PCC Stakeholder Consultation Series

Session 2 - 27 April 2023

What is the evidence supporting a person-centred care approach within the HIV response?

Person-Centred Care

With support from: GILEAD

Instructions for participants

- Please ask questions to presenters using the JamBoard. Link in chat
- The chat is for any technical issues or general questions
- Slides will be sent to all participants
- The breakout group is your chance to speak up! Please stay on mute during presentations and in discussion, unless called on

Meeting 2: Evidence for PCC with

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Meeting 2: Evidence for PCC within the HIV response

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ENG 17:23 25/04/2023

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PCC stakeholder consultation objectives

1. Provide a platform for exchange on the concept of person-centred care in the HIV response.

2. The discussions, learnings and recommendations from the series will form the basis of a joint commentary article to build consensus around the concept of person-centred care. It will provide recommendations for different groups of stakeholders as they work towards realizing the full potential of person-centred care for the HIV response.

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PCC stakeholder consultation series

	When	Topic
1	AIDS 2022	Person-centred care approaches to improve quality of life for people living with and affected by HIV
2	27 April 2023, ZOOM	What is the evidence supporting a person-centred care approach within the HIV response?
3	25 May 2023, ZOOM	What are the service delivery considerations for providing integrated person-centred care for people living with or affected by HIV throughout their life-course?
4	22 June 2023, ZOOM	What are the core elements and mechanisms for person-centred care within the HIV response and for different stakeholders?
5	IAS 2023	Interactive in-person workshop to prioritize the content for the consensus statement.

IAS

Meeting 2: What is the evidence supporting a person-centred care approach within the HIV response?

Meeting objective

To take stock of the current evidence supporting the contribution of person-centred care to the well-being and health outcomes of people living with and affected by HIV.

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Meeting 2: TODAY

Discussion questions

1. Which elements of the person-centred care frameworks resonate with you for the HIV response?
2. What is missing from the frameworks?
3. What does the evidence tell us about the contribution of person-centred care approaches to improved well-being and health outcomes for people living with and affected by HIV?
4. What are the current research gaps?
5. What priorities are emerging for person-centred care within the HIV response?
6. What does the evidence tell us about how to best operationalize person-centred care and does this differ depending on context and sub-populations?

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Order of Events

1. PCC Personal Stories
2. Presentations (25 mins)
   - Overview of PCC frameworks and WHO guidance
   - Evidence on PCC-related interventions
   - Advances in PCC within HIV programming and other health areas
   - Strategies for long-term success
3. Breakout group discussions (15 mins)
4. Report back and moderated discussion (20 mins)

Moderator:
Laura Beres

IAS

»I currently work in these hotspots to bring about change, with the experience that change is possible even on the streets. Someone held my hand when I lost hope, and I got back on my feet. Now, I'm doing the same for my fellow sex workers who have nowhere to call home and restoring hope to them that even within these hotspots, we can still take our ART and attain viral suppression.«

Annie, Peer Navigator, BHESP

Frameworks for Person and Patient Centered Services: a Research Agenda for the HIV Response

LIVE Team

Noelle Le Tourneau, Laura Beres, Chris Kemp, Marie-Claude Lavoie, Nathan Ford, Chanda Mwaba, Kombatende Sikombe, Ashley Underwood, Elvin Geng

Patient or person centeredness and the HIV public health

- Patient or person centeredness seems intuitive and comports with the spirit of the HIV response
- How do we implement and integrate it?
- The answer involves (in part)...
  - Shared conceptualization
  - How it meets needs of today's HIV response
  - Models that activate via key mechanisms
- Challenges: scarcity, new challenges (e.g., COVID), heterogeneity
- Implications for the research agenda

Patient or person centered care imperative…

CRITICAL REVIEW

OPEN

Expanding the Vision for Differentiated Service Delivery: A Call for More Inclusive and Truly Patient-Centered Care for People Living With HIV

Peter Ehrenkranz, MD, MPH,[a] Anna Grimsrud, PhD,[b] Charles B. Holmes, MD, MPH,[c] Peter Preko, MBChB, MPH,[d] and Miriam Rabkin, MD, MPH[d]

JAIDS 2021

…But systems centered delivery?

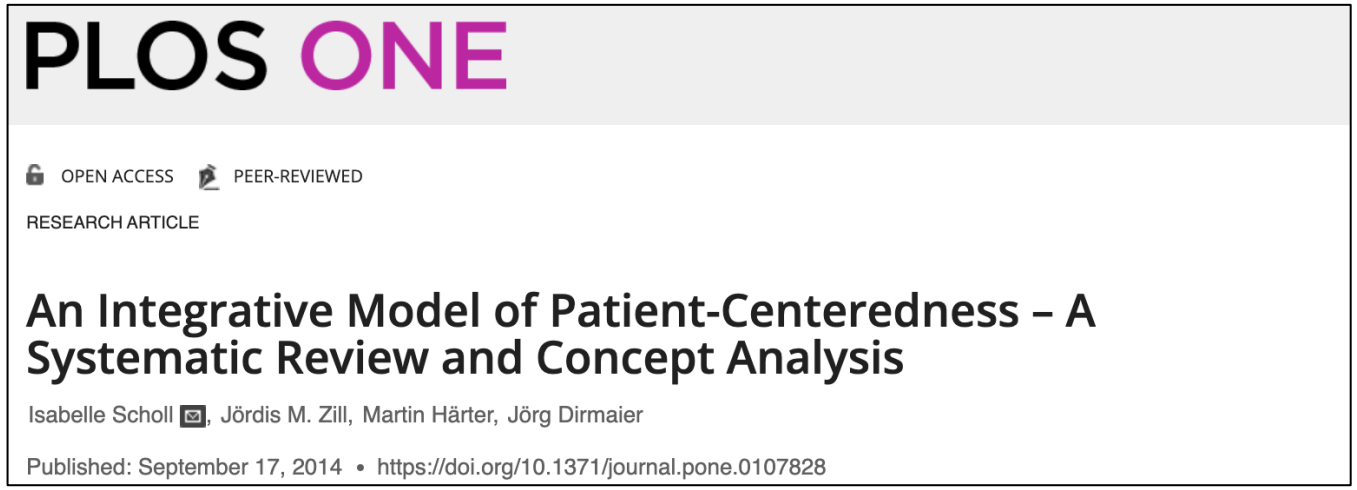
BMJ Global Health

‘They care rudely!’: resourcing and relational health system factors that influence retention in care for people living with HIV in Zambia

Chanda Mwamba,[1] Anjali Sharma,[1] Njekwa Mukamba,[1] Laura Beres,[1,2]

From concept to practice: dissecting the PCC

- Conceptual clarity
  - *Existing models of patient-centeredness reveal a lack of conceptual clarity (Scholl)*
- Mechanisms of application
  - *This paper explores the current state of PCC … potential barriers to its implementation (De Man)*
- Operationalization
  - *While numerous conceptual frameworks for PCC exist, a gap remains in practical guidance on PCC implementation (Santana)*



PLOS ONE

OPEN ACCESS PEER-REVIEWED

RESEARCH ARTICLE

An Integrative Model of Patient-Centeredness – A Systematic Review and Concept Analysis

Isabelle Scholl, Jördis M. Zill, Martin Härter, Jörg Dirmaier

Published: September 17, 2014 • https://doi.org/10.1371/journal.pone.0107828

Activities
(e.g., empowerment, shared decision making)

Principles (e.g., essential characteristics of provider; biopsychosocial view)

