



Human-Centered Design Lessons for Implementation Science: Improving the Implementation of a Patient-Centered Care Intervention

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Background: Evidence-based HIV interventions often fail to reach anticipated impact due to insufficient utilization in real-world health systems. Human-centered design (HCD) represents a novel approach in tailoring innovations to fit end-users, narrowing the gap between efficacious interventions and impact at scale.

Methods: We combined a narrative literature review of HCD in HIV programs with our experience using HCD to redesign an intervention promoting patient-centered care (PCC) practices among health care workers (HCW) in Zambia. We summarize the use and results of HCD in the global HIV response and share case study insights to advance conceptualization of HCD applications.

Results: The literature review identified 13 articles (representing 7 studies) on the use of HCD in HIV. All studies featured HCD hallmarks including empathy development, user-driven inquiry, ideation, and iterative refinement. HCD was applied to mHealth design, a management intervention and pre-exposure prophylaxis delivery. Our HCD application addressed a behavioral service delivery target: changing HCW patient-centered beliefs, attitudes, and practices. Through in-depth developer–user interaction, our HCD approach revealed specific HCW support for and resistance to PCC, suggesting intervention revisions to improve feasibility and acceptability and PCC considerations that could inform implementation in transferable settings.

Conclusions: As both a research and implementation tool, HCD has potential to improve effective implementation of the HIV response, particularly for product development; new intervention introduction; and complex system interventions. Further research on HCD application strengths and limitations is needed. Those promoting PCC may improve implementation success by seeking out resonance and anticipating the challenges our HCD process identified.

Key Words: HIV, human-centered design, implementation, Zambia

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INTRODUCTION

Although today's public health response to HIV has a robust set of evidence-based tools with which to address the global epidemic [eg, antiretroviral therapy (ART), pre-exposure prophylaxis (PrEP), and voluntary medical male circumcision], implementation has failed to achieve the tools' full preventive and therapeutic potential.¹ Failures of implementation often result from inadequate fit between available innovations and the people, processes, and contexts in which they are delivered. Although an emergency-based response focusing on access largely drove HIV service delivery strategies over the past three decades, future success depends on more effectively engaging end-users with appropriate, desirable, and accessible services.^{1,2} For example, although ART is lifesaving, both treatment initiation and retention remain suboptimal, leading to onward transmission,

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morbidities, and mortality.³ These gaps demand alternative and innovative treatment delivery models—drawing from interdisciplinary perspectives—for advancing the public health response.^{4,5}

Human-centered design (HCD) is an emerging approach with roots in industrial design, engineering, psychology, anthropology, business, computer science, ergonomics, and design that hold promise for improving implementation of evidence-based interventions for health. HCD brings end-users and developers together to cocreate health products, services, or delivery strategies that identify, prioritize, and address barriers to usability.^{6–8} Traditionally, HCD focused on product development using participatory activities emphasizing researcher and user interaction to improve intervention utility, uptake, sustainability, and effectiveness.^{7–9} Although no single definition of HCD in health exists,⁶ there are hallmarks present across HCD applications^{7–9} (Table 1). HCD uses methods likely familiar to social scientists working in health^{8,10–13} but emphasizes bringing the researchers and users together in a more empathetic way, generating breadth and flexibility in the investigation and prioritizes action over furthering scientific knowledge (Table 1, Tolley⁸).

Despite a growing literature on HCD in health,⁶ no synthetic appraisal of HCD in the public health HIV response yet exists. In this article, we seek to advance the conceptualization of the use of HCD to address HIV through both a literature review and a case study of our own experience using HCD methods to advance patient-centered care (PCC) in HIV treatment in Zambia.^{14–17} The literature review summarizes the following: (1) outcomes to which HCD has been applied, (2) methods used, (3) results and effectiveness, and (4) lessons learned. We present HCD-derived case study insights that could be informative to others seeking to optimize the delivery of PCC HIV interventions in transferable contexts. In addition, we hope this article will call attention to opportunities to advance HCD as a tool for adapting implementation strategies to particular contexts and end-user populations to strengthen the public health response to HIV.

METHODS

Literature Review

We conducted a narrative literature review^{18,19} of published articles and the grey literature on HCD in the global HIV response. Article inclusion criteria are as follows: (1) published through the search date of May 22, 2019, (2) related to HIV, and (3) presented data on HCD. Articles were excluded if they did not describe a design process or if they explicitly attributed their methods to non-HCD methodology (see Appendix 1, Supplemental Digital Content, <http://links.lww.com/QAI/B389>, PubMed search strategy). To identify the grey literature, we conducted targeted searches of websites from 3 HCD design leaders⁶ and another organization using HCD for health known to the authors, including any HIV-related cases on the website as of the search date. Case studies not articulating HCD methods or results were excluded. LB screened identified titles, abstracts, and case summaries using the inclusion criteria. LB and AB reviewed relevant full-text articles, abstracting the study author,

participants and setting, HCD methods described, results, strengths, limitations, and lessons learned.

Human-Centered Co-Design Workshop

We supplement the literature review with our experience applying HCD to shape a PCC intervention. The “Person Centred Public Health for HIV Treatment in Zambia Study” (PCPH) is a stepped wedge, cluster-randomized trial of a PCC

TABLE 1. Summarized Key Elements of a HCD Process*

HCD Element	Brief Description
Empathy development	Meaningful understanding and appreciation of user priorities, strengths, needs, and context through interaction between users, user influencers, and developers of the product/process/intervention of interest. Cultivation of empathy runs throughout the other elements.
Creativity	HCD uses nonstandard research approaches that can include visual, narrative, and bodily engagement focused on exploration and problem-solving. These techniques help designers to surface insights and innovations that might be otherwise difficult to capture.
Co-design/user-guided investigation	The investigative goal is to understand the user context and the holistic user experience with the product/process/intervention of interest. This is performed through active collaboration between developers and end-users to generate context-relevant insights and solutions. User-focused research proactively supports identification of user ideas, assets on which to build, and capacity for change instead of focusing exclusively on challenges or reactively identifying feedback and preferences. It intends to promote trust, cooperation, and ownership of solutions among users. Engaging a broad range of user and influencers perspectives, as well as openness to exploration throughout the design process, promotes essential breadth of investigation.
Identification of actionable insights	The investigation is generally guided by open-ended questions (such as those in the “how might we...” format ⁹) related to the design topic of interest and informed by existing knowledge or research. The investigation is conducted using participatory activities, some of which are familiar to SBR and many of which are discussed in examples of HCD toolkits ⁹ and reports. ¹⁴ Rapid documentation of learning throughout the HCD process using notes, visual representations, and other media. Rapid reflection on documented insights (1) informs new questions to guide the investigation, (2) generates valued, contextually appropriate solutions, and (3) rapidly refines solutions.

