teams at 8 pilot facilities
- 6 local HIV community-based partners
- 30 peer educators who led exit interview
- PEPFAR and USAID
- IHAP-HK project staff and fellow co-authors

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

Find it here> <https://www.path.org/programs/mdht/living-labs-initiative/>

Check out the full Journal of the International AIDS Society special issue on person-centered approaches in HIV here> <https://onlinelibrary.wiley.com/toc/17582652/2023/26/S1>



PEPFAR

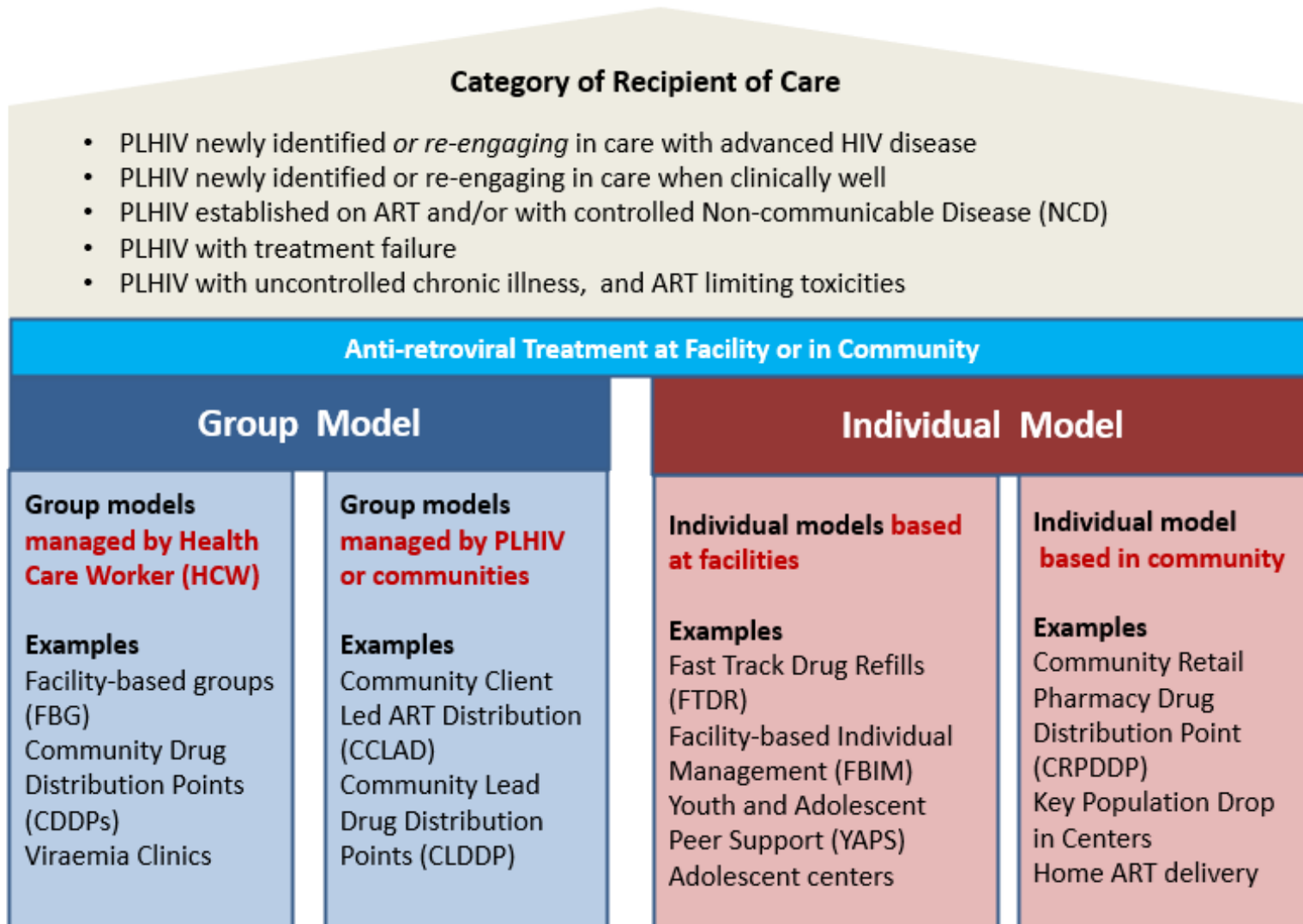


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Improved clinical outcomes for clients on preferred differentiated ART in Uganda

Esther Nkolo
USAID Uganda

Uganda national HIV treatment guidelines provides for DSD models to advance person-centered care for improved HIV treatment outcomes

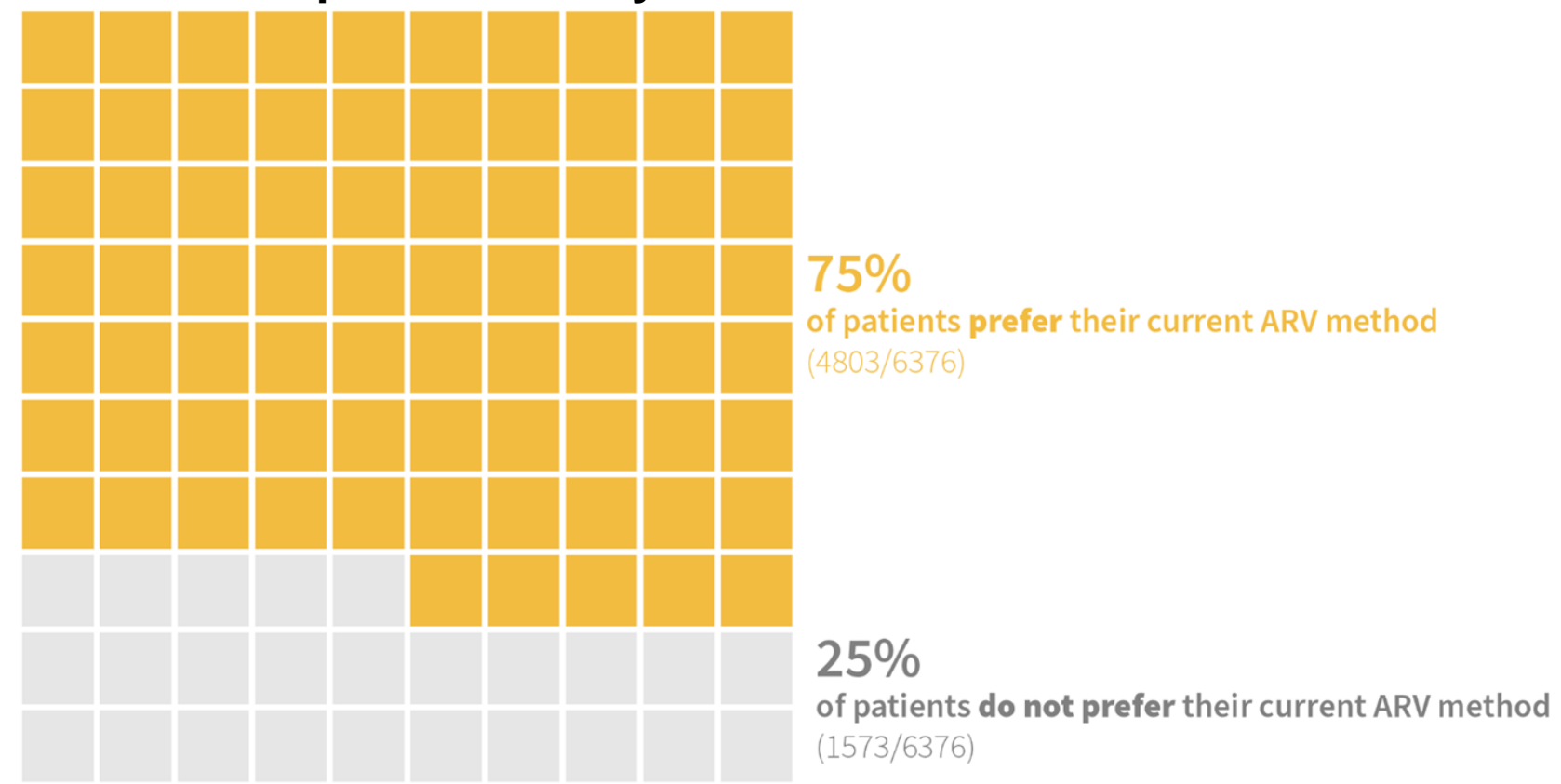


Revised 2022 national treatment guidelines has **lifted restrictions for DSD eligibility** from previous restrictions on age, WHO stage, and non-suppression.