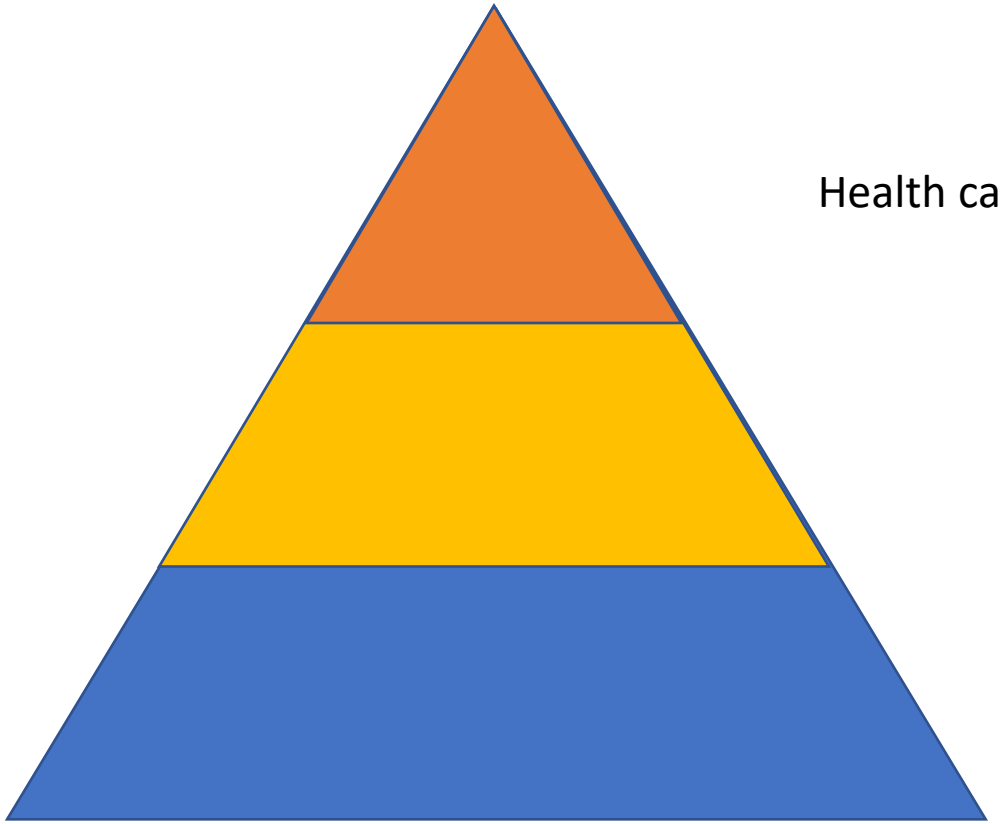
Enablers (e.g., integration, access, coordination)

The International Journal of Person Centered Medicine 2016 Vol 6 Issue 3 pp 162-173

ARTICLE

Patient-Centered Care and People-Centered Health Systems in Sub-Saharan Africa: Why So Little of Something So Badly Needed?

Jeroen De Man MD MPH[a], Roy William Mayega MBChB MPH PhD[b], Nandini Sarkar MA[c],



Health care worker (e.g., training)

Structural (e.g., funding, verticalization)

Socio-economic (e.g., culture, legal systems)

ORIGINAL RESEARCH & CONTRIBUTIONS

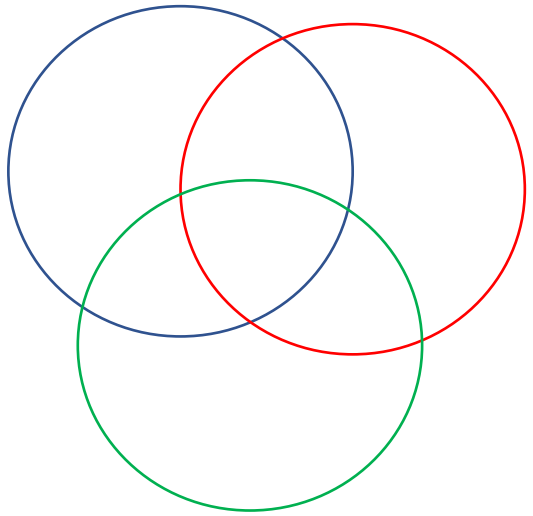
Special Report

A Framework for Making Patient-Centered Care Front and Center

Sarah M Greene, MPH; Leah Tuzzio, MPH; Dan Cherkin, PhD

Perm J 2012 Summer;16(3):49-53

Interpersonal (e.g., communications training)



Structural (e.g., clinic design)

Clinical (e.g., portal)

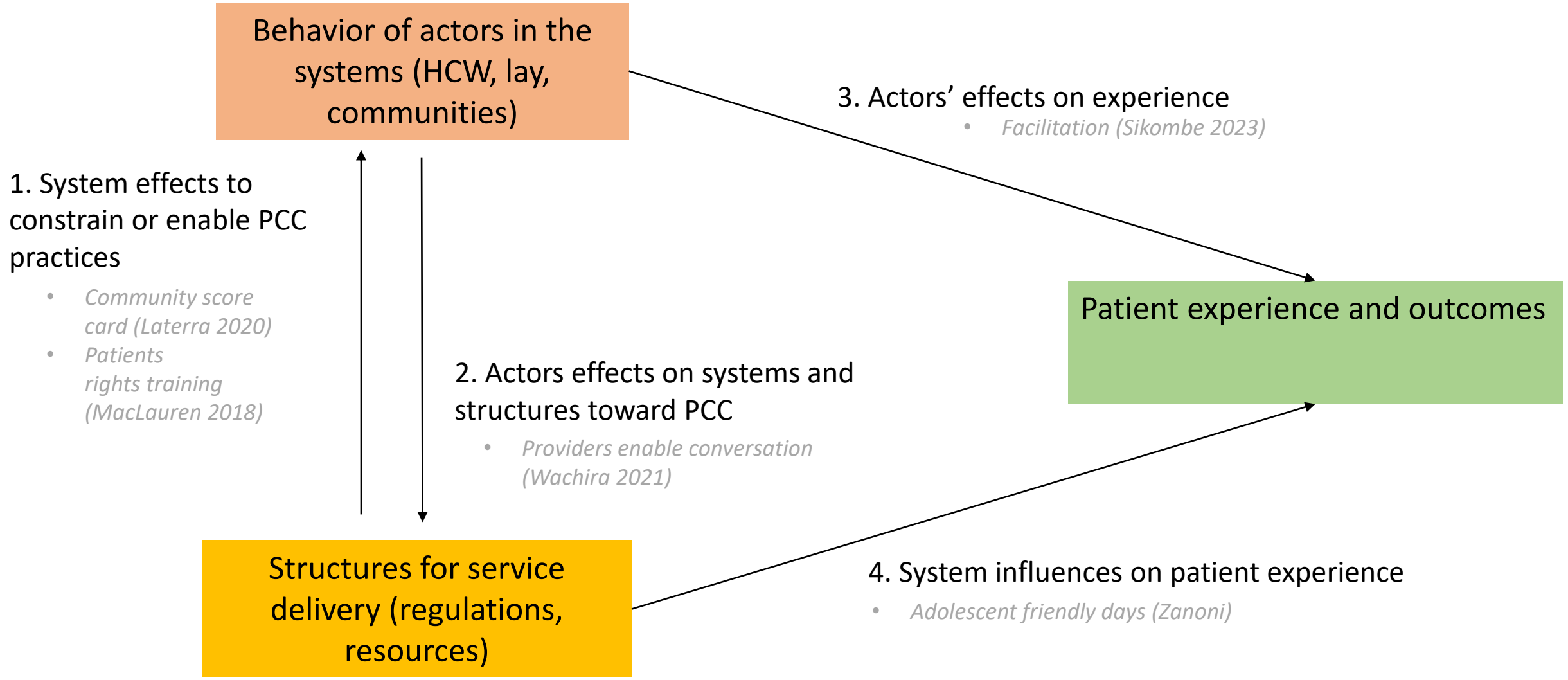
The Health Foundation

What we do | Funding and partnerships | News and comment | Publications | Search

Home > Publications

Person-centred care made simple

Gidden's Structuration Theory: PCC as a Social System



Challenges and needs for PCC in the HIV research agenda

- Empowerment and Activism vs. Stigma and Marginalization
- Verticalized Funding vs. Universal Health Coverage
- Workforce vs. Moral Injury and Burnout
- Target Driven Performance vs. Personalization

Conclusions

- Getting to the finish line in public health is not about who gets there first, but what we can do to make sure that all arrive.
- Bringing personalized public health into practice will require us to turn the idea of meeting patients halfway from a notion into a genuine scientific agenda.
- Creating a shared research agenda on the conceptualization (particularly with LMIC perspectives), to models of care, can help push the agenda forward

Evidence on person-centred care interventions among people living with HIV in low and middle-income countries: A systematic review

IAS-convened stakeholder consultation series

Marie-Claude Lavoie, PhD
Assistant professor
University of Maryland School of Medicine

April 27, 2023

Team members

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- Elvin Geng, Washington University in St. Louis (WUSTL)
- Ingrid Eshun-Wilson, WUSTL
- Chris Kemp, JHSPH
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- Sheree Schwartz, JHSPH
- Stefan Baral, JHSPH
- LIVE team

Washington University in St. Louis

Johns Hopkins University

University of Maryland School of Medicine

1 Background

PCC systematic review objectives

1. What **types of PCC interventions**, intended to improve **patient- provider interactions**, have been employed to support HIV-related outcomes among people living with HIV in low- and middle-income countries (LIMCs)?

2. What are the **effects of PCC strategies** that focus on **improving patient-provider interactions** on HIV cascade outcomes and patient/provider experiences in LMICs?