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TABLE 1. (Continued) Summarized Key Elements of a HCD Process*

HCD Element	Brief Description
Rapid ideation & iteration	Building on insights, rapidly generate numerous ideas that address the priorities identified during the investigation. Prioritize actionable ideas and create product/process/intervention prototypes for further feedback or testing with users (ideally supporting rapid failure cycles, enabling rapid learning and adaptation). Refine solutions based on user feedback and re-test for implementation. This allows designers to embrace intuition and spontaneity, exploring the margins of what may be feasible in practical implementation.

*No single, accepted definition of HCD in the health context exists.

intervention to improve HIV patient retention in care in Lusaka, Zambia, starting in mid-2019 implemented by the Centre for Infectious Disease Research in Zambia (CIDRZ), a partner to the Ministry of Health in HIV service provision since 2003. Our previous research in Zambia identified poor patient-provider interactions²⁰⁻²² and a desire for differentiated care delivery options^{20,23} as drivers of poor retention, with high health facility-level variability.²⁴ In response, the PCPH study’s intervention was conceived to comprise (1) training of health care workers (HCW) in the principles and practices of

patient-centeredness; (2) collecting and sharing data with HCW on the patient experience at the health facility; (3) HCW coaching; (4) supporting facility-level quality improvement; and (5) incentives for improved practice.

Before trial implementation, we undertook a pilot study implementing elements 1–3 of the planned intervention in 2 facilities to understand the context and test and refine the intervention. We conducted formative research on intervention components using interviews and focus-group discussions (FGDs). We then held a 5-day HCD workshop to engage HCWs who experienced the pilot in co-design activities to further refine the study intervention. Key HCD workshop strategies included the following: (1) developers cultivating empathy with HCWs and learning from insights and experiences, (2) developers and HCWs collaborating in investigation and creative problem-solving, and (3) defining actionable approaches for intervention improvement. Drawing on previous research and pilot findings, we defined 3 “How Might We...?” questions⁹ (HMW) to guide the workshop:

- Coaching: How might coaches be best positioned in health facilities to guide and support HCWs in delivering PCC according to best practices and in ways that are appropriate to facility context?;
- HCW support and motivation: How might we foster a workplace culture that empowers and motivates health care providers to provide PCC?;
- Information management: How might we make new and existing information on patient experience and patient

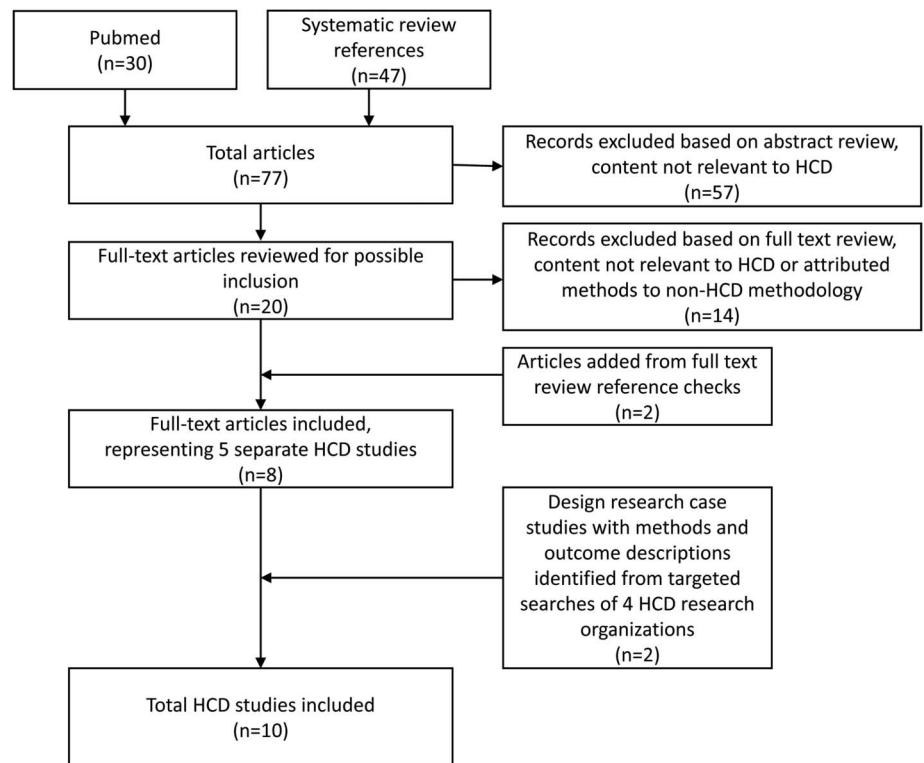


FIGURE 1. Narrative literature review HCD study inclusion.