Guidelines allow for ARV **3-6 months multi-month dispensing**

A client preference survey from 6,376 HIV positive individuals on treatment showed only **75%** of participants were currently in their preferred model of ARV dispensing

Share of Participants Currently in Preferred DSD Model



Period of survey: January 2022

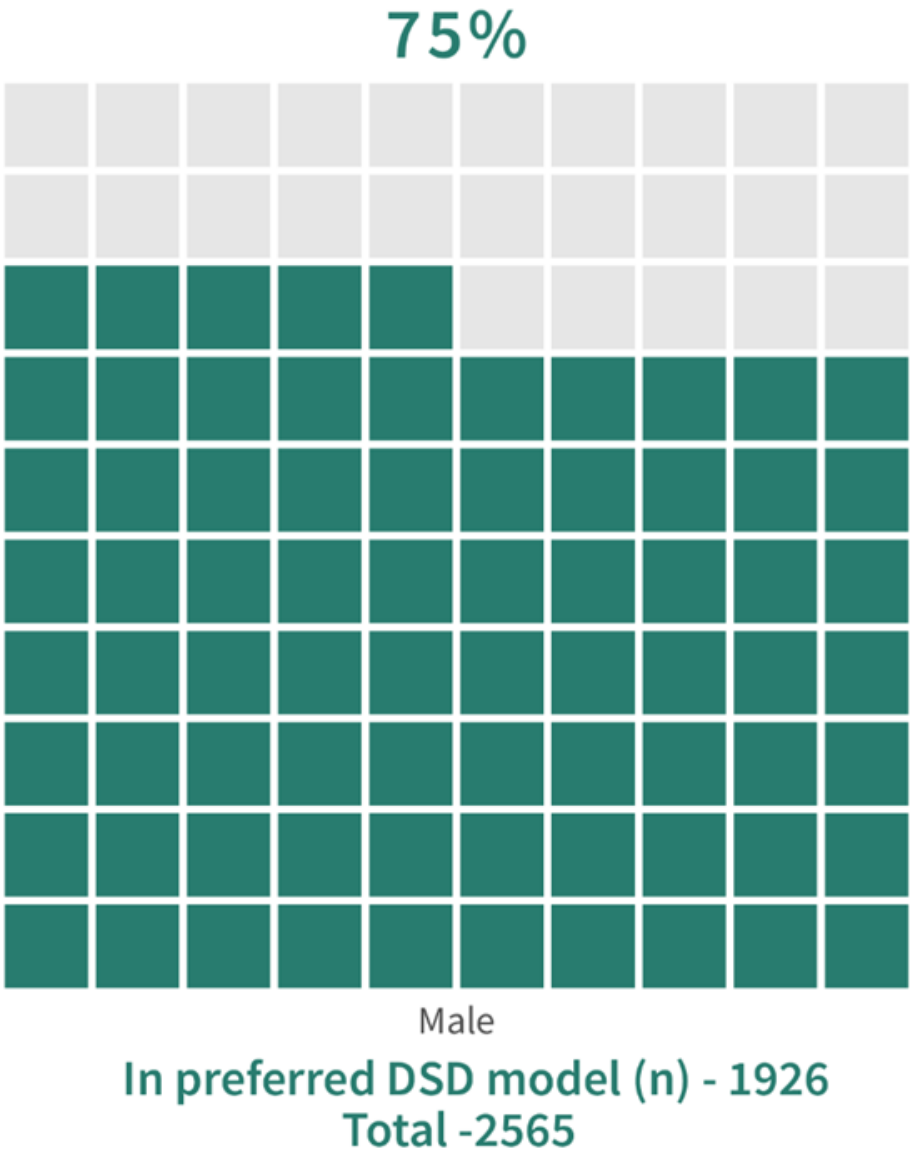
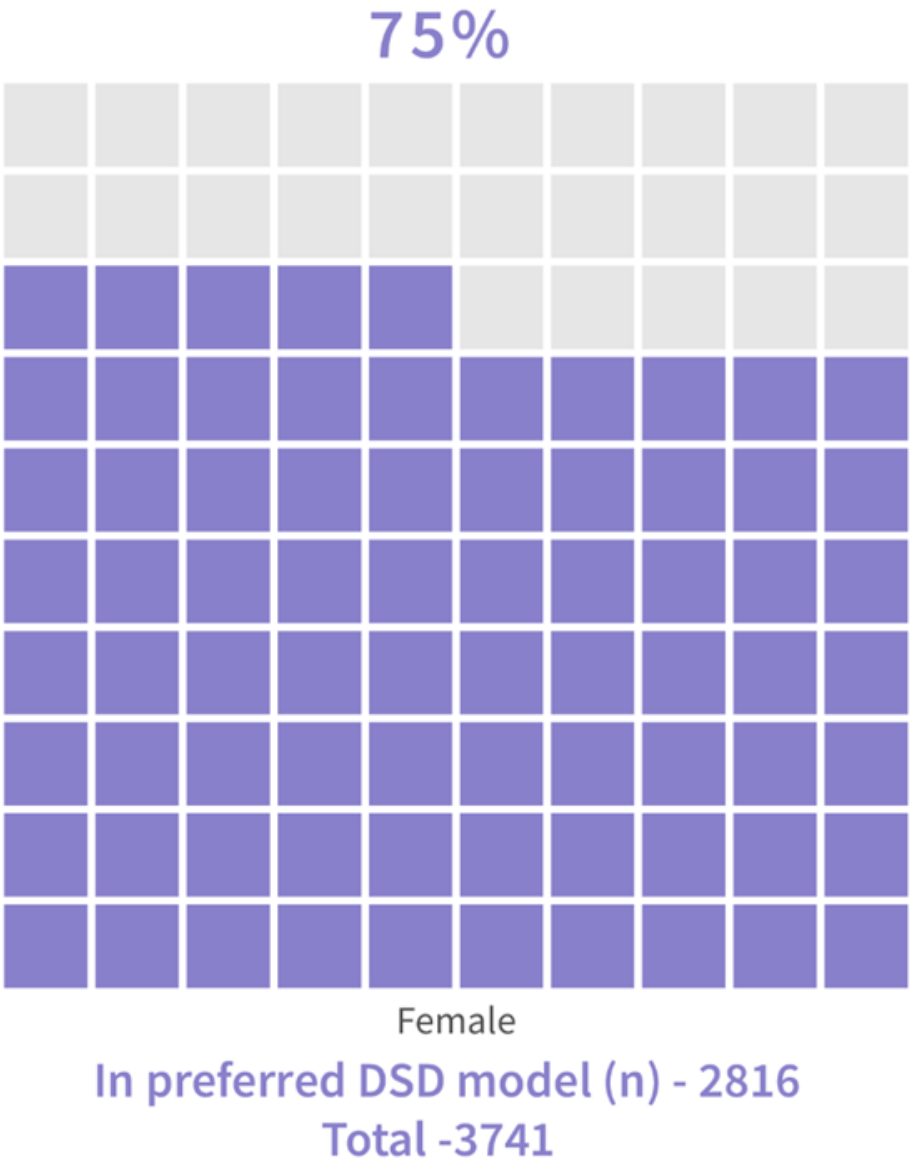
Sample size: 6,376

Age: from 1yr old to 50+

Sample sites: conducted in **113 sites** in nine regions and included public and private not-for-profit health facilities (sites).