2 Methods

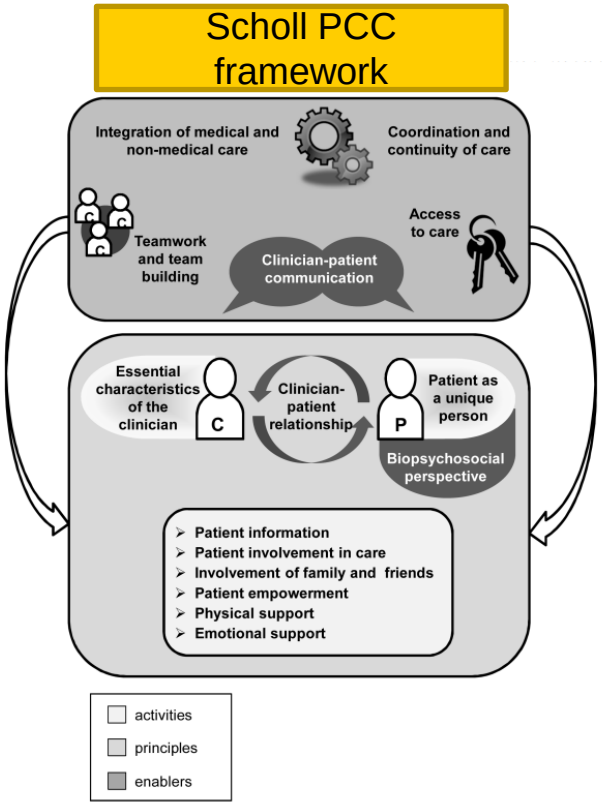
Methods

Search

- We searched Embase, Medline, Scopus, Cochrane, CINAHL and select HIV-related conferences (i.e., IAS/AIDS, ICASA, Adherence)
- Search conducted up to January 2023

Guiding frameworks

- PCC interventions- Scholl and De Man
- Implementation outcomes- Proctor's framework
- Intervention specification – Hickey, et al.



Scholl I, Zill JM, Härter M, Dirmaier J. PLoS One. 2014; De Man J, et al. Int J Pers Cent Med. 2016; Proctor et al., Adm Policy Ment Health. 2011, Hickey et al. Implementation Sci. 2017.

Methods

Synthesis

- Descriptive
- Narrative synthesis

Risk of bias

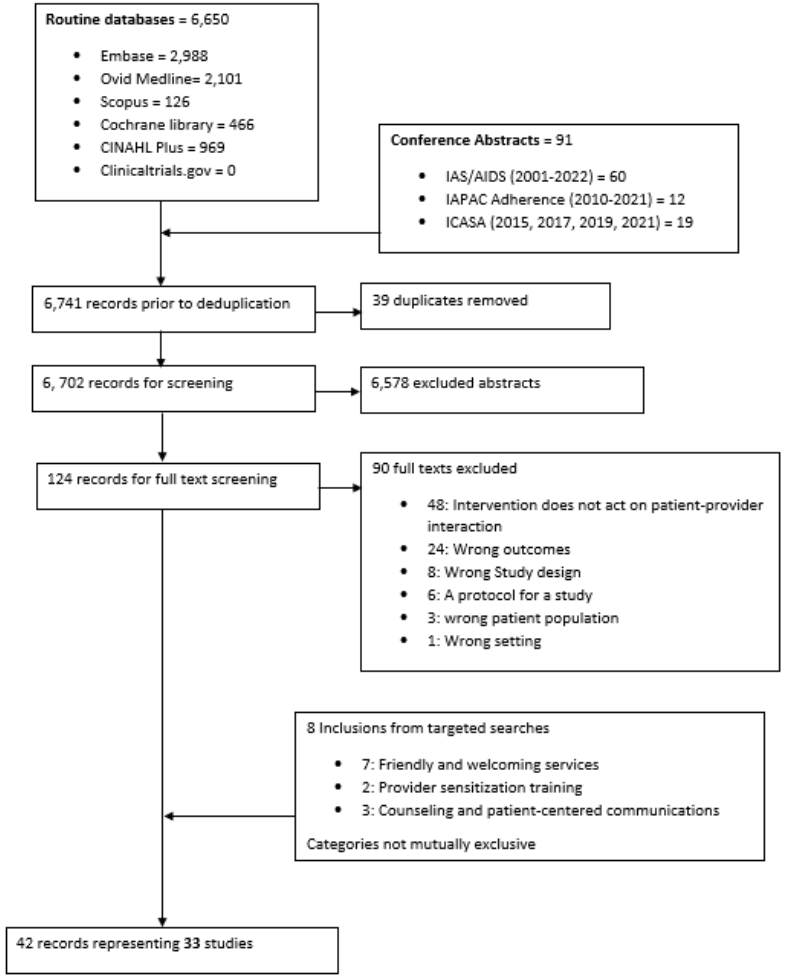
- Cochrane Risk of Bias (RCT)
- Newcastle-Ottawa Scale tool (non-RCT)
- Joanna Briggs Institute (JBI) critical appraisal checklist (qualitative)
- Mixed Methods Appraisal Tool (MMAT) (mixed methods)

3

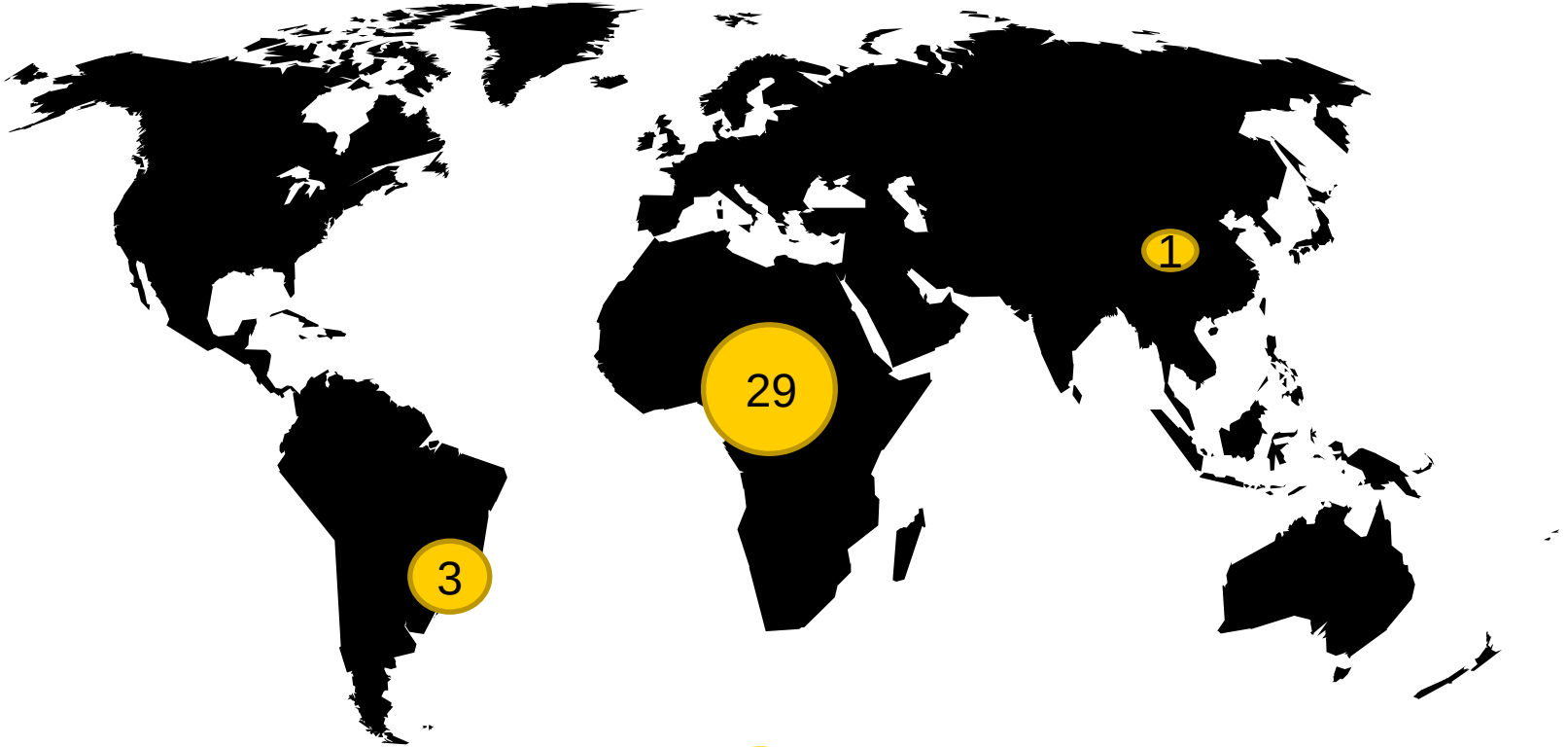
PCC systematic review preliminary findings