TABLE 2. Literature Review Results on Use of HCD in HIV

Author & Year	Participants & Setting	Study Design	HCD Goal	HCD Methods	Results of HCD Design Process	HCD Strengths	HCD Limitations	Key Lessons/ Guidance
Bautista-Arredondo et al. ²⁷ 2018	32 Society for family health or USAID-funded community-based organizations (CBOs) serving female sex workers with HIV prevention services, 14 Nigerian states	Qualitative formative design phase; cluster-randomized control trial protocol to assess the impact of a management intervention on costs of HIV services for FSWs in Nigeria	To inform the creation of the management intervention to improve service delivery efficiency	4 phases: (1) “empathize” with the user, (2) “define” the issue, (3) “ideate” or brainstorm solutions, and (4) “prototype” 1) collect and review management journals of activities and challenges; conduct key informant interviews; and non-participant observations at the CBO sites 2) reviewed and organized findings: distilled them into “insights”; mapped challenges, opportunities and insights to program planning and implementation 3) brainstormed >20 “prototype” intervention components 4) tested prototypes in 3 focus group discussions (FGDs); used FGDs to finalize intervention	Key priorities for CBO managers, staff, and volunteers included “meeting targets, funding constraints, and complications in transportation and communication” Results by domain: Domain: planning & training Activities: mapping, goal setting, recruitment, advocacy Insight: leaders who are more engaged catalyze greater volunteer commitment Opportunity: collaborative goal setting Domain: execution & implementation Activities: education, testing, referrals, field monitoring Insight: It is hard for volunteers to communicate constantly changing schedules Opportunity: improve communication link and connection between volunteers and CBOs Domain: closing & reflection Activities: Behavior maintenance, follow-up, monthly reporting Insight: Officers feel framework constrains actionable feedback Opportunity: Create feedback opportunities, reward accomplishments			Design thinking helped to define needs the intervention should address and identify opportunities the intervention could leverage.
Catalani et al. ²⁸ 2014	24 AMPATH health facilities, Western Kenya	Mixed qualitative and quantitative methods design phase: impact evaluation of clinical decision support tool to integrate TB and HIV care (described elsewhere)	To explore, refine, and deliver a decision support system to improve the proportion of eligible HIV patients starting TB isoniazid preventive therapy (IPT)	3 phases: hear, create & deliver Hear: site observation sessions & key informant interviews; Create: Laboratory simulation testing with mock patients & in-context clinical usability prototype testing Deliver: roll out of second version of clinical decision support system & impact evaluation	Hear: Understood clinician’s IPT attitudes, knowledge & practices; clinician’s perceptions of information systems, available clinical IPT case-finding resources Create: Iteratively achieved zero-error accuracy of decision support system for mock patients; gained usability insights into the decision support system’s data, algorithm, content, and medium of delivery. Assessed understandability, importance, helpfulness, and practicality/ feasibility of IPT messages, and accuracy and actionability of support system, identifying gaps in knowledge and other barriers. Deliver: Delivery included addressing technology systems requirements including using a paper-based system; clinical requirements; and provider knowledge.	HCD facilitates communication and consensus, which may support process implementation. HCD can improve adoption and usability.	Purposive sampling limits generalizability; possible reporting bias of qualitative data about a program perceived to be supported by employer	1) The HCD approach encouraged iterative efficacy and safety testing of an m-health tool. It engaged key stakeholders and end users. This resulted in an end process requiring minimal changes to current workflows that was readily embraced. It identified the limitations and opportunities of the decision support tool as originally conceived. 2) While perhaps not generalizable, lessons applied across a large health system and may be transferable within other similarly resourced health systems. 3) “... the process of engaging stakeholders may be particularly helpful in gaining the trust, buy-in, and permission needed to implement change within a complex health system”

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TABLE 2. (Continued) Literature Review Results on Use of HCD in HIV

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Erguera et al, ³¹ 2019	Young people (18–29 year old) living with HIV, San Francisco Bay area, CA	Theory-guided formative design research and design of feasibility and acceptability trial	To develop an mHealth application (app) for improved engagement in HIV care and ART adherence among youth living with HIV (YLWH)	The intervention design was guided by the information, motivation, behavioral skills (IMB) SBR model. Design steps included: systematic literature review, interviews, focus group discussions and surveys with YLWH; interviews with health care providers for YLWH. The research was conducted by YLWH, health care technology consultants, mobile developers, and study co-investigators. Used agile methodology, conducting incremental, iterative development cycles, adjusting the app design at the end of each design "sprint." Conducted a 10-week field test of the initial application with 2 study team members, 8 YLWH who reported bugs, crashes and suggested modifications and reflected during a focus group discussion. Conducted interviews with the health care providers of 2 pilot testers to understand ideal health care provider and app-user interactions.	Built a native mobile app with 3 modules: 1) My health: Formative research showed "the importance of user's desires for keeping track of their medication information, visualizing their adherence and laboratory data and understanding their health" 2) My team: Formative research showed that "providing resources and facilitation of communication with health care team members can improve retention in care" 3) My community: formative research showed that "social support from peers, connecting with community resources and staying up-to-date on health-related news from the research community are important for YLWH" The field test and subsequent qualitative research lead to the creation of version 2.0 to address suggested refinements.	HCD allows for iteration and adjusting to dynamic changes to requirements; increases potential acceptability and impact	Design of the app with YLWH in the San Francisco Bay area may limit generalizability to other settings.	
Ramos et al, ³² 2017	25 English-speaking patients seeking HIV care at an urban, academic, hospital-based clinic in New York City, NY, that provides care to patients with federal and state medical coverage	Mixed qualitative and quantitative methods	To design and test the usefulness, ease of use, preference, and comprehension of a health information exchange e-consent user interface (UI)	1) Five semi-structured interviews presenting four e-consent (UI) icon prototypes and simplified text for each consent topic to facilitation discussion. Patient feedback analyzed from interview transcripts informed the iterative UI design. 2) 20 patients randomly completed either the UI or the paper consent process first, followed by the other consent. Participants then completed a 4-item Likert scale survey and a semi-structured interview to gauge comprehension, perceptions and preferences. Surveys were analyzed using descriptive statistics and interview transcripts using thematic analysis.	1) Four iterations of the e-consent UI prototype were created with the icons selected from the participant interviews. UI creation was also guided by Wilbanks' three-layered stacked approach to electronic application design, Mayer's multimedia principles and a heuristic assessment. 2) There was not a clear majority preference for either consent approach. Comprehension about health information exchange (HIE) sharing remained poor for several participants and may suggest the need for human interaction in the consent process.		It is important to integrate patients into the design of an HIE e-consent UI early in the process, as their feedback changed prototypes.	
Schnall et al, ^{33–36} 2015, 2016	English or Spanish-speaking, HIV positive persons aged 13–65 years, New York City, NY	Mixed qualitative and quantitative methods guided by the information system research framework (ISR)	Usability evaluation of an HIV self-management application (app) and creation of a design document for a health management app for PLWH	Series of participatory user-centered design activities: Cycle I, the relevance cycle: Focus group discussions with 50 participants to identify desired features in app ³³ Cycle II, the rigor cycle: Systematic review of literature and ecological scan of apps Cycle III, part 1, the design cycle: Design session I—5 participants, discussion of FGD results to inform prototype of app, design session II—6 participants, sketched user interface for app, reviewed and commented on features of existing apps, discussed app preferences ³⁴ Cycle III, part 2, the evaluation cycle: Expert Heuristic evaluation of 8 use cases for app by 5 expert informaticians; usability testing of 8 use cases by 10 PLWH ³⁵	Cycle I: Identified 5 categories of functional requirements for the app: my information management, managing my medication, staying healthy, provider communication: Provider & peer, resources. Suggestions for tools and other functionalities to include such as reminders, lab tracking, notes, chat boxes, and others. Cycle II: guided theories and methods used to design and evaluate design document Cycle III, part 1: Identified content, features, and usability factors that would increase likelihood of app use; created prototype of user-interface based on whiteboard designs, created map of screen order in app Cycle III, part 2: 77 changes made to mock-ups of app guided by experts, 83 changes made to mock-ups of app guided by user recommendations; final design document created	Identifying end-user needs can improve app usability. ³⁶ Findings likely transferable to populations that are similar to the involved users. ³⁶	Findings likely not generalizable. Methods used cannot determine effectiveness. ³⁶	Process allows for addressing end-user feedback and expert opinion in the app development. This can increase ease of use and utility. ³⁶