Source: DSD Patient Reference Export, 16 Feb 2022

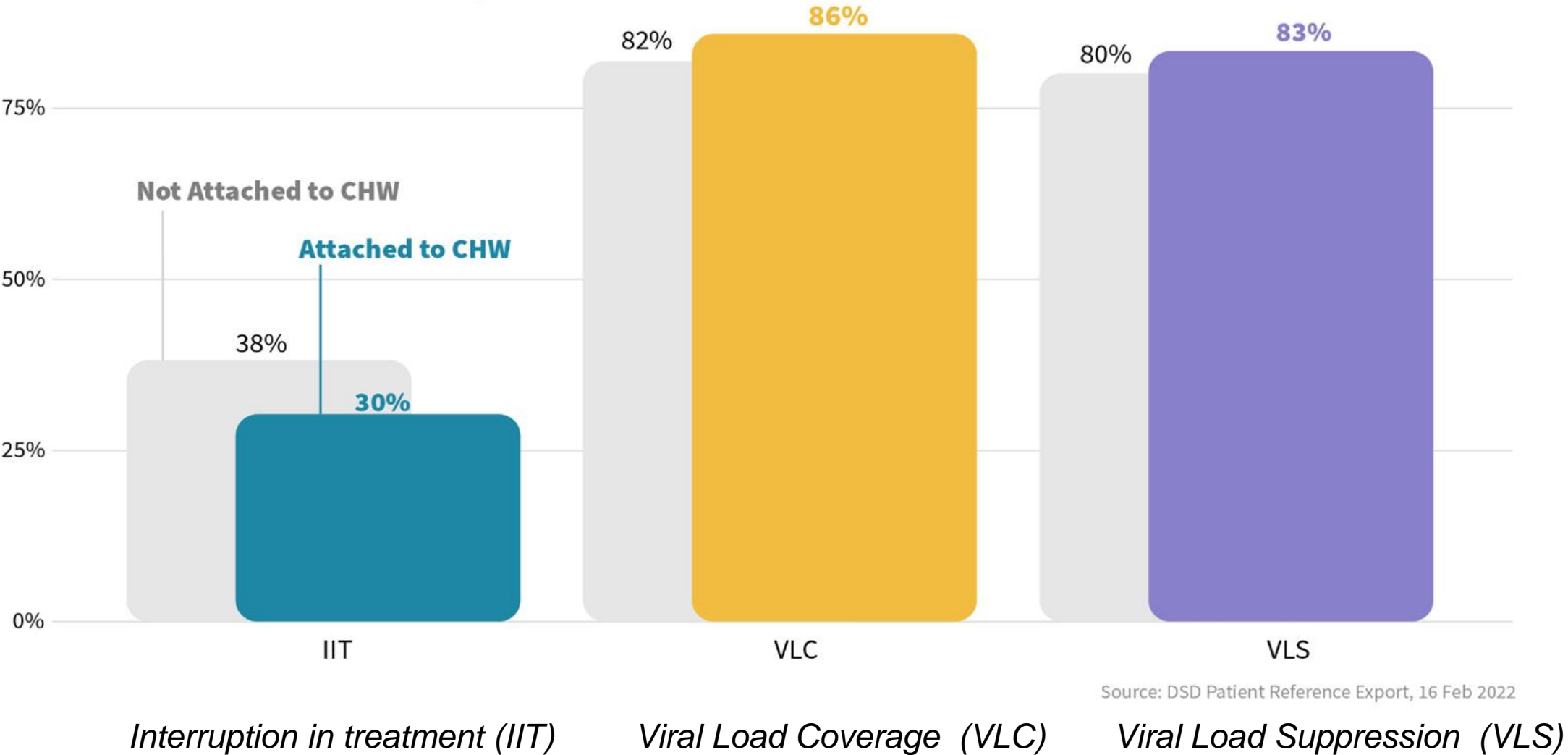
Across both male and female participants, 75% of participants in the sample are currently in their preferred model of ARV dispensing



Attachment to a Community Health Worker or resource person is associated with improved treatment outcomes

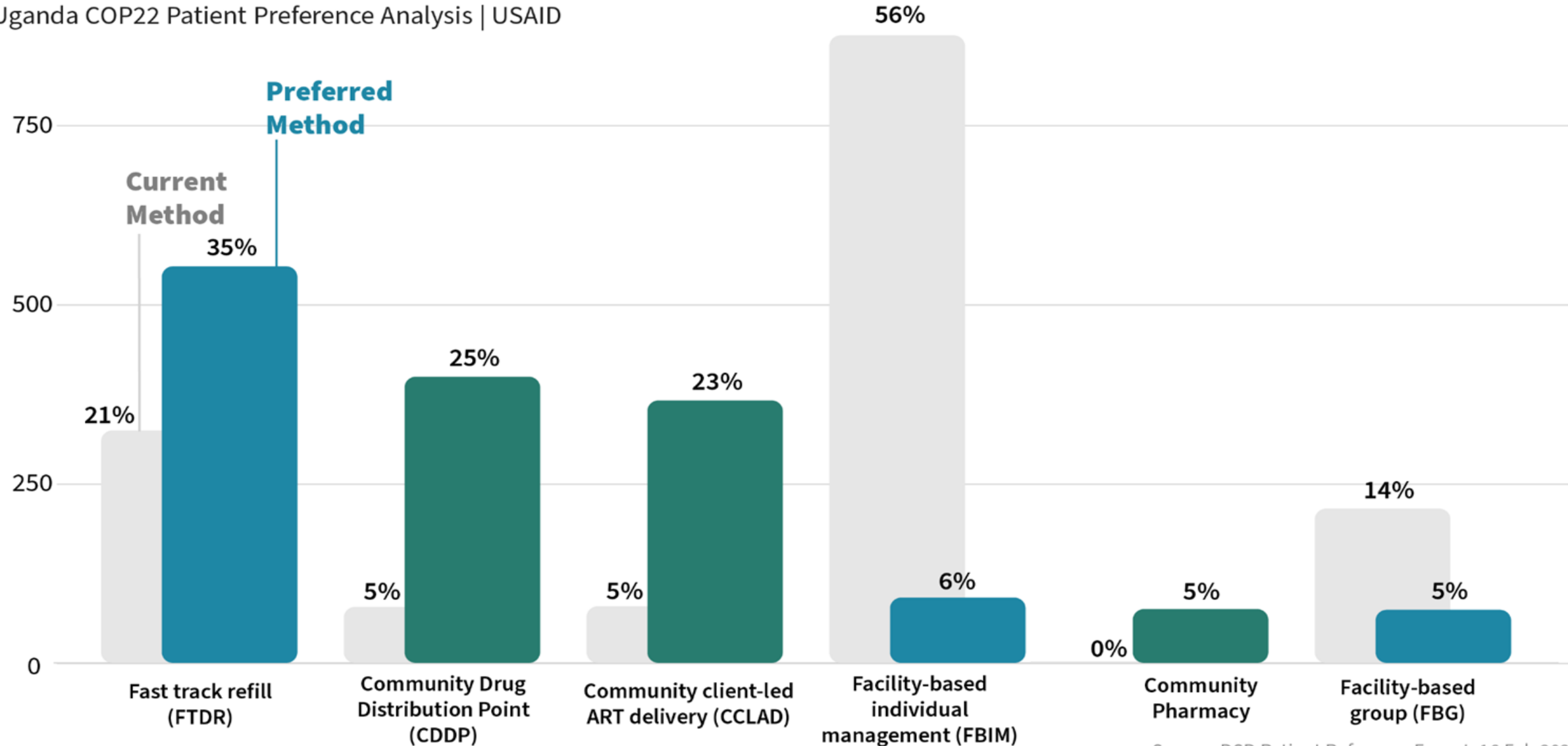
Attachment to a community health worker is associated with **fewer missed appointments**, **more participants with updated viral loads**, and **more participants achieving viral suppression**

Uganda COP22 Patient Preference Analysis | USAID



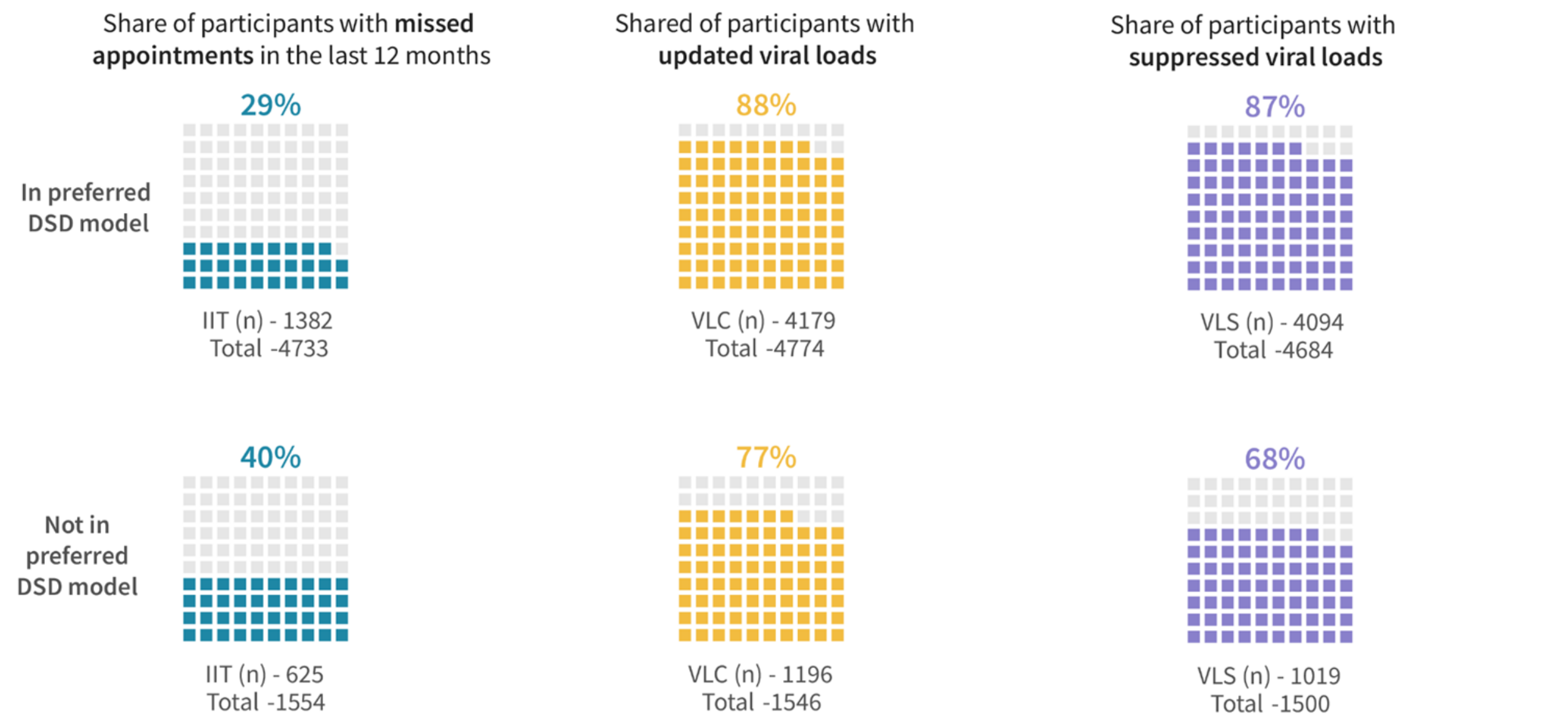
While the majority participants not on their preferred ARV dispensing method preferred **community-based DSD models (53%)** to **facility-based models (46%)**, the most preferred method was the **fast track refill model (35%)**