Study Selection

- 6650 records screened
- **33 unique studies included,** represented in 42 records



Included studies: geographic distribution



Characteristics of included studies (N=33)

Study design	n	%
Observational	10	30
RCT or cRCT	9	27
Pre and post	7	21
Controlled before and after	1	3
Mixed methods	4	12
Qualitative	2	6

Study population	n	%
Children or children and adults	2	6
Adolescents or adolescents and young adults	9	27
Pregnant/Breastfeeding women	4	12
Adults	16	48
Key population (sex workers)	2	6

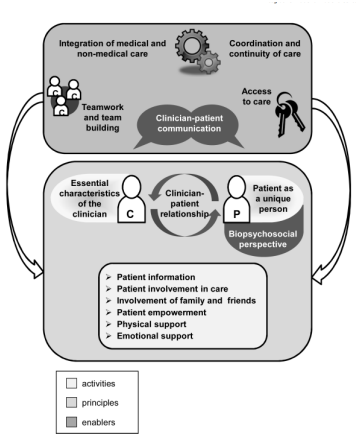
Interventions: PCC intervention types

- 20 studies (61%) had PCC intervention as part of a multicomponent intervention (versus PCC as the sole intervention)
- 6 inductively identified types of PCC interventions employed

PCC intervention type category*	n	%
1. Providing friendly and welcoming services	16	48
2. Individualized counseling and patient-centered communication	15	45
3. Additional patient outreach	9	27
4. Provider sensitization training	8	24
5. Training patients in empowerment and communication skills	7	21
6. Feedback to health workers regarding patient concerns and evaluations of service quality	4	12

*Not exclusive- studies may be included in ≥1 PCC categories

Scholl PCC Dimensions



Scholl dimensions*	n	%
1. Clinician-patient relationship	30	91
2. Clinician-patient communication	21	64
3. Patient involvement in care	15	45
4. Biopsychosocial perspective	13	39
5. Patient information	13	39
6. Access to care	12	36
7. Essential characteristics of the clinician	11	33
8. Patient empowerment	8	24
9. Coordination and continuity of care	7	21
10. Patient as a unique person	7	21
11. Physical support	5	15
12. Emotional support	5	15
13. Integration of medical & non-medical care	4	12
14. Teamwork and teambuilding	3	9
15. Involvement of family and friends	3	9

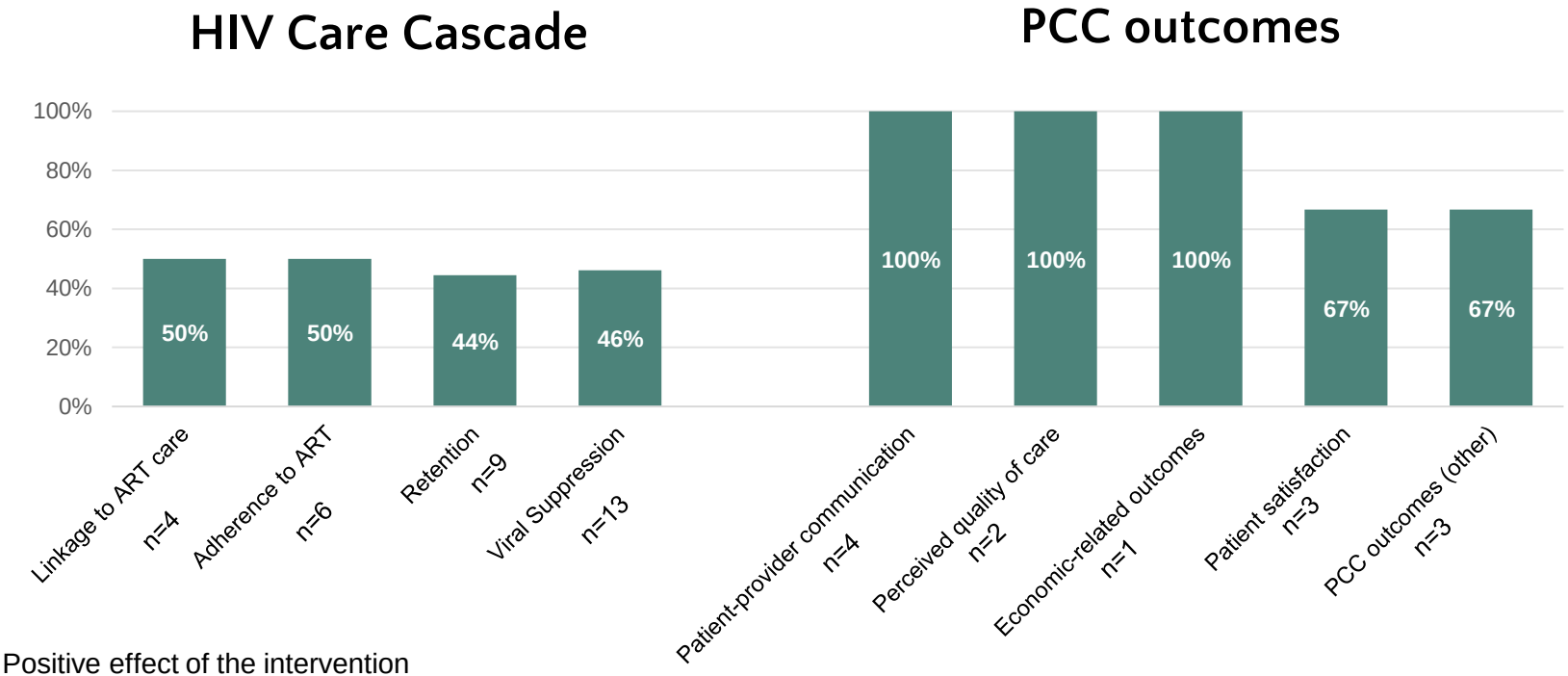
*Not exclusive- studies may be included in ≥1 PCC components

Study outcomes reported (N=33)

Outcomes reported	n	%
Linkage to HIV care or ART initiation	6	18
Retention in care	12	36
Adherence to ART	6	18
Viral suppression	15	45
PCC-related outcomes*	8	24

*e.g., patient satisfaction, patient-provider communication, quality of services, economic-related outcomes

Percentage of studies with a comparison group reporting a positive effect of the intervention



Percentage of outcomes among studies with a comparison group reporting a positive effect of the intervention by category of PCC intervention type

	PCC Intervention Type					
Outcome	**Pt outreach**	**Friendly services**	**Pt training**	**Pt communication**	**HCW feedback**	**HCW sensitization**
Linkage to HIV service		100%		100%		100%
ART initiation		0%		0%		0%
Adherence			50%	60%		100%
Viral suppression	100%	86%	50%	38%	100%	50%
Retention	100%	100%	25%	20%	100%	100%
Economic-related outcomes	100%	100%				
PCC Outcome- Patient satisfaction			100%	50%		100%
PCC Outcome- Patient-provider comm			100%	100%	100%	
PCC Outcome- Perceived quality of care					100%	100%

4

Discussion

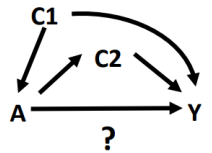
Challenges and opportunities to advance PCC

Summary of key findings

- HIV care cascade outcomes; 44%-50% of studies reported a positive effect of the intervention (remaining studies had no effect).
- Among studies reporting PCC-related outcomes with a comparison group, 100% reported at least one outcome with a positive effect of the intervention.
- Most studies included adults with few studies focusing on children (n=2) and KP (n=2)
- PCC-related outcomes were measured in 24% of studies with broad diversity in measurements and PCC-related outcomes.