TABLE 2. (Continued) Literature Review Results on Use of HCD in HIV

Author & Year	Participants & Setting	Study Design	HCD Goal	HCD Methods	Results of HCD Design Process	HCD Strengths	HCD Limitations	Key Lessons/ Guidance
EMOTION, ^{29, 30, 39} 2017	Recruitment focus: Young women aged 18–30; participants also included men, health care workers, traditional healers, CAPRISA clinical trial staff members, and sex workers, South Africa	Mixed methods, sequential study design using HCD. Aim 1: microbicide product design Aim 2: product manufacturing and message pilot testing Aim 3: sociobehavioral study comparing the HCD branded experience product to unbranded product and standard of care experiences Aim 4: pilot test introduction and outreach for PrEP/microbicides	Design question: how can design create an experience that makes women want to use HIV prevention products like microbicides?	Aims 1 & 2: 10 phases 1: Ideation—Selected 8 dosage forms, used HMW questions to develop 3 design directions, designed prototypes and materials 2: Design research—spoke with people using developed tools including in-depth interviews, end-user feedback on prototypes 3: Strategy—1 wk debriefing and sense-making, identified insights and design principles 4: Design—Created initial designs for two dosage forms (1 oral, 1 vaginal/rectal), branding and touchpoints for experience 5: Design research—Interviews and interactions over 2-week period 6: Strategy—Made design adjustments based on feedback from phase 5 7: Design + communication—Made final recommendations for dosage forms, packaging, brand and experience blueprint design 8: Design—Adapted messaging to South African regulations, and developed additional messaging 9: Message testing in 15 immersion sessions with potential end-users, user influencers, HCWs 10: Strategy—Further synthesis to confirm and refine designs and messaging ^{29,39} Aims 3 & 4: Information not yet available.	Engaged with following participants in phases: 2: n = 51 5: n = 237 9: n = 253 Identified key cultural, relationship, HIV category, product, and HCW and pharmacy insights that shaped implementation design. Example insights: Cultural: In South Africa, word of mouth can make or break you Product: A female product is more discreet by being boldly graphic. HCW and pharmacy: Health care providers need their own set of reminders, cues and incentives to talk about products. Identified 5 design principles for the HIV prevention product: 1. Be delightfully discreet 2. Spark confidence and trust 3. Give me a reason to care 4. Empower me with choice 5. Build on existing moments Created product, brand, packaging and experience for testing, including adherence support options. ^{29,30} Creation of open-source design materials for implementation by others.	Designing the prevention experience is anticipated to reduce stigma and increase use. Surprising outcome that a bold product was needed to be discrete with a message focused on female empowerment instead of HIV prevention. ³²	The study required a multi-phase, multi-partner approach.	
Dapivirine ring design guide ^{14,40} 2017	18–28-year-old females and their influencers, South Africa and Uganda		What are ways to increase and sustain use of the dapivirine ring by understanding and engaging young sub-Saharan African women and their influencer?	4 phases: 1: Immersion—Gathering insights, interviewing experts, landscaping and literature review 2: Research—Identifying opportunities, participatory qualitative research methods such as interviews, scenario-based mad-lib acting activity, ecosystem cards, girl talk events, sexual and reproductive health gallery tour, lady talk WhatsApp groups 3: Concepting—Generating & testing ideas, collaborative sessions with end-users and influencers generating and voting on concepts, rapid prototyping, community feedback 4: Strategy—Recommendations & materials, translate findings into solutions and recommendations	1: Developed insight hypotheses 2: Identified 6 priority personas with different needs, motivations and behaviors related to key factors influencing ring access and use: individual empowerment and external support. ¹⁴ 3: Identified key design concepts around health communication, service delivery, user tools, and community building. Example design concepts: Male messaging—community: Men want to feel part of the ring Ring cycle—messaging material with a visual overview of the monthly cycle of a ring and how it fits into a woman's life to avoid questions/issues that might arise ¹⁴ 4: Published guide with design concepts and research approaches including journey mapping and persona development, and supplementary asset library with templates and supporting visuals. ¹⁴	HCD approach identified steps in the ring journey, challenges at each step, key interactions with the ring at each step & real-life experiences at each step. Local relationships grounding the research were important for trust and buy-in. HCD can guide appropriate responses to challenges. For example: Challenge: “Discontinuation is discouraging” Design response: “Make it okay to falter, encourage when she falls off track” ¹⁴ Identification of context-specific elements that may influence implementation. Example: South African health infrastructure and more literate population allows for easier adaptation while conservative Ugandan culture and less developed health infrastructure may require slower paced introduction.	Working with young women and their influencers was important for understanding the end-user experience.	

TABLE 3. Resonance: Support Articulated for PCC by Health Care Workers

Key Support for PCC	Description of the Facilitator	Reflection Points for Efforts to Improve Patient Centeredness
This is the work I want to do	HCWs repeatedly articulated that supporting patients to do well was a key motivation for their chosen profession	Starting with the premise that HCWs want to work in a patient-centered way is important for supporting more patient-centered practices. How can interventions leverage the existing support and focus on the mechanisms of implementation, not only the concept of it?
It feels good to help patients	HCWs derive satisfaction from helping patients	Personal and professional satisfaction can provide strong motivation. How can you use true stories from HCWs and their colleagues or other strategies to build on this feeling?
HCWs told stories of applying PCC principles despite difficult conditions during HCD dialogues	The specific facilitators of PCC were unique to each patient and circumstance	Examples of successfully doing what may seem daunting can: (1) create momentum for others to see how they have done it and can do it, (2) support creative solutions to navigate challenges for other patients, and (3) identify facilitators that could be fostered to make PCC easier for all patients.

outcomes accessible, desirable, and useable for facility staff and other key users?