Uganda COP22 Patient Preference Analysis | USAID

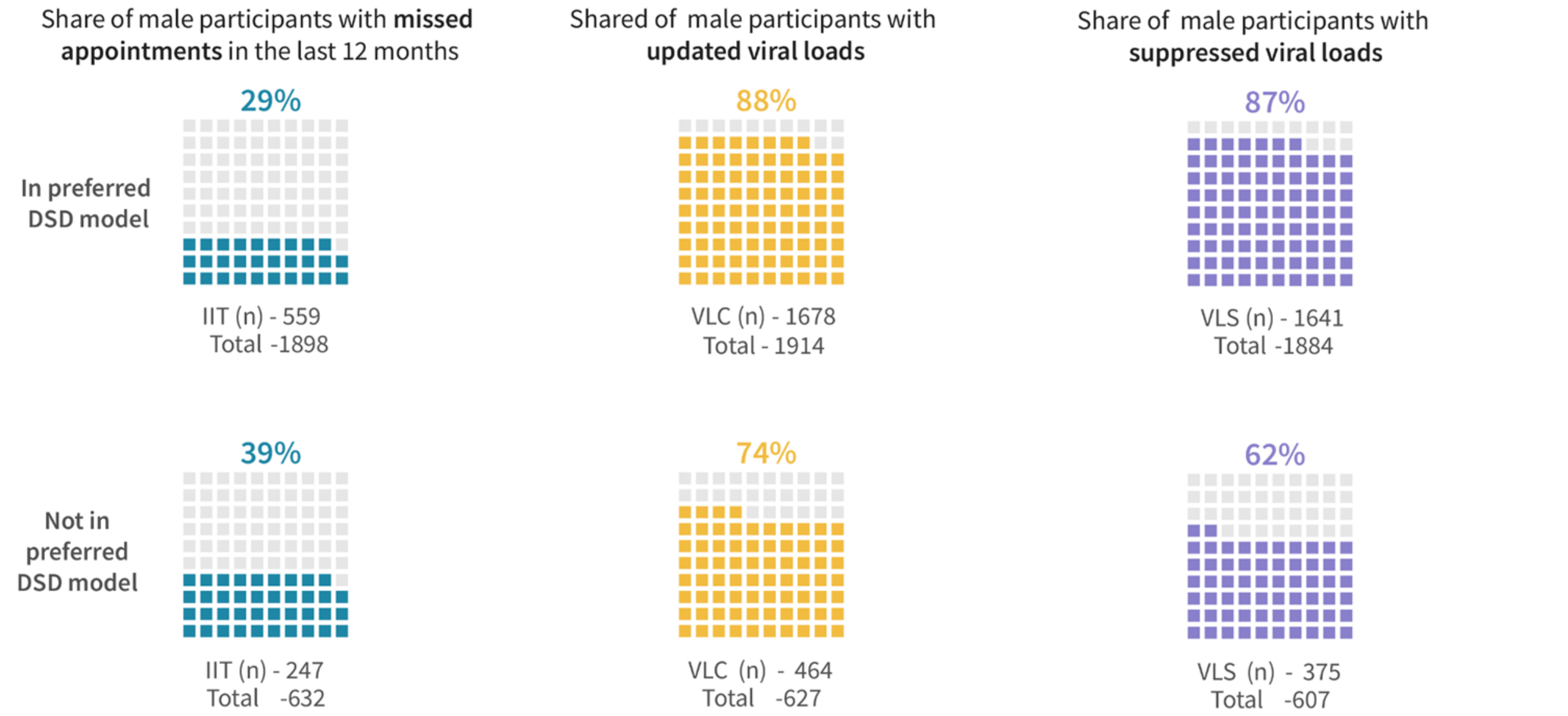


Source: DSD Patient Reference Export, 16 Feb 2022

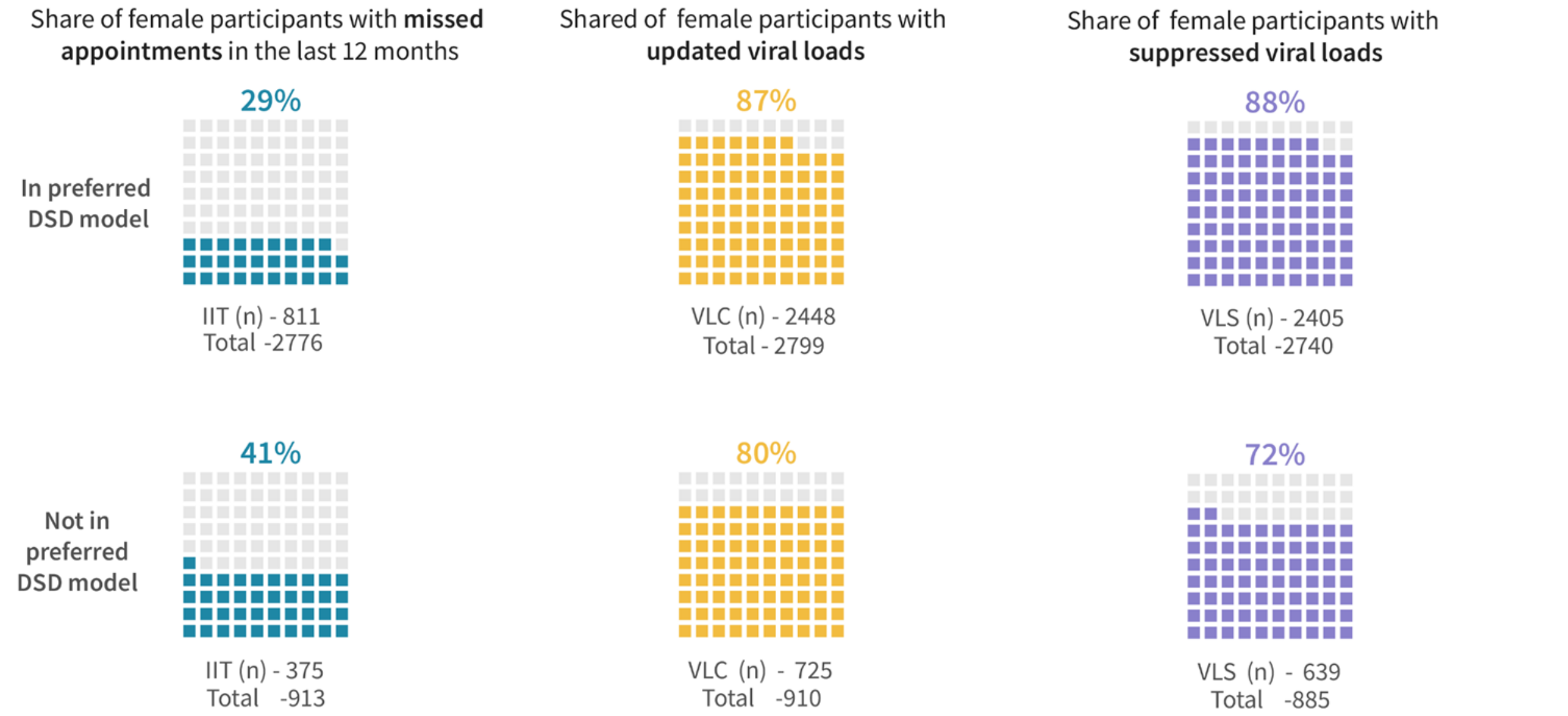
Participants in their preferred DSD model had **fewer missed appointments** and more **updated** and **suppressed** viral loads than participants not in their preferred DSD model