Challenges/gaps

- Limited description of the intervention and understanding the mechanisms of how the interventions work
- Heterogeneity in outcome definitions and measurements
- Inconsistent inclusion of PCC-related outcomes-patient's voices often missing
- Few studies included key populations (n=2)



Opportunities to advance PCC

- Realist reviews with stakeholder engagement to better understand mechanisms to inform guidelines and policy
- Guidance on PCC-related outcomes and measurements to improve consistency, comparison, and application
- From PCC good practice statements to guidelines (how?)
- Inclusion of participatory research

Acknowledgement

- LIVE team
- Bill and Melinda Gates Foundation
- WHO
- IAS

April 27, 2023

Integrated person-centered care in HIV as a bridge to Universal Health Coverage

Dr. Ibou Thior | Senior Technical Advisor | PATH
Chris Collins | President & CEO | Friends of the Global Fight against AIDS, Tuberculosis, and Malaria

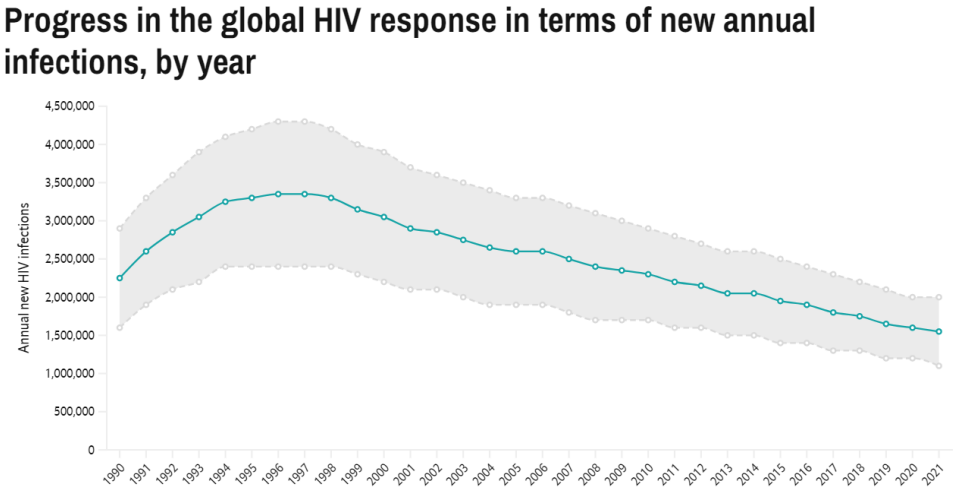
PATH

FRIENDS OF THE GLOBAL FIGHT

JSI

2030 global health goals → how do we get there?

- HIV response has pioneered service delivery strategies that work for diverse people in different settings.
- Despite gains, progress towards 2030 HIV epidemic control goals has stalled.
- Concurrently working towards ensuring all people can access affordable, equitable, non-discriminatory, and high-quality services through universal health coverage (UHC) by 2030.
- Call for investing in integrated person-centered care (IPCC) as a mechanism to get the HIV response back on track and forge a pathway towards UHC.



Source: UNAIDS. A triple dividend: The health, social and economic gains from financing the HIV response in Africa. 2023.

Understanding IPCC in HIV and its potential as a pathway to Universal Health Coverage

Questions we sought to answer

- How can HIV services better deliver IPCC that responds to the broader health care needs of people living with and affected by HIV?
- How can IPCC within the HIV platform be expanded to address other health needs and barriers hampering expansion?
- How can these identified models influence efforts to expand access to primary health care (PHC)?

How we answered them

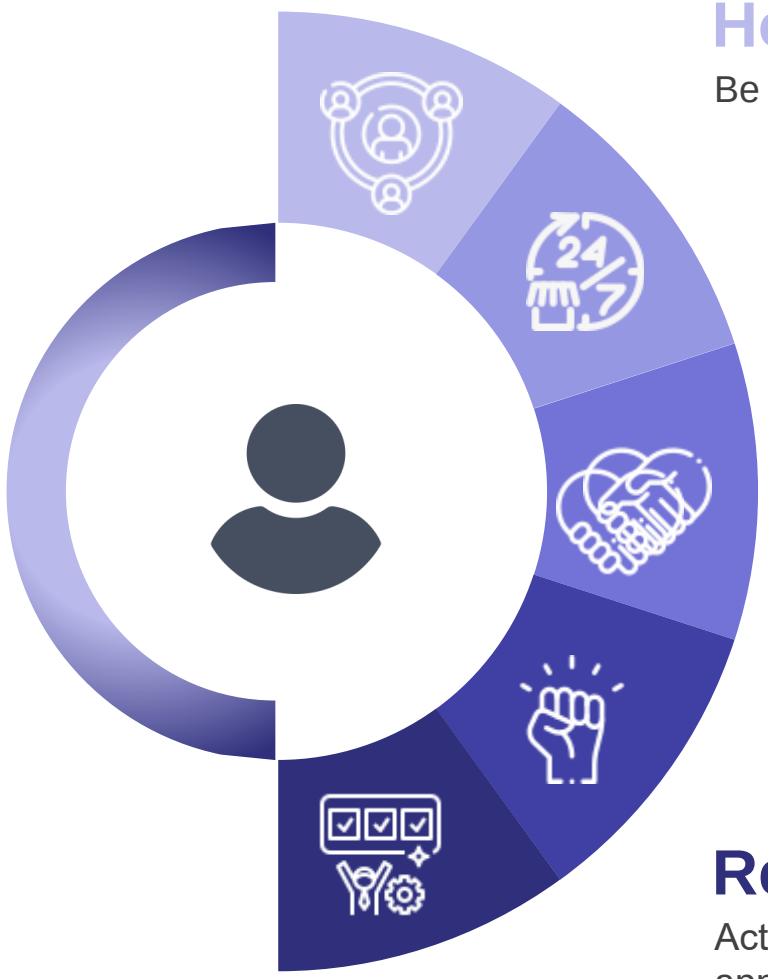
- Desk review → peer-reviewed scientific and grey literature on service integration and person-centered health service delivery approaches.
- Key stakeholder interviews

Multiple definitions → How are we defining IPCC?

Integrated person-centered care

We define IPCC to be "integrated care that is designed and delivered in a manner that is responsive to the broader health and wellness needs of individuals through their life course and tailored to reflect their preferences."

Key attributes of IPCC



Holistic

Be comprehensive, holistic, and coordinated.

Convenient

Prioritize individual convenience, making it for individuals to access needed services while reducing disincentives to avoid needing health care.

Respectful

Respect each individual's values and differences.

Empowering

Empower clients and their households and communities to participate actively in their own care.

Responsive

Actively solicit clients' feedback and adapt service approaches in response.

Lessons learned from delivering IPCC through the HIV response

What have we learned from applying IPCC to the HIV response?

When it comes to IPCC in HIV, one size does not fit all.

- Differentiated service delivery (DSD) → **Facilitates client choice** by providing menu of options for how, where, from whom, and when to receive services.
- Integration of HIV services in mainstream PHC systems improves access and satisfaction for some, but not all.
- Important to offer integrated service packages through specialized delivery channels for key and marginalized populations who are not well-served at public health/PHC facilities.

Improving the convenience of health services improves health outcomes.

Three approaches:

- **"One stop shop" models:** 1) integrate services in a single site; 2) use a multi-disciplinary team approach to offer various services.
- **DSD** through multi-month dispensing, decentralized dispensing at non-facility outlets, extended service hours, or community or virtual approaches for follow-up care.
- **Advances in health technology** that facilitate point-of-care diagnostics and offer multiple methods for delivering treatment or prevention.

Communities are essential partners in IPCC.

- **Community-led responses** are a key pillar in the HIV response; critical for mitigating health systems gaps.
- Communities play multiple roles to optimize the well-being of people living with or affected by HIV—accountability watchdogs, service providers, implementers, researchers, advocates, citizens.
- **Community contributions** need to be **recognized**; **further scaled** through human-centered design/co-design and community-led service delivery and monitoring; and **compensated**.

What have we learned from applying IPCC to the HIV response?

HIV can contribute to health service integration.

Two ways to integrate HIV and non-HIV services:

1) Non-HIV-specific services into HIV service delivery platforms: Example: Sexual health services, and screening and treatment for non-communicable diseases (NCDs) and viral hepatitis as part of care packages for people living with HIV.
2) HIV services into non-HIV-specific service delivery platforms: Example: HIV screening and linkage to care at family planning and reproductive health wards.

HIV response has strengthened health systems, enabling IPCC expansion.

HIV programming and investments have contributed to overall pandemic response and health systems strengthening:

- Upgrading health facility infrastructure
- Advancing laboratory, surveillance, and health information systems.
- Enabling multi-disease diagnostic platforms.
- Financing and training health care workers.

Proof point: HIV-financed infrastructure and platforms rapidly pivoted to contribute to COVID-19 response.

- Vietnam: Staff from key population-led/owned clinics providing HIV services rapidly pivoted to deliver COVID-19 vaccinations in government campaigns.
- India: The national HIV health information system provided a learning platform to rapidly gather client-level COVID-19 diagnoses in real-time.

Recommendations for scaling IPCC

How can we build on these lessons to scale IPCC?

Further scale up IPCC within HIV services.

Lack of metrics and mechanisms to measure progress towards and the degree to which services adhere to IPCC attributes and principles.

1

Further work to **make IPCC standard practice for HIV services** across all settings and populations, most critically for prevention (integrating HIV, sexual and reproductive health, and gender-based violence) and comorbidities, including NCDs and mental health.