The design workshop included 31 purposefully²⁵ invited HCWs (users) from the pilot facilities (see Appendix 2, Supplemental Digital Content, <http://links.lww.com/QAI/B389>), 6 district health management team representatives (influencers) and 12 research team members (developers). The workshop agenda (see Appendix 3, Supplemental Digital Content, <http://links.lww.com/QAI/B389>) included common HCD insight gathering activities such as “journey maps”⁹ and personas²⁶ to realize the workshop strategies. Workshop facilitation was led by an external HCD expert and co-facilitated by research team members.

To synthesize insights, participants generated visualized activity outputs common to HCD (see Appendix 4, Supplemental Digital Content, <http://links.lww.com/QAI/B389>). The developers took notes during each workshop session and, each day, reviewed outputs and notes, and dialogued to identify key questions, emergent insights, and direct feedback on intervention components. Developers then categorized the insights through mapping and rapid thematic analysis⁸ and proposed intervention revisions. Critical insights and themes were discussed with HCWs.

Ethics

Study activities were conducted under a health facility-level waiver of consent, approved by the University of Zambia Biomedical Research Ethics Committee and University of Alabama at Birmingham IRB.

RESULTS

Literature Review

The search strategy identified 77 published articles, of which 8 were relevant to the research question, representing 5 studies. The grey literature searching identified 4 studies, of

which 2 had sufficient information for inclusion (Fig. 1). Studies came from Nigeria,²⁷ Kenya,²⁸ South Africa,^{26,29,30} Uganda,²⁶ and the United States^{31–36} and included adults and youth. Four studies designed an mhealth tool,^{27,31–36} 1, a management process,²⁸ and 2, PrEP delivery approaches with young women.^{26,29,30} All studies specified a phased process, including each of the elements described in Table 1. The order, structure, and intensity of those elements differed by the study. All but one included study³⁶ articulated plans for a feasibility or effectiveness evaluation of the outcome resulting from the HCD process. However, although planned for 1 case study,³⁷ no studies estimated the effect of the HCD process itself by comparing the implementation of the outcome designed to either (1) outcome implementation not informed by users or (2) informed by another formative research approach (Table 2).

In each study, the HCD application was guided by the current state of research and the user behaviors desired by the developers. Most of the studies sought to create and optimize a specific outcome (ie, a management intervention to improve efficiency,²⁷ a decision support tool to integrate HIV and TB clinical care,²⁸ and a mobile application to improve HIV management or patient decision-making^{31,32,36}), the basic form of which was justified by previous research. Two studies,^{29,38} both focused on a newer product and a less well-understood user group (PrEP for young women), sought more broadly to understand experiences and approaches relevant to increasing and sustaining PrEP use and then proceeded to design and refine specific PrEP products and processes. Articles reflect that even when specific products are of interest, HCD processes require sufficient flexibility during the user-driven investigation stages to allow for user priorities to guide the focus and form of the final solutions designed. For example, although based on an electronic medical record system, the final HIV-TB integration support tool design utilized paper-based messaging to clinicians as the most feasible form of communication.²⁸

TABLE 4. Resistance: Conceptual, Emotional, Cognitive, and Structural Challenges to Implementing Patient-Centered Practices Voiced by Health Care Workers

Challenge Voiced to Implementing Patient-Centered Practices	Description of the Barrier	Reflection Points for Efforts to Improve Patient Centeredness in Transferable Settings
“Punishment works”	If a patient does not adhere to regular appointments or medication schedules, punishing them by: (1) making them wait until others are served, (2) requiring them to return for more frequent visits, and/or (3), especially for drug supply and counselling, speaking harshly to them will help them to be more adherent in the future.	<p>How can evidence that patient fear of scolding is a barrier to return be translated into reformed practices?</p> <p>What examples of kindness leading to reformed patient practices are available?</p> <p>What can be done about the notion that patients who miss their appointments automatically need repeated counselling visits to reform?</p>
Floodgates	If a HCW asks open-ended questions, is kind to patients, and practices shared decision making with some patients, all patients will want that sort of treatment.	<p>What can patient-centeredness be understood as a way of working for all patients, instead of a special approach to only some patients?</p> <p>What resources are needed to support patient-centered practice?</p> <p>What patient-centered practices are possible given the limited resources available?</p> <p>How can HCWs be encouraged to implement PCC among patients that have varied needs?</p>
“Spoiling the children”	If other patients find out that a patient who was not adherent to regular appointments or medication schedules was not punished, all of the patients will stop being adherent.	<p>How can interventions help HCWs to think about the variety of factors that encourage adherence, and to see that in many cases punishment discourages adherence among patients who are struggling to adhere?</p>
“The patient is not my boss”	When discussing using shared decision making to ensure feasible care plans for patients, some HCWs noted that they know best because they have undergone medical training. The patients should take direction from HCWs, not the other way around.	<p>How can interventions help HCWs to separate out authority and respect from feasible care?</p> <p>How can interventions help HCWs to recognize that treatment is not limited to medicine, and that while HCWs have medical knowledge, the patients are the experts in their own living circumstances?</p> <p>How can interventions help HCWs to combine HCW and patient expertise in a holistic approach to support successful long-term treatment?</p>
Professionals cannot be rude	When discussing the benefits of greeting a patient, using kind words, offering affirmation and understanding & noting that patients reported not coming to the clinic after rude treatment, several HCWs expressed that they are professionals and, as such, they cannot be rude.	<p>How can interventions avoid labels such as “rude” and consider real life stories that may demonstrate different types of interactions and the possible reasons and consequences for HCWs and patients?</p> <p>How can interventions help HCWs to embrace that professionalism is not undercut by being courteous? (eg, that HCWs can be both firm and polite)</p>
We must follow the guidelines	When discussing topics such as identifying barriers to patient retention in care and making a plan to accommodate them, HCWs expressed that guidelines dictated their practice and left little or no room for variation. For example, if a patient missed many appointments, they were forced to return weekly, even if their main barrier was leaving work.	<p>How can interventions identify and review potentially problematic guidelines, understand what is required, and discuss interpretation or needed changes with HCW superiors and policy makers?</p> <p>How can interventions help HCWs to exercise flexibility/discretionary power to meet patients’ varying needs within the existing guidelines?</p>
No time/sustainability	Being patient-centered will require additional time and, perhaps, additional resources. It is not possible to sustain it, so it is best not to do it at all.	<p>How can interventions assess what resources are needed to support patient-centered practice?</p> <p>What patient-centered practices are possible given the limited resources available?</p> <p>How can interventions help HCWs to view PCC as part of their everyday work (service delivery) and not separate service/added responsibility?</p>