Male participants in their preferred DSD model had **fewer missed appointments** and more **updated** and **suppressed** viral loads than male participants not in their preferred DSD model

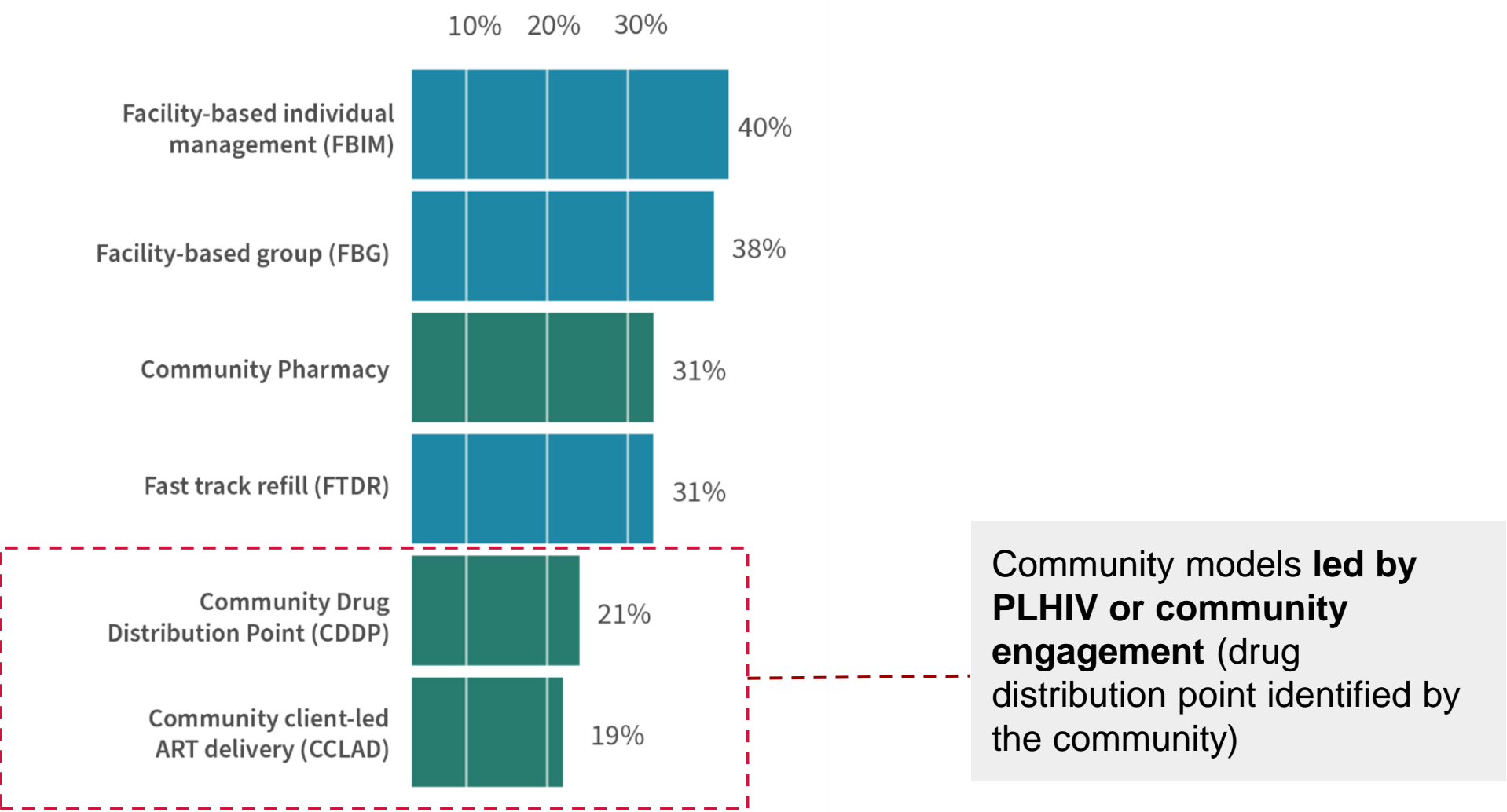


Female participants in their preferred DSD model had **fewer missed appointments** and more **updated** and **suppressed** viral loads than female participants not in their preferred DSD model



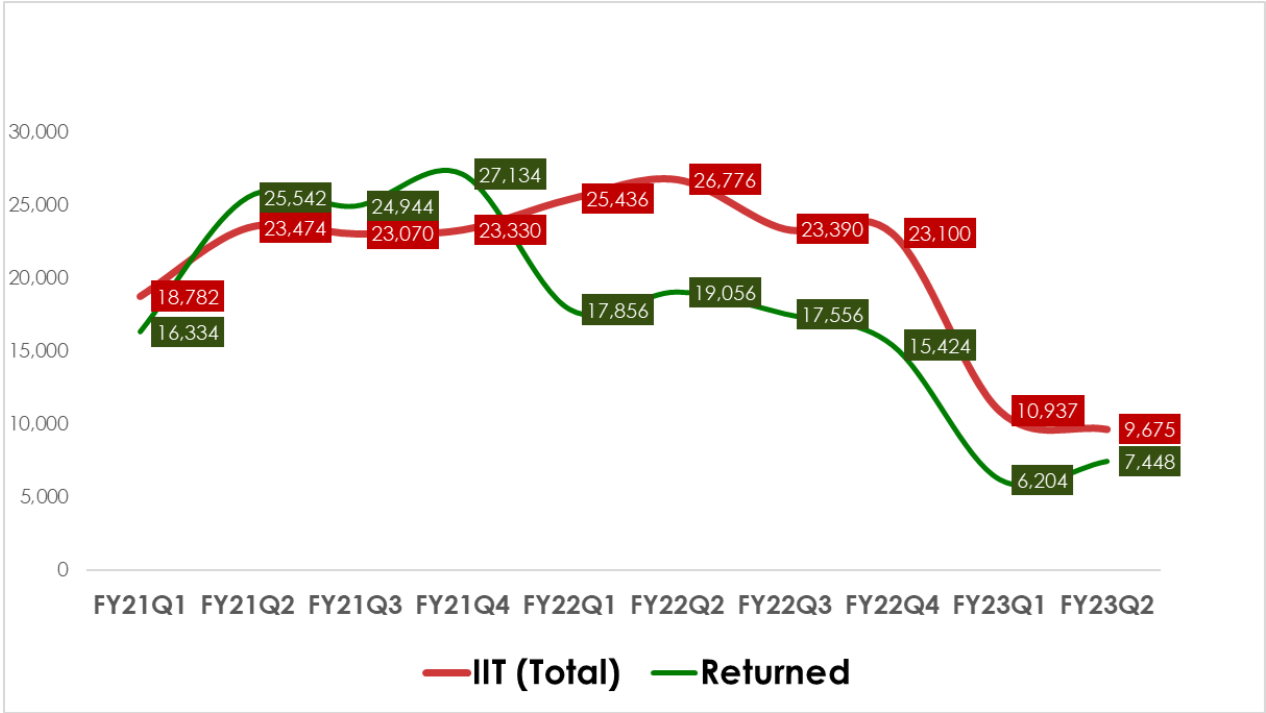
Community models missed reported less appointments

Share of clients with missed appointments by current ARV dispensing model



FY2023Q2: Interruption in Treatment (IIT) and Return to Treatment (RTT)

Programs with high coverage of such priority strategies demonstrate positive performance trend



A substantial reduction in IIT and RTT. Starting to see an upward trend in RTT and reduction in IIT – need to sustain this trajectory



High coverage of priority strategies resulting in sustained improvements in IIT and RTT.