Integrate services incrementally and learn by doing.

Rapid acceleration of HIV-related IPCC to other health areas could compromise the quality of HIV services.

2

Stepwise approach to scale IPCC beyond HIV, enabling programs to incrementally address core issues (financing, policy frameworks, client confidentiality, health worker skills building) sustainably without losing the unique attributes of HIV.

How can we build on these lessons to scale IPCC?

Monitor and use results to inform IPCC expansion.

Faltering progress towards global 2030 HIV epidemic control goals → slowdown in preventing new HIV infections and AIDS-related deaths driven by inequities.

3

1) Development of **indicators to measure IPCC**, including quality-focused indicators; 2) **Complementary mechanisms to measure progress** against IPCC indicators and facilitate client, provider, and community perspectives (community-led monitoring; service quality feedback mechanisms).

Recognize that service integration is not appropriate for all.

Services offered by public sector systems do not effectively address key and marginalized populations' needs, with many seeking services through other "non-traditional" models.

4

Need to **preserve and sustainably finance these dedicated, community-tailored systems** that exist outside the traditional public-sector system, while advancing service integration within these specialized channels.

How can we build on these lessons to scale IPCC?

Incentivize innovation in the scale-up of IPCC.

COVID-19 highlighted opportunities to further mainstream IPCC within HIV and broader PHC services.

5

Technological innovations and HIV DSD models introduced during **COVID-19 highlighted pathways for additional IPCC expansion**. Funders to **incentivize IPCC beyond HIV**, with IPCC-related metrics used for accountability and advocacy to ensure advancement.

Make new health investments to enable IPCC scale-up.

Relative lack of focused financing to address weaknesses in national health systems and cross-cutting systems platforms.

6

Added investments in key areas—workforce training, community-led responses, health information systems—to bolster the foundation for scaled IPCC, while allowing greater **flexibility in existing financing** streams and **leveraging of national health insurance mechanisms**.

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How can we build on these lessons to scale IPCC?

Prepare the health workforce to deliver IPCC.

Current health workforce (especially those financed by a vertical health area) tend to be specialized and have limited experience offering services in other areas.

7

Substantial and **sustained investment** in tailored and continuous **training, mentoring, and supporting** (technical [job aids; workflow tools]; and financial [incentives; improved pay]) clinic, community, and lay **health workforce** cadres.

Ensure transparent, inclusive engagement and governance.

Inadequate involvement of communities in designing, planning, monitoring, and demanding IPCC across all health areas.

8

1) Informing communities of the **tangible benefits of IPCC** and UHC; 2) Enhanced **processes for citizen engagement** in demanding IPCC; 3) Ensure **community representation at health policy decision-making bodies**.

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Three critical actions to fully realize the promise of IPCC

Invest in the health workforce:

The health care workforce is essential to success, pointing to the importance of training and ongoing support to enable health workers to own and carry forward the additional tasks required for IPCC.

Strengthen and support community responses:

Community systems need sufficient resources to play their critical role in IPCC, serving as a liaison between communities and health facilities and having the capacity to move quickly in the event of a health emergency.

Use monitoring to improve service quality:

Routine client feedback systems must be in place and used to improve the quality, fit and impact of health services.

FRIENDS
OF THE GLOBAL FIGHT

HIV updates:
Strategies for long-term success

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

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@JVLazarus

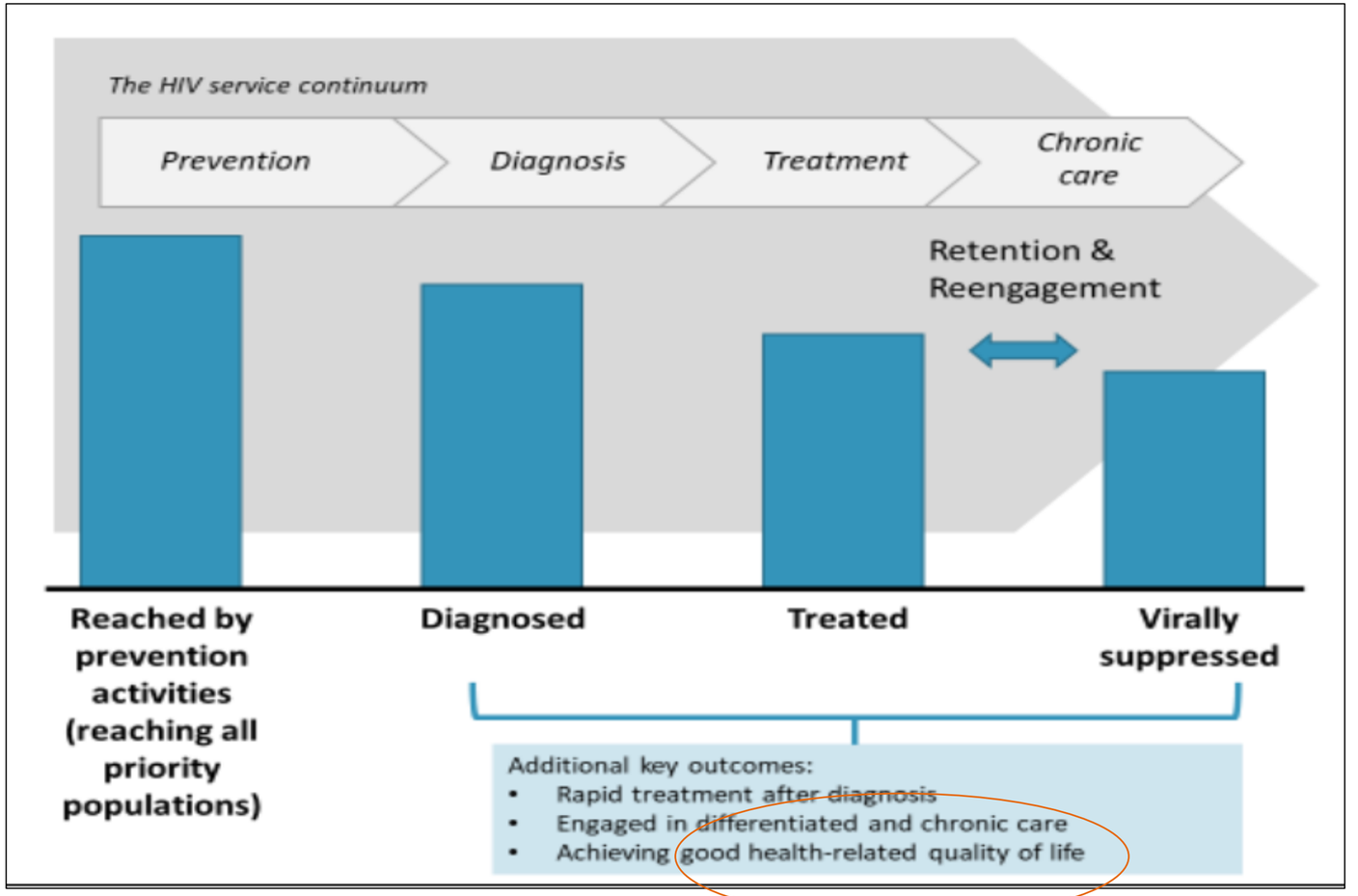
WHO Global health sector strategy on HIV for the period 2022–2030

- 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

ART, antiretroviral therapy; HRQoL, health-related quality of life; NCD, non-communicable disease.

Source: WHO. The 2022–2030 global health sector strategies on, respectively, HIV, viral hepatitis and sexually transmitted infections. Published 18 July 2022. Available at: https://apps.who.int/iris/rest/bitstreams/1451670/retrieve [Accessed July 2022].

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

HRQoL, health related quality of life; WHO, World Health Organization.
Source:. Lazarus JV et al. *JIAS Viewpoint* 2022 (submitted).

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

Focus on ART and viral suppression

Focus on long-term well-being and HRQoL

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

nature COMMUNICATIONS

PERSPECTIVE

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

Check for updates

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

Jeffrey V. Lazarus[1✉], Kelly Safreed-Harmon[1], Adeeba Kamarulzaman[2,3], Jane Anderson[4], Ricardo Baptista Leite[5], Georg Behrens[6], Linda-Gail Bekker[7], Sanjay Bhagani[8], Darren Brown[9], Graham Brown[10], Susan Buchbinder[11], Carlos Caceres[12], Pedro E. Cahn[13], Patrizia Carrieri[14], Georgina Caswell[15], Graham S. Cooke[16], Antonella d'Arminio Monforte[17], Nikos Dedes[18], Julia del Amo[19], Richard Elliott[20], Wafaa M. El-Sadr[21], María José Fuster-Ruiz de Apodaca[22,23], Giovanni Guaraldi[24], Tim Hallett[16], Richard Harding[25], Margaret Hellard[26], Shabbar Jaffar[27], Meaghan Kall[28], Marina Klein[29], Sharon R. Lewin[30,31,32], Ken Mayer[33], Jose A. Pérez-Molina[34], Doreen Moraa[35], Denise Naniche[1], Denis Nash[36], Teymur Noori[37], Anton Pozniak[9,38], Reena Rajasuriar[2], Peter Reiss[39], Nesrine Rizk[40], Jürgen Rockstroh[41], Diana Romero[36], Caroline Sabin[42], David Serwadda[43] & Laura Waters[44]

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.