(continued on next page)

TABLE 4. (Continued) Resistance: Conceptual, Emotional, Cognitive, and Structural Challenges to Implementing Patient-Centered Practices Voiced by Health Care Workers

Challenge Voiced to Implementing Patient-Centered Practices	Description of the Barrier	Reflection Points for Efforts to Improve Patient Centeredness in Transferable Settings
It's the boss's problem	There was a perspective from some that as a HCW, they have tasks to complete and they do them as well as they can given difficult circumstances. If patients are not happy or not doing what they need to do to stay healthy, ie, for the HCW supervisors to consider and direct the HCWs to do different things, accordingly. It should not be on the individual health worker to direct change.	How can interventions engage all levels of a health facility, understand how teams function, and address team dynamics to foster the support that may be necessary to implement more patient-centered practices? How can interventions appeal to intrinsic motivations that many HCWs have to help patients by adopting different ways of working, instead of responding to orders for specific tasks?
"Patient are liars"	Asking patients open-ended questions about their challenges and trying to identify ways to overcome them will not work because patients are not truthful. It is better to tell patients what to do.	How can interventions help HCWs to see things from the patient perspective? How can HCWs be more engaging with patients who they think are not being totally truthful? (eg, understanding that sometimes patients may lie out of fear)
Patients are rude/drunk/disorderly	No matter what you do, some patients are rude or arrive drunk or are disrespectful. These patients will take out their frustrations on health care workers and not appreciate them. That is exhausting and difficult for HCWs, so you cannot add patient-centeredness on top of that. HCWs will be more tired and feel hurt.	How can interventions consider extreme patient behaviors that do exist and consider practical solutions to such problems? How can interventions identify what, if any, positive sources of feedback and support HCWs get to bolster themselves against tough clients? How can the intervention increase those supportive reserves?
VIP problem	Some patients are important people and expect special treatment (eg, relatives of HCWs, political cadres, media, etc.). These VIP (very important people) prevent HCWs from attending to others.	How can interventions consider extreme patient behaviors and difficult circumstances that do exist and consider practical solutions to such problems? If VIPs represent a minority of patients, how can interventions help HCWs to consider these circumstances as the exception, instead of the rule that would always prevent patient-centered practices?
The worst patients	When thinking about patients who need help, HCWs often identified every possible negative trait and challenge and mentally assigned them to a single patient. As approaches were identified to deal with a challenge, the next challenge would arise, precluding the acceptance of the possible utility of patient-centered practices by always having a "next problem" at the ready.	Mentally assigning all problems to one person makes PCC seem overwhelming and impossible. How can interventions highlight more realistic example patient who have several challenges each when working through cases, instead of allowing every possible challenge to be mentally assigned to one patient? To avoid dismissal of PCC, how can interventions help HCWs respond to the patient at hand, realizing that not every patient is very, very difficult patient (even if some truly are)? How can interventions brainstorm with HCWs about true worst patient scenarios and how they handled the situations, how they can be supported by their superiors and facilities to do so? This may help to avoid dismissal by acknowledging the existence of real difficult patients and thinking through what is possible.

TABLE 4. (Continued) Resistance: Conceptual, Emotional, Cognitive, and Structural Challenges to Implementing Patient-Centered Practices Voiced by Health Care Workers

Challenge Voiced to Implementing Patient-Centered Practices	Description of the Barrier	Reflection Points for Efforts to Improve Patient Centeredness in Transferable Settings
All or nothing/everyone or no one	Not all aspects of patient-centered care that are described are possible with each patient, so “patient-centered care is not possible.”	<p>How can interventions show patient-centered care as a box of different tools that can be used in different situations and with different people, instead of as a single practice ie, very complex and will only work if all done together?</p> <p>How can interventions use stories, case studies and other means to highlight that PCC likely means something different for different clients, so it does not mean needing to do the same thing for everyone?</p> <p>How can interventions help HCWs to offer different patient-centered approaches when they have standardized treatment plans (eg, standardized sets of questions, etc.?)</p>
Who do you represent?	When discussing the idea that a HCW can make a patient feel better by acknowledging that the queue is long, or that navigating care is difficult, HCWs workers said that some patients interpret apologies from HCWs as indictments of the government that runs the clinic, instead of it being a sign of empathy toward the patient. It is best not to say anything and avoid any political suspicion that you may be critical of your ministry or the party in power.	It is necessary to consider the political environment in which HCWs operate. How can interventions understand specific concerns about what might put HCWs at perceived risk and help them to identify alternate ways to achieve the same outcomes?
No resources	HCWs shared that in some circumstances, even basic tools such as blood pressure cuffs may be missing. If ie, true, how can anything like PCC be done?	<p>How can interventions assess what resources are needed to support patient-centered practice?</p> <p>What patient-centered practices are possible given the limited resources available?</p> <p>How can stories of success in patient-centered practice that happened in the current environment help to identify solutions to difficult situations?</p>
Limited space	The health facility lacks the physical space necessary to offer privacy and other elements of patient-centered practice, so it is not possible.	<p>How can interventions assess what resources are needed to support patient-centered practice?</p> <p>What patient-centered practices are possible given the limited resources available?</p> <p>How can stories of success in patient-centered practice that happened in the current environment help to identify solutions to difficult situations?</p>
Tired and hungry	Health care workers are already doing the best they can in very difficult conditions. How can HCWs be open and kind when they are themselves, exhausted, and have not taken food in many hours?	How can interventions support self-care and stress relief for HCWs as a part of encouraging patient-centered practices?
It takes a village	To practice patient centeredness, it sounds like the different departments and teams must work together. Some colleagues will not do that, so PCC is not possible.	<p>How can interventions encourage teamwork as a necessary component of patient-centered practice?</p> <p>How can interventions help HCWs to think about what they can do to increase patient centeredness, even in the absence of a supportive team environment?</p> <p>How can interventions support HCWs to “spread the patient-centeredness fire once ignited”? (eg, share PCC with other HCWs who may not implement those practices)</p>
PHD (pull her/him down)	If a health care worker starts doing too well, other colleagues will try to limit her or his success	<p>How can patient-centered practices be normalized as part of routine care that everyone provides instead of something “special” at which certain people excel?</p> <p>How can interventions help HCWs to embrace that effective implementation requiring collaborative effort and skills sharing?</p>