SERVICE COVERAGE GAPS ACROSS REGIONS FOR CALHIV FROM JANUARY PATIENT AUDIT TOOL

Comparing January (and November) audit tools, biggest gaps have improved: VL bleeding is 49% (from 27%), community contact is 69% (from 43%), Index testing of sexual partners is 25% (from 19%), IAC is 86% (from 72%)

	All USAID	G2G Gulu	G2G Jinja	G2G Kabale	G2G Lira	G2G Mbale	G2G Mbarara	G2G Moroto	Mbale Region	Jinja Region	Moroto Region	Kabale Region	Lira Region	Gulu Region	Mbarara Region	UPMB LSDA
VLC	75%	61%	91%	75%	73%	40%	84%	79%	64%	78%	75%	79%	85%	86%	62%	73%
VL bleeding	49%	34%	38%	26%	37%	0%	15%	82%	25%	48%	38%	55%	34%	47%	28%	94%
TPT	95%	99%	96%	91%	94%	99%	100%	93%	93%	94%	96%	95%	98%	96%	93%	96%
TB screening	100%	100%	98%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	80%	100%
OVC screening	97%	100%	97%	99%	99%	100%	100%	100%	96%	99%	100%	99%	99%	98%	84%	100%
OVC enrolment	94%	100%	100%	100%	100%	100%	ND	ND	100%	100%	100%	100%	100%	100%	72%	100%
MMD ≥ 3months	77%	76%	60%	94%	76%	91%	89%	84%	81%	67%	88%	85%	65%	64%	77%	84%
ICT- Sexual Partners	25%	24%	67%	0%	8%	0%	0%	3%	24%	74%	60%	14%	34%	8%	74%	66%
ICT- Children	95%	100%	84%	56%	87%	100%	100%	76%	88%	96%	88%	95%	99%	97%	89%	96%
IAC	86%	85%	100%	0%	80%	98%	100%	100%	82%	93%	80%	87%	88%	82%	74%	95%
DTG	98%	99%	98%	98%	97%	96%	95%	100%	98%	98%	99%	98%	98%	97%	99%	99%
Community contact	69%	59%	74%	90%	60%	92%	85%	0%	94%	63%	67%	56%	53%	44%	64%	86%
CHW attachment	98%	100%	100%	7%	98%	100%	100%	100%	100%	99%	100%	94%	99%	100%	100%	98%
Appt keeping	93%	66%	95%	98%	92%	97%	100%	91%	98%	95%	96%	96%	91%	87%	89%	98%

We are able to identify and respond to pediatric service gaps at district, site, and individual level

Screenshot of the audit tool at a facility level

Region	District	Facility Name	 ART/HIV Clinic N	SERVICES ELIGIBLE FOR: "RED"																
				Index testing of siblings/children	Index testing of sexual partners	VL sampling	DTG Transition	IAC initiation	HIVDR sample	Switching	TPT Initiation	TB screening	PSS	MMD	FollowUP	ANC Screening Assessment	Attachment to CHW	Number of services required	Overall suppression	ART Initiation of new H
UPMB_LSDA_Region	UPMB_LSDA	St Benedic	STB 705														2			
UPMB_LSDA_Region	UPMB_LSDA	St Benedic	STB 761														0			
UPMB_LSDA_Region	UPMB_LSDA	St Benedic	STB 973														1			
UPMB_LSDA_Region	UPMB_LSDA	St Benedic	STB 127														4			
UPMB_LSDA_Region	UPMB_LSDA	St Benedic	STB 1296														1			
UPMB_LSDA_Region	UPMB_LSDA	St Benedic	STB789														0			
UPMB_LSDA_Region	UPMB_LSDA	St Benedic	STB 384														1			
UPMB_LSDA_Region	UPMB_LSDA	St Benedic	STB 1243														1			
UPMB_LSDA_Region	UPMB_LSDA	St Benedic	STB 402														2			
UPMB_LSDA_Region	UPMB_LSDA	St Benedic	STB 093														2			
UPMB_LSDA_Region	UPMB_LSDA	St Benedic	STB191														0			
UPMB_LSDA_Region	UPMB_LSDA	St Benedic	STB 015														2			
UPMB_LSDA_Region	UPMB_LSDA	St Benedic	STB 814														2			
UPMB_LSDA_Region	UPMB_LSDA	St Benedic	STB 1321														2			
UPMB_LSDA_Region	UPMB_LSDA	St Benedic	STB 1133														0			
UPMB_LSDA_Region	UPMB_LSDA	St Benedic	STB 1297														1			



PEPFAR



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THANK YOU!



Maggie Munsamy, National Department of Health, South Africa

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

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



 **IAS 2023**

23 – 26 July · Brisbane and virtual

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Conflict of interest disclosure



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I have no relevant financial relationships with ineligible companies to disclose.

Purpose and objectives of the article



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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 medication distribution from Eswatini and South Africa, focusing on programmatic successes and implementation challenges.



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“Person-centred programming places individuals’ values and preferences at the centre of all aspects of program design and implementation.”

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

Background



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1. The aging population of people living with HIV has increased and so has the prevalence of noncommunicable diseases (NCDs). Despite increasing NCD prevalence, there is a lack of high-quality published evidence to support person-centred NCD/HIV integration models in sub-Saharan Africa.
2. Specifically, there is little research on integration of hypertension and diabetes care—two common NCDs—with differentiated models of HIV service delivery.
3. Integration may increase access to hypertension and diabetes care among people living with HIV who have limited access to relevant services and may potentially improve health outcomes and reduce mortality.

Methodology



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1. Programmatic data from Community Health Commodities Distribution (CHCD) in Eswatini from April 2020 to December 2021.
2. Programmatic data from Central Chronic Medicines Dispensing and Distribution (CCMDD) in South Africa from January 2016 to December 2021.

Results: Eswatini



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1. 83 PEPFAR-supported facilities and 721 functional community distribution points implemented CHCD from April, 2020 to December, 2021, providing over 28,000 people with and without HIV with integrated services including multi-disease screening, HIV testing, CD4 and VL testing, ART refills, and PrEP alongside NCD services including blood pressure and glucose monitoring, hypertension and diabetes medication refills. No out-of-pocket costs.
2. The 26,776 clients enrolled represent people living with and without HIV; 63% female and 4% below 15 years of age.
3. Eligible clients receive decentralized services at convenient public health facilities or decentralized pickup points, including under a tree, schools, churches, bus stops, community halls, football pitches, and shops.

Results: Eswatini



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4. Initially HIV medication distribution was only entry point due to existing HIV programmatic foundation; due to client perceptions of HIV stigma, however, CHCD added NCDs, FP, and other services, allowing those without HIV to also participate in CHCD.
5. Only 1% of CHCD clients missed appointments in this program compared to 7% who missed appointments for facility-based refills.
6. Less than 10% of all clients receiving ART from facilities that conduct CHCD collected medications from pickup points; the preference for facility-based care may be due to perceived HIV-related stigma as CHCD was initially designated only for people living with HIV.

Challenges: Eswatini



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1. Some people living with HIV who require more comprehensive medical management continue to prefer facility-based care.
2. 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.
3. The lack of funding for client transportation is another challenge.
4. Financial sustainability

RESULTS SOUTH AFRICA



The CCMDD programme is the flagship programme for National Health Insurance (NHI) that provides an alternative access to **chronic** medicine for **stable** patients.

External pick-up points (PuPs) provide the patient with a more convenient option for the collection of their repeat medicine which has been dispensed and distributed via the programme.



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RESULTS SOUTH AFRICA



The programme 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, including smart lockers, facility “fast lanes” and adherence clubs.

The 2855 contracted PuPs may be nearer to their homes or workplace and can result in reduced transport costs.
There is no out of pocket payment.

By October 2021, among those receiving ART and other chronic disease medications, 25% utilized facility PUPs, called fast lanes.
19% participated in adherence clubs and 56% used external PUPs

Number of people living with HIV and co morbidities



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%)



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Reducing HIV related stigma



Person-centred innovations include:

- 1.clients selecting their own language for written medication instructions
- 2.clients deciding where they want to collect their medicine parcel
- 3.clients choosing the exact date of medication pickup (within a 7-day window);
- 4.clients feedback informing the design of medication packaging and labelling.
- 5.Integrating NCD/ART medication pickup at pick out points,
- 6.using uniformly labelled medication packages,
- 7.ensuring visual and audio privacy in dispensing areas.

CHALLENGES: SOUTH AFRICA



1. In rolling out the web-based system for CCMDD, the lack of internet connectivity impacts the use of the electronic prescribing
2. Energy crisis causing disruption in electricity is problematic for the programme
3. Due to insufficient storage space at popular pick-up points, when they reach capacity, the pick-up point is blocked on the electronic temporarily, until the storage stabilizes.



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Conclusions



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1. Eswatini and South Africa demonstrate scalable, person-centred models for HIV and NCD integration through decentralized drug distribution. This approach adapts medication delivery to serve individual needs while decongesting health facilities, efficiently delivering NCD care, reducing healthcare costs borne by clients with multiple comorbidities, and decreasing HIV related stigma.
2. Ministry of health leadership, public-private partnerships, nongovernmental organizations, PEPFAR implementing partners and international donors were crucial to the success of both programs, as was the absence of out-of-pocket costs to clients in both programs.
3. To bolster program uptake, additional reporting of integrated decentralized drug distribution models should include HIV and NCD health outcomes and mortality trends.

Next steps



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1. Further evaluation for integrated HIV/NCD drug distribution programs 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 DDD program utilized and by demographic factors
 - risk factors for loss of viral suppression;
 - client preference data on stigma, provider trust and factors influencing choice of facility type.
2. additional reporting of integrated NCD and HIV decentralized drug distribution models is needed on client-level clinical outcomes including blood pressure and glycemic control, HIV including 95-95-95 benchmarks, and
3. longer-term mortality trends through modelling studies.