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.

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

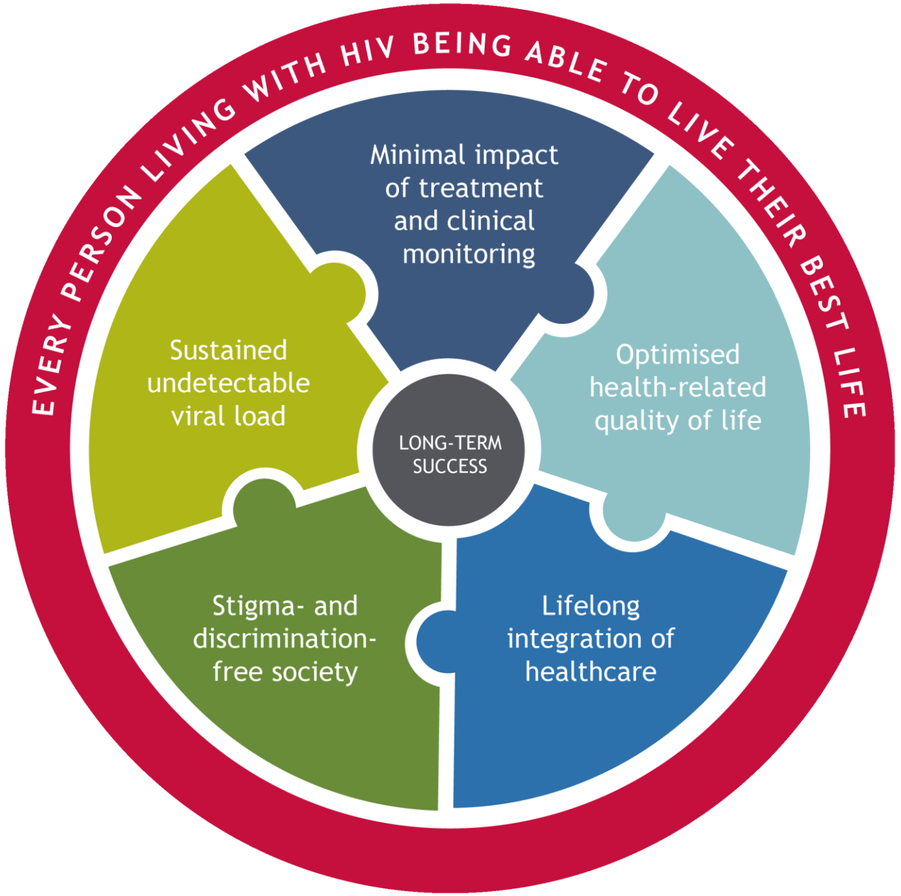
Box 3 | Key next steps for health systems to advance the long-term well-being of people living with HIV

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.

HRQoL, health-related quality of life; PLHIV, people living with HIV.
Source: Lazarus JV et al. *Nat Commun* 2021;12(1):4450.

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***.



Sources: 1. Lazarus JV, *et al.* Long-term success for people living with HIV: a framework to guide practice. *HIV Medicine*, in press 2023. DOI: 10.1111/hiv.13460
2.Fuster-RuizdeApodaca M, *et al.* Why we need to re-define long-term success for people living with HIV. *HIV Medicine,* in press 2023. DOI 10.1111/hiv.13460

Five pillars were identified by the expert panel that support the vision for LTS [1,2]

		Desired outcome
1	**Getting viral load to undetectable** was identified as the primary treatment goal	**Sustained undetectable viral load**
2	**Treatment-related factors and excessive clinic visits** were identified as the **most notable burden of living with HIV**	**Minimal impact of treatment and clinical monitoring**
3	**Maintaining "optimal" health-related QoL** was identified as **an important goal for people living with HIV**	**Optimised health-related quality of life**
4	**Consistency of care** among different HCPs was identified as **a key factor** in improving healthcare outcomes	**Lifelong integration of healthcare**
5	**Stigma and discrimination** were identified as **key barriers** to achieving optimal healthcare outcomes for people living with HIV	**Freedom from stigma and discrimination**

HCP, healthcare professional; HIV, human immunodeficiency virus; LTTS, long-term treatment success; QoL, quality of life.

Sources: 1.Lazarus JV, et al. Long-term success for people living with HIV: a framework to guide practice. *HIV Medicine,* 2023. DOI: 10.1111/hiv.13460
2.Fuster-RuizdeApodaca M, et al. Why we need to re-define long-term success for people living with HIV. *HIV Medicine*, 2023

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

PREM, patient-reported experience measure; PROM, patient-reported outcome measure.

Source: Lazarus JV et al. *JIAS Viewpoint* 2022 (submitted). 2. WHO. The 2022–2030 global health sector strategies on, respectively, HIV, viral hepatitis and sexually transmitted infections. Published 18 July 2022. Available at: https://apps.who.int/iris/rest/bitstreams/1451670/retrieve [Accessed July 2022].

Acknowledgements

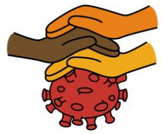
Everyone *who has contributed to the cited slides, the WHO Global Health Sector Strategy on HIV team*.

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

Contact: Jeffrey.Lazarus@ISGlobal.org

INTE-AFRICA
INTEGRATING AND DECENTRALISING HIV, DIABETES AND HYPERTENSION SERVICES

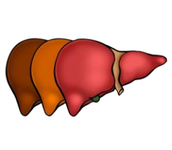


ENDING THE COVID-19 PANDEMIC AS A PUBLIC HEALTH THREAT

HBV COMSAVA

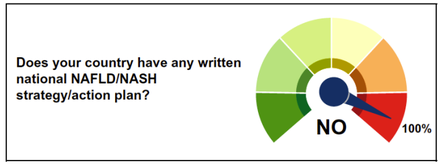
Hepatitis C
Free Balears

NOhep
Hepatitis C micro-elimination



VIRAL HEPATITIS COMSAVAC

Multi-Country Community Screening, Vaccination, and Care



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

Center for Outcomes Research in Liver Diseases

ALIANZA PARA LA ELIMINACIÓN DE LAS HEPATITIS VÍRICAS EN ESPAÑA

HIVOutcomes BEYOND VIRAL SUPPRESSION

COALITION FOR GLOBAL HEPATITIS ELIMINATION

EASL The Home of Hepatology

ICE-HBV International Coalition to Eliminate HBV

NOBODY LEFT OUTSIDE Improving healthcare access for marginalised people

CUNY SPH GRADUATE SCHOOL OF PUBLIC HEALTH & HEALTH POLICY

@JVLazarus

PCC Stakeholder Consultation Series

Session 2 - 27 April 2023

What is the evidence supporting a person-centred care approach within the HIV response?

Person-Centred Care

With support from: GILEAD

IAS

Order of Events

1. **PCC Personal Stories**
2. **Presentations (25 mins)**
   - Overview of PCC frameworks and WHO guidance
   - Evidence on PCC-related interventions
   - Advances in PCC within HIV programming and other health areas
   - Strategies for long-term success
3. **Breakout group discussions (15 mins)**
4. **Report back and moderated discussion (20 mins)**

Moderator:
Laura Beres

Reflections on PCC personal stories

Daisy Kwala, health rights activist and counsellor, Bar Hostess and Empowerment Support Programme, Kenya

Charmaine Chu, registered psychologist, Xavier University, Ateneo de Cagayan University, Philippines

Rodenie Olete, registered nurse, National Cheng Kung University, Taiwan, Republic of China

Viral suppression NO LONGER is the MOST important, in USA for older PWH but comorbidities are NOW MOST IMPORTANT, not viral suppression.

WE NEED BETTER CARE in CLINIC for OLDER PWH !!!!!!!

I put aging in USA NHAS.

We elderly PWH are worried about alzheimers.

PCC is aimed to provide an all-inclusive approach when it comes to management of HIV. Aspects included: psychological, economical well-being, education

We have 23 aging/HIV clinics in USA.

in USA all medical visits are now 20 minute. An elderly PWH cannot get the care they need in 20 minutes.