TABLE 5. Example Revisions to PCC Intervention From HCD Workshop

Intervention Revision	Summary of Insights Leading to Revision
<p>HMW #1: How might coaches be best positioned in facilities to guide and support HCW in delivering PCC according to best practices and in ways that are appropriate to facility context?</p> <p>Increase curriculum delivery time</p>	<p>Too much content in too little time felt overwhelming and created barriers to learning.</p>
<p>Have coaches support identification of cadre-specific small goals instead of facility-wide goals</p>	<p>PCC practice recommendations were presented with examples most relevant to the behaviors offer doctors, nurses, and counselors. Making PCC practices concrete for cadres including pharmacy, data and others helped to identify care coordination opportunities.</p>
<p>Instead of relying on stories identified during past research and qualitative work to motivate training and coaching examples, draw stories of successful PCC practice implementation from participants themselves.</p>	<p>Although the stories shared during training were true, HCWs said they wanted to share “real” stories. We understood this to mean their stories of patient-centered experiences. Several HCWs were able to articulate stories of implementing patient-centered practice in the few weeks between the coach-delivered PCC curriculum training and the HCD workshop.</p>
<p>HMW #2: How might we foster a workplace culture that empowers and motivates health care providers to provide PCC?</p> <p>Formally incorporate health care worker experience in the study theory of change.</p>	<p>Changes in the HCW experience may mediate intervention effects.</p>
<p>Expand coverage of study sensitization and curriculum participation to include a minimum of 75% of the facility, with ideally 100% of staff members reached.</p>	<p>HCWs who supported PCC practices needed a broader foundation built at their facility to allow them to encourage others to adopt PCC practices. More and greater access to initial information can help reduce suspicion and encourage wider access to perceived advantages study participation may convey.</p>
<p>Orient the PCC intervention to be both patient and provider-centered in its implementation. Begin PCC intervention activities with HCWs by recognizing the HCW perspectives on care delivery instead of beginning with the challenges patients face.</p>	<p>PCC interventions should lead to care ie, optimized for patients. However, it is important to recognize that HCWs are the users of an intervention encouraging them to adopt more patient-centered practices. Patient-centered care interventions are better received, and likely more effective, if presented and implemented in a provider-centered way. This must balance patient needs, but reduce common feelings of blame and HCW judgment.</p>
<p>Introduce quantitative survey measuring HCW satisfaction and experience to expand and anonymize HCW feedback beyond qualitative focus group discussion-based data collection.</p>	<p>While focus group discussions were planned with HCWs, they only offered limited participation opportunities and were not anonymous. Because patients were being asked about HCWs, HCWs wanted more opportunities to share their experiences, including identifying what positive and negative feedback they receive to do their work.</p>
<p>HMW #3: How might we make new and existing information on patient experience and on patient outcomes accessible, desirable, and useable for facility staff and other key users?</p> <p>Instead of sharing average patient satisfaction scores or other aggregate indicators of facility performance, share disaggregated data by question to help HCWs to identify specific areas of high performance or those needing improvement.</p>	<p>HCWs were interested in the specifics of what is happening to understand the source of a problem and what may be needed for change, not averages or summaries. For example, an average patient satisfaction score was of much less interest than scores for each question used to measure satisfaction.</p>

All published studies identified beneficial changes to the product/process being designed. This represents the potential for HCD application. Potential publication bias may limit available data on HCD processes that failed to yield meaningful, actionable insights. Ramos et al,³² however, conclude that the HCD-improved HIE user interface still resulted in poor HIE comprehension and suggest that human interaction may be necessary for understanding. This may demonstrate that 1 cycle of iteration and testing may be insufficient to identify an optimized implementation design, indicating that implementers planning to use HCD need to allow time, resources, and/or strategies to support sufficient re-design and testing.

An HCD approach may itself be an implementation strategy, in addition to providing formative research to optimize and intervention. Catalani et al²⁸ conducted their HCD work with stakeholders in the same health system where their intervention would be implemented. The authors reflect that the user engagement required for HCD facilitated the trust and acceptance required to intervene in a complex health system.

An extant literature suggests that HCD may be particularly apt for improving the usability of a specific product or tool for a relatively well-defined user group; identifying and addressing relevant concerns in a complex system or process; and identifying and avoiding implementation barriers for a new product or product access by a poorly understood user group. The limitations of HCD raised by study authors were poor generalizability of the designed outcomes^{28,31,34} and the inability of HCD as an approach to estimate effectiveness.³⁶

Human-Centered Co-Design Workshop

Our application expanded HCD to a behavioral service delivery target: changing HCW patient-centered beliefs, attitudes, and practices. Like several published studies, we aimed to refine an evidence-based intervention with predetermined components based on extensive previous and formative research. The depth of the interactions between the HCWs and research team members during the workshop, as well as the creativity encouraged by the facilitator, allowed

for a breadth and openness of conversation not achieved during the formative focus group discussions. The insights gained during our workshop may be partially explained by the open relationships established and intervention feedback received during the pilot.

HCD revealed that patient-centeredness principles (eg, understanding the whole person, 2-way communication) resonated with HCW but met resistance with some HCWs such as time constraints and beliefs that punitive measures improve patient compliance. During HCD activity dialogues, HCW participants shared stories of using kindness to help struggling patients to re-engage in care, highlighting the ability to implement PCC under less-than-ideal conditions and the benefits of positive interactions. The explicit encouragement of HCD to offer multiple perspectives and dialogues and embrace a co-creative environment allowed for the interactions, which revealed these various perspectives. The key points of resonance with PCC (Table 3) and resistance (Table 4) were voiced directly or indirectly by HCWs and codified through rapid thematic analysis. While an unanticipated HCD workshop result, they present both likely challenges and promising solutions to promoting PCC practice. They would not apply to every situation; however, they offer guidance for the trial intervention coaches to anticipate and may address barriers to PCC adoption in transferable settings.