Acknowledgement of contributors



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Brian Minalga, MSW | Fred Hutchinson Cancer Center
Satellite session: Person-centred approaches to address the health
needs of people living with HIV and co-infections and co-morbidities

Lessons Learned from Community Engagement in HIV Phylogenetic Research



 **IAS** 2023

23 – 26 July • Brisbane and virtual

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Conflict of interest disclosure



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I have no relevant financial relationships with ineligible companies to disclose.

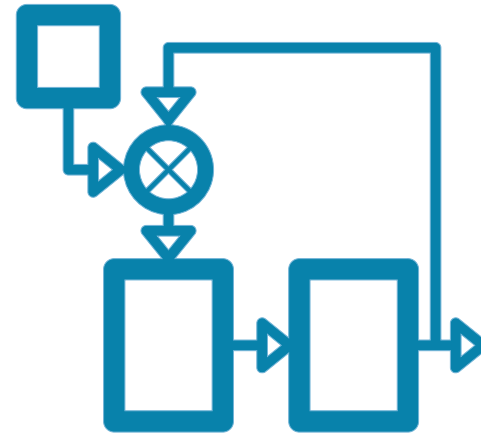
Background



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Phylodynamic Model of HIV Transmission

“Black men have an X% probability of acquiring/transmitting HIV from/to another Black man.”



“Young men have an X% probability of acquiring/transmitting HIV from/to older men.”

Original Study: Phylodynamic Modeling of HIV Transmission



IAS 2023

Research Question: Is there phylogenetic evidence of assortative HIV transmission by age, race, or ethnicity among men who have sex with men in King County, Washington, USA?

Original Study: Phylodynamic Modeling of HIV Transmission

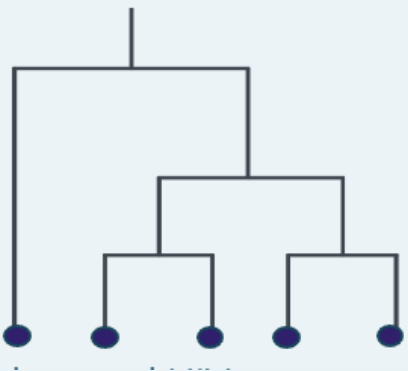


IAS 2023

Research Question: Is there phylogenetic evidence of assortative HIV transmission by age, race, or ethnicity among men who have sex with men in King County, Washington, USA?

Inputs

1. Phylogenetic Tree of HIV Sequences collected via MHS

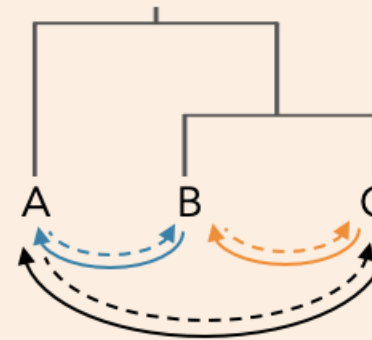


2. Linked Data

- Demographic information (**age, race, ethnicity**)
- CD4+ counts
- date of HIV sequence sampling

Outputs

1. Estimate a transmission probability weight for all pairs of HIV sequences



2. Predict population-level patterns



Addressing Ethical Challenges in US-Based HIV Phylogenetic Research

Liza Dawson,^{1,2} Nanette Benbow,² Faith E. Fletcher,² Seble Kassaye,⁴ Amy Killelea,⁵ Stephen R. Latham,⁶ Lisa M. Lee,⁷ Thomas Leitner,⁸ Susan J. Little,⁹ Sanjay R. Mehta,^{1,10} Omar Martinez,¹⁰ Brian Minalga,¹¹ Art Poon,¹² Stuart Rennie,¹³ Jeremy Sugarman,¹⁴ Patricia Sweeney,¹⁵ Lucia V. Torian,¹⁶ and Joel O. Wertheim¹



Open Letter to the CDC: Networks of People Living with HIV Demand a Moratorium on Molecular HIV Surveillance

CORRESPONDENCE | VOLUME 6, ISSUE 7, E420, JULY 01, 2019

Consent and criminalisation concerns over phylogenetic analysis of surveillance data

Cecilia Chung • Naina Khanna • Barb Cardell • Andrew Spieldenner •

Sean Strub • Alexander McClelland • et al. [Show all authors](#)

Published: July, 2019 • DOI: [https://doi.org/10.1016/S2352-3018\(19\)30138-9](https://doi.org/10.1016/S2352-3018(19)30138-9)

Guest Editorial

We Are People, Not Clusters!

Edwin J. Bernard, Alexander McClelland, Barb Cardell, Cecilia Chung, Marco Castro-Bojorquez, Martin French, Devin Hursey, Naina Khanna, Mx Brian Minalga, Andrew Spieldenner & Sean Strub [... show less](#)

Pages 1-4 | Published online: 18 Sep 2020

NTTQMFNSW -TGH--ST?K G*-?GN--ET
NTTQMFNSTW -NGT--NT?Q G*-?GN--DT
NTTQMFNSTW -NG?-?ST?GY-?G--NF

Without Our Consent

Centering People Living with HIV in HIV Genetic Sequencing

NTTQMFNSTW -NGT
NTTQMFNSTW -NGT
NTTQMFNSTW -NGT

THE AMERICAN JOURNAL OF BIOETHICS
2020, VOL. 20, NO. 10, 44-47
<https://doi.org/10.1080/15265161.2020.1806392>



nam

HIV & AIDS - sharing knowledge

Confidentiality, Consent

OPEN PEER COMMENTARIES

HIV Molecular Epidemiology: Tool of Oppression or Empowerment?

Stuart Rennie, Kristen Sullivan, and Ann Dennis

University of North Carolina at Chapel Hill

Molecular HIV surveillance: friend or foe?

Krishen Samuel | 18 January 2021

THE AMERICAN JOURNAL OF BIOETHICS
2020, VOL. 20, NO. 10, 10-23

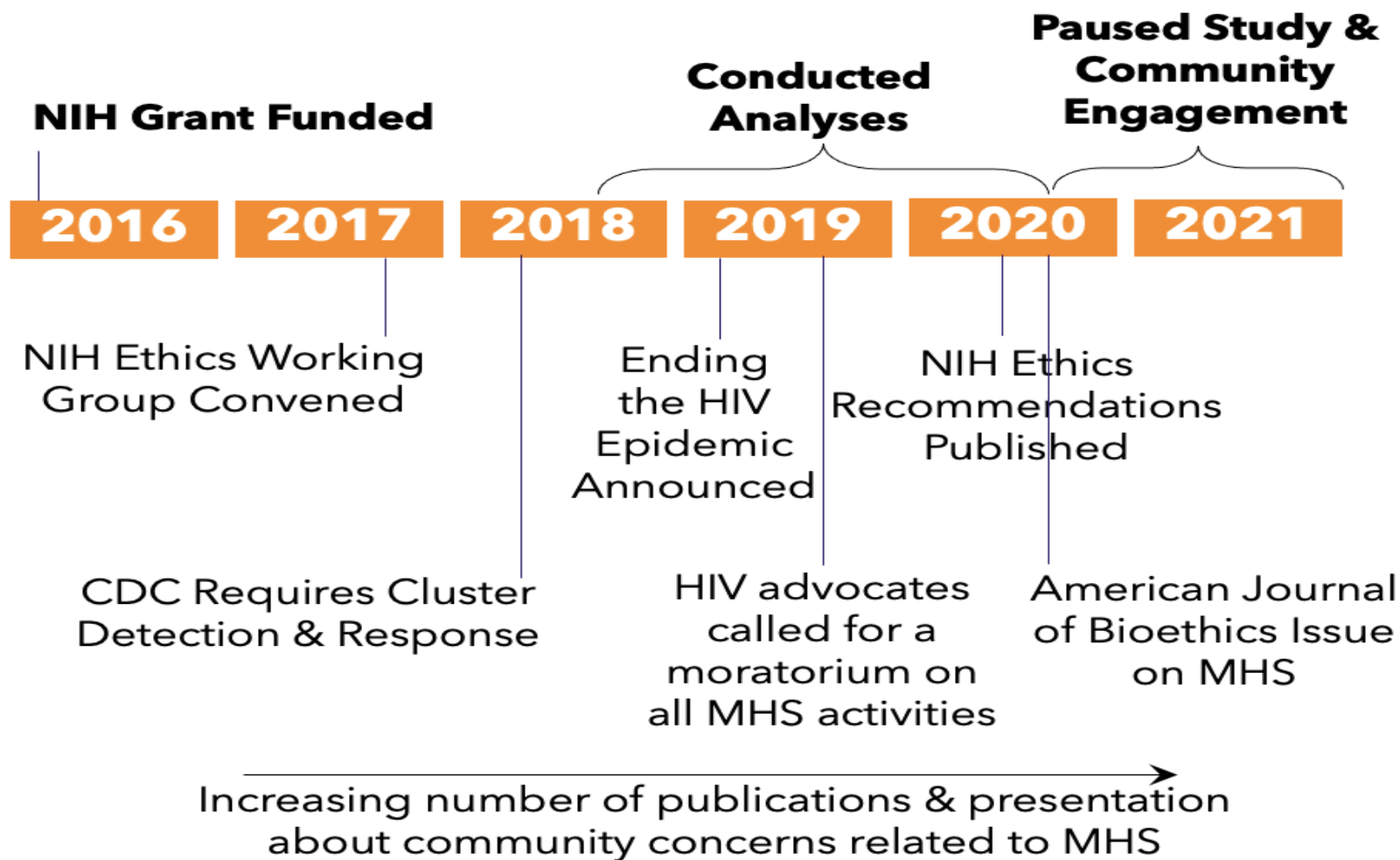
Reassessing the Ethics of Molecular HIV Surveillance in the Era of Cluster Detection and Response: Toward HIV Data Justice