Optimal ACCESS is critical to us elderly PWH >65. We do not have good & optimal care. The clinics in NY & USA are very constricted and hard to get care needs met for PWH >65.

I am 73 yr old PWH with multi-comorbidities including declining physical function. I cm tell you once your health declines care is ALL that matter.

Great to hear from healthcare providers as well as clients

I helped create these aging/HIV clinics.

what about self-support and peer support?

Support by care clinic is MOST important.

Good care for PWH >65 is MOST critical. Care is horrible for elderly PWH.

There are no mental health care services available.

Eldery PWH >65 need priority in getting good care.

Thank you for highlighting mental health needs!

Clinics are NOT providing good care to elderly PWH

Good care from clinic is more important than peer support.

There is geriatric testing in clinics: bone mineral density, cognitive impairmemt, frailty.

Elvin Geng

Overview of PCC frameworks and WHO guidance on PCC

Questions:

Patient-centered vs. person-centered vs. people-centered --> curious to get a better understanding of the implications of each term and when each should be used.

How do we accommodate the different interpersonal aspects of patients to meet the threshold of PCC?

How do we deal with PCC HIV in different countries as we have exchange programmes in our countries and being in a country with strong relation with the country i am country i

One of the articles shown in the slides differentiated between patient-centered care (individual) vs. people-centered care (systems)--helpful to see this nuance

I would want to know what is in the PCC for health professionals living with HIV to stop stigma and discrimination? As well as sometimes harassment and bullying from HIV prof

New Thoughts Provoked:

Good to see Santana model mentioned, some update on it here: https://pubmed.ncbi.nlm.nih.gov/33303515/

Which role for lay stakeholders such as peer educators that are badly or not paid at all? And not considered....

I agree with the cyclical impact of structural factors and the actors/service providers

From Nyarayi Hwayire in chat: How do we deal with PCC HIV in different countries as we have exchange programmes in our countries and being in a country with strong relation with the coun

From Nyarayi Hwayire in chat: i would want know what is in the PCC for health professionals living with HIV to stop stigma and discrimination? As well as sometimes har

ONCE A PWH gets to be 65 & has multi-comorbidities better care is all that matters !!!!! Care is horrible or older PWH in NYC & USA.

NH in chat: Stressing PCC data and confidentiality. In the PCC understand consent and when PLHIV refuses interventions. I am mainly focusing on Health professionals li

From NH in chat: I am mainly focusing on Health professionals living with HIV treatment in work places at health setting. Direct discrimination and indirect discriminatio

Marie-Claude Lavoie

Evidence on PCC related interventions for people living with HIV in low and middle-income countries

Questions:

For countries with limited staff-client ratios, how can health providers maintain quality interactions with clients while meeting workload deliverables?

What is in the PCC framework in terms of surveillance and control of health professionals living with HIV rights and wrongs

Which size are the effects when positive on the several steps of the cascade? Significant but large enough?

Very good point. We will include this detailed information in the systematic review so readers can see the effect size and confidence interval.

New Thoughts Provoked:

Real great review - v helpful to understand helpful activities. It would be great to better understand some of the mechanisms of action- HOW are outcomes achieved?

Yes, I agree! It will be the next part of the work related to this systematic review.

Good to also learn about implementation- what encourages staff to "act differently"?

There is indeed a need for more participatory research to improve PCC interventions.

I agree!

We need better care or elderly PWH >65. Good care is not there for older PWH. Elderly & older PWH withcomorbidities need better care. Viral suppresion is not that important.

Thank you for your comments. We will look more closely at the age groups included in the study population and highlight this gap if identified.

Ibou Thior & Chris Collins

Advances in PCC within HIV programming and in other health areas, as a bridge towards primary health care and universal health coverage, including a discussion on barriers to implementing PCC

Questions:

Thank you for emphasizing "co-location" as an important factor of PCC. Do we have studies explaining the cost-effectiveness of co-located services?

New Thoughts Provoked:

All older PWH need geriatric screenings: bone mineral testing, frailty, cognitive impairment & BETTER CARE.

We need aging/HIV clinics which provide geriatric care all over globe

In USA we now hsve 23 aging./HIV clinics. Which I plyed key role in implementing. Colocation of care is critical

Mental health care & services re absent in HIV clinics

On behalf of global health, HIV specific responses are under attack!

Jeffrey V. Lazarus

HIV updates: Strategies for long-term success

Questions:

I am based in NYC & the care is horrible for older & worse for elderly PWH.

Why are you not talking about greater needs of older PWH ?

20 minute visits are mandated & an older PWH CANNOT get the care they need & clinics are getting more & more constricted.

HRQL is multidimensional : which dimensions should be reasonnably improved with Person centered care?

What effective strategies are done to eliminate stigma and discrimination in traditional countries?

New Thoughts Provoked:

the elderly PWH >65 are the most at risk & need the most improved care.

Interact on these notes & add your own!

Implementation: reluctance of implementers in mainstreaming other health needs of PLHIV

i (integrated) in the iPCC

Building trust and knowing providers and clients well.

Which elements of the PCC framework resonate with you for the HIV response?

Challenge of acceptability of PCC from the perspectives of health providers. Lacking evaluation tools in checking PCC's feasibility for HCPs.

centering on the person. holistic care. understanding day-in, day-out it's a journey over a life. needs do and will change. barriers are real. consider social determinants.AskQtns

What is missing from the frameworks?

Challenge of acceptability of PCC from the perspectives of health providers. Lacking evaluation tools in checking PCC's feasibility for HCPs.

Need for interprofessional guidance to make healthcare professionals work together, across health areas and integrate.

Last campaign for HIV awareness was 30 years ago in Italy

We don't get ANY support from the government here in Italy

Frameworks are missing guidance for healthcare professionals living with HIV

Access to care for migrants!! We in Europe can access ART but what about migrants to Europe.

Barriers to funding from faith based organizations that ideologically oppose our way of life

Emphasis on changing the work culture to promote PCC (health system factors)

Sustainability of funding is a BIG issue. Too much PROJECT based funding

include/consider the individual's Cultural determinants of health and wellbeing (see research by Prof Lovett, https://researchers.anu.edu.au/researchers/lovett-rw)

Very good point. We will include this detailed information in the systematic review so readers can see the effect size and confidence interval. Most studies had a significant effect.

Only half improved cascade but by how much?? Are the effects still significant!!?

Very good point. We will include this detailed information in the systematic review so readers can see the effect size and confidence interval. Most studies had a significant effect.

What does the evidence tell us about the contribution of person-centred care approaches to improved well-being and health outcomes for people living with and affected by HIV?

Service integration guidance is needed

PCC-related outcomes and measurements

What are the current research gaps?

Stigma & discrimination remain as the barrier, especially within the healthcare setting.

Service integration

Other integrated health services might still be inaccessible if S&D remains. Measurable processing and addressing S&D should be developed.

Operationalizing PCC for practice and policy

Confidentiality and data protection

What priorities are emerging for person-centred care within the HIV response?

There has been no discussion about research investments for PCC interventions for the children adolescents who are disproportionately more unsuppressed in Africa

What does the evidence tell us about how to best operationalize person-centred care and does this differ depending on context and sub-populations?

Other reflections:

IAS

PCC stakeholder consultation series

	When	Topic
1	AIDS 2022	Person-centred care approaches to improve quality of life for people living with and affected by HIV
2	27 April 2023, ZOOM	What is the evidence supporting a person-centred care approach within the HIV response?
3	25 May 2023, ZOOM	What are the service delivery considerations for providing integrated person-centred care for people living with or affected by HIV throughout their life-course?
4	22 June 2023, ZOOM	What are the core elements and mechanisms for person-centred care within the HIV response and for different stakeholders?
5	IAS 2023	Interactive in-person workshop to prioritize the content for the consensus statement.

IAS

Meeting 3: What are the service delivery considerations for providing integrated person-centred care for people living with or affected by HIV throughout their life course?

Meeting objective

To reflect on the practical service delivery considerations for delivering integrated person-centred care services, as well as the role of client-reported outcomes and quality of life measures.

IAS

Meeting 3: 25 May 2023

Discussion questions

1. What actionable feedback can we provide to healthcare workers and health system administrators on clients' needs and preferences?
2. At the policy and financing level, what measures should be considered to promote person-centred care approaches?
3. What type of demand-creation and awareness-raising activities (Including about client rights, existing services and eligibility criteria for different services) should be implemented to support clients in taking informed choices about their health?
4. What can we learn from the development of differentiated service delivery frameworks and their implementation?

Thank you for your participation