Intervention components that will be tested in our stepped-wedge trial were revised to improve acceptability, appropriateness, and feasibility of PCC practices, including better-using intervention mentoring and data collection to help HCWs feel visible, appreciated, and accountable. For example, HCD insights led us to augment the planned HCW FGD data collection with a quantitative HCW survey to expand and anonymize HCW feedback (additional examples in Table 5). The limited workshop days allowed for little formal iteration on proposed revisions beyond sharing ideas and eliciting additional HCW feedback. Our study, however, used further pilot period implementation to test some of the proposed changes. The rigor of our HCD process may have improved with extended time for formal iteration and testing.

DISCUSSION

Our review suggested that HCD offers an important and emerging tool for adapting strategies to enhance ART services. While traditionally applied to products or mHealth practices, we and others have also begun to apply these principles to shape and refine the service delivery context and patient experience. Overall, HCD has the potential to improve the HIV response by more closely aligning the implementation of evidence-based products and processes with user priorities and context. In an HIV response that has to date rightly prioritized scale-up and standardization, but which now must shift to a more targeted efforts to continue improvements, HCD offers a theoretically based, robustly mapped set of practices that seek to improve outcomes through active engagement and respect for end-user views; encouragement of broad, creative inquiry; and support for iterative idea refinement in response to testing and feedback.

Rigorous, successful HCD outcomes are no panacea however, and likely depend on relationships, time, and other resources required for authentic engagement and responsiveness, which may not always be available.

Extant evidence lacks an assessment of the comparative effectiveness of HCD and non-HCD processes in implementation optimization. Recent research, however, offers interesting insight into potential HCD gains. A study of the national scale-up of PrEP in Kenya identified that in addition to other stigma types, product stigma, including the similar appearance of PrEP bottles and ARV bottles, was a barrier to PrEP use.^{39,40} The HCD approach in EMOTION^{29,30,37} identified that the medical appearance of PrEP was associated with illness, creating a likely barrier to young women's uptake and use. EMOTION²⁹ thus prototyped PrEP starter kits that resemble make-up bags and stickers to disguise standard labels. User engagement lessons may facilitate use in similar populations.

HCD approaches are not the only user-engagement methods that may support improved implementation. A 2017 landscape mapping of end-user research in HIV prevention for young women in sub-Saharan Africa identified 53 projects, of which 3 were explicitly HCD.⁴¹ There is often overlap in objectives and methods between HCD, more traditional qualitative methodologies^{42,43}; participatory research¹¹; engineering approaches^{44,45}; and discrete choice experiments as formative research.⁴⁶ Although efforts have been made to compare and contrast approaches,⁸ distinctions are not concrete. Authors struggled to adjudicate use of HCD in some studies in our literature review. The Schnall et al³⁴ study discussed a user-centered design process but grounded their research in the Information System Research Framework and described some of their methods as participatory action research. We erred on the side of inclusion, but the multidisciplinary nature of user-centered approaches requires reviewers' interpretation of methods. HCD distinguishes itself in by focus on empathy; flexibility in inquiry as directed by users; iterative, rapid testing cycles; and emphasis on practical outcomes. Our own case study included both traditional formative research and HCD. Although our more traditional formative research raised the issue of HCW context and the need to avoid blame to increase receptivity of HCWs to PCC, the empathy established and nuance understood through the HCD workshop elevated the HCW experience to formally include improvement in the HCW experience in the study Theory of Change.

The limitations of HCD identified in the literature review including a lack of generalizability and inability to estimate effectiveness are not dissimilar to other qualitative methodologies. Instead of limitations, they are features of the approach. HCD findings may be transferable,⁴⁷ a metric of qualitative rigor that considers the applicability of findings from one setting to a different setting with a similar context, instead of generalizable. Potential for transferability was noted in several literature review studies,^{26,28,29} as well as our own HCD case study. Critical reflection on HCD limitations would enhance future use. For example, thin preliminary knowledge of the evidence-based intervention may lead to poor design questions. An HCD process that is

too rapid to allow for sufficient iteration or diversity of user engagement may produce results that lack rigor. Based on the importance of open discussion in our workshop, we believe that an absence of mutual respect and trust between users and developers could prevent empathetic interactions and produce inauthentic HCD outcomes.

An important HCD insight from our workshop was that effective implementation of an intervention to increase the patient-centeredness of care through HCW behavior change needs to be implemented in a provider-centered way. This does not diminish the central role of patients in their care processes and outcomes. It highlights that just as the lived realities of the patients' need to inform HCW engagement with patients as care partners, the lived realities of the HCWs demand that interventions to change HCW practice prioritize feasible, acceptable, and appropriate implementation strategies. HCD may be particularly appropriate in complex settings that need to consider patient, provider, and systems realities. The compendium of resonance and resistance to PCC (Tables 3 and 5) provide concrete illustrations of how using HCD can reveal challenges and opportunities that may influence intervention effectiveness. Consistent with the reflections of Catalani et al,²⁸ our team felt that the communication, collaboration, and engagement between planners and users during HCD can support successful intervention implementation subsequent to the design phase.

Limitations

Our review may have missed relevant case studies given the limited grey literature search and the practical outputs of many HCD studies, which are less likely to be published in peer-reviewed manuscripts. Similarly, we focused on HIV-related HCD, excluding possible lessons from other health areas. Owing to time and resource constraints, our HCD process did not include patients, the intended intervention beneficiaries, and key actors in their own care and treatment. Inclusion of patients would almost certainly have identified additional insights and intervention revisions. Our choice to focus on the HCWs allowed us to engage with the primary users of the planned intervention, to conduct our HCD approach in limited time, and to manage identified power dynamics within HCW cadres based on shared knowledge and vocabulary from the pilot phase.

CONCLUSIONS

HCD has the potential to improve effective implementation of the HIV response by tailoring implementation strategies to enhance evidence-based interventions in particular service delivery settings. Although HCD is a promising and increasingly advocated^{48,49} approach to bridge this gap; more studies that document and critically reflect on the use and impact of HCD methods in the global HIV response are needed to guide their effective use. Those seeking to promote PCC may improve implementation success by seeking out the

resonance and anticipating and defusing the challenges our HCD process identified.

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