Stephen Molldrem^a and Anthony K J Smith^b

Timeline



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Methodology: Community Consultation Process



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Meetings and presentations:

- Center for AIDS Research Community Engagement Office
- Dialogue with researchers and clinicians (~50)
- Dialogue with community-based organizations and advocates (~15)



***Consultation with a National Coalition on molecular HIV surveillance:**

- What are the perceived benefits of this project?
- What are the potential harms?



Reflexive writing/journaling



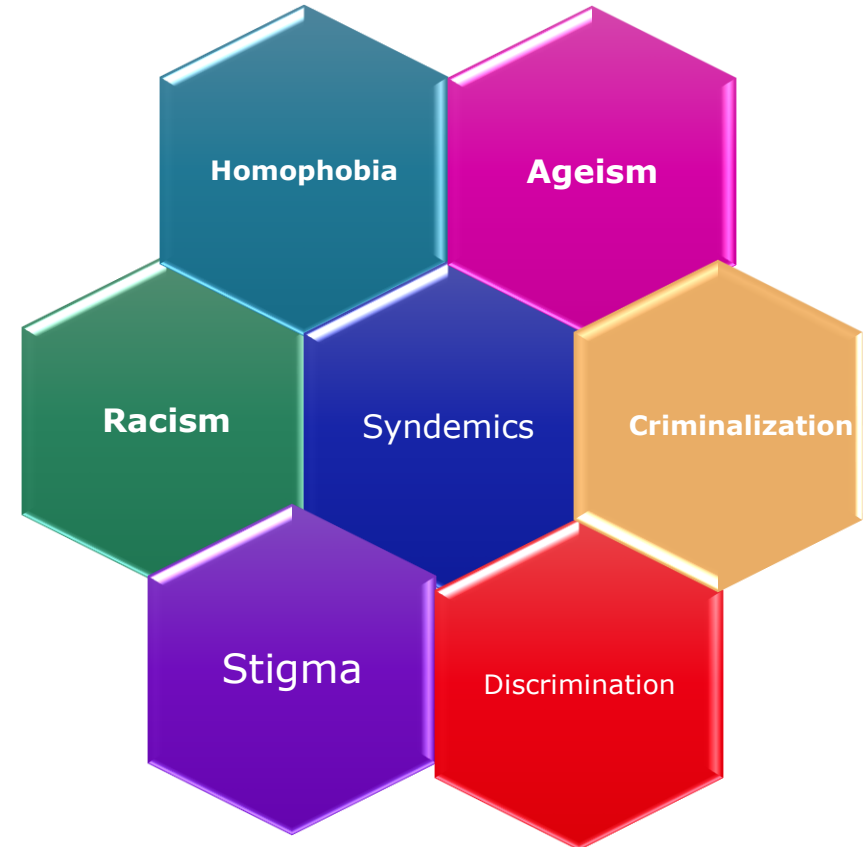
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Issues

Informed Consent



Interlocking Systems of Oppression



Decision Not to Publish



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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 and nonmaleficence*)
3. Does this research equitably distribute benefits and risks to people living with HIV as well as people susceptible to acquiring HIV? (*Justice*)

Alternate Publication



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“Lessons Learned from Community Engagement Regarding Phylogenetic Research Using Molecular HIV Surveillance Data”

- Our community engagement process
- What we learned from the community
- Decision not to publish
- Recommendations for other researchers
- Originally published in 2022 as a pre-print—until now!

Conclusions



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HIV: The H stands for Human!

HIV research must ***never*** serve to exploit human suffering or disease for academic profit or intrigue.

HIV research must ***always*** center people.



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Thank you!

Coauthors: Diana Tordoff, Alfredo Trejo, Alic Shook, Roxanne P. Kerani, and Joshua T. Herbeck.

The Community Coalition on Molecular HIV Surveillance, including Alexander McClelland, Andrew Spieldenner, Ronald Johnson, Marco Castro-Bojorquez, and Edwin Bernard.

Positive Women's Network-USA, including Naina Khanna, Victoria Siciliano, and Kelly Flannery.

Everyone who contributed to our community engagement process including Stephau Wallace and the Community Engagement Office with the University of Washington/Fred Hutch Center for AIDS Research; the attendees of the Public Health-Seattle & King County Lunchbox Talk and Salon Presentation as well as its organizers, Susan Buskin and Jsani Henry.

This work was funded by the US National Institute of Allergy and Infectious Diseases (R01AI127232).

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Tung Doan, The Global Network of Young people living with HIV (Y+ Global)

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

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



 **IAS 2023**

JIAS Viewpoint by PATA and Y+ Global

23 – 26 July · Brisbane and virtual

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Conflict of interest disclosure



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I have no relevant financial relationships with ineligible companies to disclose.



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Purpose and objectives of the article/study



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The specific goal is to investigate the idea of person-centred care (PCC) in the context of health services geared towards adolescents and young people.





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Person-centred care (PCC) refers to an approach in healthcare that shifts the power dynamic from the healthcare provider to the patient or service user.

It involves engaging the patient in decision making, promoting effective communication, offering multiple choices and fostering patient empowerment, autonomy, and trust in their healthcare journey.

Y+ Global and PATA



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PCC fundamental principles
Client is a unique person
Client should be fully involved in care
Client must be given the power to
make their own decisions

Y+ Global and PATA

Methodology

PATA collaborated with Y+ Global to bring together health providers and AYPLHIV, creating a unique platform for promoting and enhancing a more equal and empowering relationship between service providers and users.

Practical strategies and recommendations are informed by joint program implementation and a systematic review of person-centred care within the context of HIV treatment settings in sub-Saharan Africa.



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Lessons Learned



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Health provider attitude

Multiple, ongoing and layered sensitization strategies are required to deliver PPC that is adolescent-friendly, including:

- Values clarification training supporting health providers to reflect on and redefine their values
- Relationship-building sessions to support health providers to engage more meaningfully
- PCC champions to lead the process of shifting power and changing entrenched mindsets within the health facility



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Lessons Learned



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Peer support



- AYPLHIV peer supporters working in partnership with health care teams can facilitate a fundamental shift in health facility power structures
 - Engaging AYPLHIV can break down inequalities and challenge often ingrained practices and beliefs
- Teen clubs and adolescent-friendly safe spaces – for psychosocial support, counselling and health promotion – improve retention in care and viral suppression
 - Effective peer support requires successful health facility integration with mutually agreed upon roles and responsibilities



Lessons Learned



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Community-led monitoring and service quality improvement

- Community-led monitoring assists health care teams and service users to identify service delivery challenges, develop quality improvement plans and hence promote PCC.
- AYPLHIV should be involved in the design and implementation of community-monitoring tools.
- Health facilities and clients (AYPLHIV) should collectively review feedback and collaboratively determine interventions for action



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Conclusions



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1. Strengthening health systems to provide PCC requires institutional commitment and considered implementation across designated roles
2. An enabling environment with available resources that respond to the clients' needs will go a long way to increase health providers intrinsic motivation and attitude to providing person-centred care.



Calls to action / Next steps in your work



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1. Invest in healthcare staff capacity building, sensitization and composition
2. Engage the community in the service supply chain.
3. Facilitate community-led monitoring and continuous quality improvement



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Acknowledgement of contributors



Y+ Global and PATA team members who co-authored the Viewpoint:

- Lynn Phillips, PATA
- Heleen Soeters, PATA
- Maximina Jokonya, Y+ Global
- Allen Kyendikuwa, Y+ Global
- Luann Hatane, PATA