



# A youth-centred approach to improving engagement in HIV services: human-centred design methods and outcomes in a research trial in Kisumu County, Kenya

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**Introduction** Innovative interventions are needed to improve HIV outcomes among adolescents and young adults (AYAs) living with HIV. Engaging AYAs in intervention development could increase effectiveness and youth acceptance, yet research is limited. We applied human-centred design (HCD) to refine adherence-support interventions pretrial and assessed HCD workshop acceptability.

**Methods** We applied an iterative, four-phased HCD process in Kenya that included: (1) systematic review of extant knowledge, (2) prioritisation of design challenges, (3) a co-creation workshop and (4) translation tables to pair insights with trial intervention adaptations. The co-creation workshop was co-led by youth facilitators employing participatory activities to inform intervention adaptations. Iterative data analysis included rapid thematic analysis of visualised workshop outputs and notes using affinity mapping and dialogue to identify key themes. We conducted a survey to assess workshop acceptability among participants.

**Results** Twenty-two participants engaged in the 4-day workshop. Co-creation activities yielded recommendations for improving planned interventions (eg, message frequency and content; strategies to engage hard-to-reach participants), critical principles to employ across interventions (eg, personalisation, AYA empowerment) and identification of unanticipated AYA HIV treatment priorities (eg, drug holidays, transition from adolescent to adult services). We revised intervention content, peer navigator training materials and study inclusion criteria in response to findings. The youth-led HCD workshop was highly acceptable to participants.

**Conclusions** Research employing HCD among youth can improve interventions preimplementation through empathy, youth-led inquiry and real-time problem solving. Peer navigation may be most influential in improving retention when engagement with young people is based on mutual trust, respect, privacy and extends beyond HIV-specific support. Identifying opportunities for personalisation and adaptation within intervention delivery is important for AYAs. Patient engagement interventions that target young people should prioritise improved transition between youth and adult services, youth HIV status disclosure, AYA

## WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Innovative approaches to facilitate improved adolescent and young adult engagement in HIV care are urgently needed to reduce morbidity and mortality.

## WHAT THIS STUDY ADDS

⇒ This study presents a novel application of a phased, youth-led, human-centred design approach to enhance HIV retention interventions in Kenya. It demonstrates human-centred design (HCD) workshop acceptability, youth-led priority identification and development of concrete, unique solutions related to HIV treatment engagement for pretrial implementation.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This study demonstrates how to engage prior research to inform design questions, leverage underlying participatory methodologies to collect data in research-based HCD with youth, and systematically approach iterative translation of findings into empathy-informed research adaptations. Youth prioritisation of personalisation, supportive relationship quality, self-management and decision-making advance the person-centred care agenda in HIV service provision.

empowerment and healthcare worker responsiveness in interactions and episodic adherence interruptions.

## INTRODUCTION

Innovations in HIV service delivery are needed to reduce persistent high attrition, viral failure and mortality among adolescents and young adults (AYAs) living with HIV.<sup>1–3</sup>

The United Nations define AYAs as youths aged 15–24 years.<sup>4</sup> Notably, lost to follow-up after starting antiretroviral therapy (ART) and viral failure are 25%–50% higher among AYAs than adults.<sup>1–3</sup> Compared with adults, AYAs face more diverse and amplified barriers to adherence and retention. As a result, HIV is a key driver of deaths among AYAs in Africa.<sup>5</sup> Current service delivery approaches, often designed by adults, fail to accommodate AYA-specific barriers and strengths, and are less effective for this age group.<sup>3 6</sup> AYAs are the experts on themselves but are frequently excluded from efforts to improve services. There is an urgent need to meaningfully engage AYAs in designing and implementing retention interventions and services to respond to their unique needs and preferences.<sup>7 8</sup>

Several studies from low-income and middle-income countries (LMICs) have tested interventions to improve HIV treatment linkage and outcomes for AYAs with varied success. Adolescent-friendly services, provider training, adherence support and mHealth approaches have shown some efficacy in increasing AYA retention in care and viral suppression.<sup>9–11</sup> However, recent systematic reviews of interventions to improve adherence and retention in AYAs in LMICs note that many of these studies lack rigour, limiting the strength and generalisability of their findings.<sup>11 12</sup> Significant gaps remain in our understanding of how to improve intervention acceptability and effectiveness, which youth subgroups would benefit most from interventional support, and when support is needed.

Engaging AYAs in creating solutions to HIV care challenges is recognised as an approach that may increase ownership and youth acceptance, yet established methods to effectively and meaningfully engage young people in research are limited.<sup>12 13</sup> Traditional trials often use researcher-designed interventions and only assess outcomes at trial conclusion. Formative research methods may more rapidly obtain youth perspectives and opinions yet may fail to optimally apply them if methods are not youth led.<sup>14</sup> Human-centred design (HCD) is a novel, participatory and formative approach, relatively new in the global health research arena, to problem solving that may facilitate meaningful AYA involvement in research to improve HIV treatment outcomes.<sup>15</sup> HCD applies empathy while placing end users at the centre of design through highly interactive and thought-provoking activities.<sup>16</sup> HCD approaches have been applied in HIV prevention intervention development<sup>17 18</sup> to integrate chronic disease care into HIV treatment and to improve the HIV care cascade.<sup>19–21</sup> Youth-led HCD research is currently limited, yet it may be vital to addressing treatment gaps for this unique population<sup>19–21</sup>

We used an HCD approach to tailor interventions for a randomised controlled trial to improve AYA retention and outcomes in HIV services in Kisumu County, Kenya: the Adaptive Strategies for Preventing and Treating Lapses of Retention in HIV Care for Adolescents study (A4A).<sup>22</sup> To engage AYAs in intervention design and

improve intervention implementation pretrial, we used a four-phase HCD approach cofacilitated by young people living with HIV. We aimed to identify opportunities to improve the proposed multicomponent adherence-support interventions in A4A and understand AYAs support priorities. Additionally, we assessed the acceptability of a youth-led HCD workshop approach with AYAs in Kisumu County, Kenya.

## METHODS

### Study background

The A4A study, launched in 2019 (NCT04432571), uses a sequential multiple assignment randomised trial design to optimise AYA HIV treatment engagement and assess the comparative effectiveness of three interventions among AYAs 14–24 years old on ART in Kisumu County, Kenya.<sup>22</sup> For more details on the study design and procedures please see our protocol paper.<sup>22</sup> Kisumu County is among the highest HIV burden regions in the country.<sup>23</sup> Three intervention prototypes were developed using prior study team research and extant literature: (1) electronic patient navigation (eNAV) using electronic communication platforms (short message system (SMS) messages, phone calls) combined with peer support, (2) in-person patient NAV (IP-NAV) in which peer navigators influence retention and adherence behaviours among AYAs through in-person sessions and (3) conditional cash transfers (CCT), money disbursed for AYAs attending scheduled clinic visits and having suppressed viral loads. To improve the likelihood of intervention acceptability and effectiveness pretrial, concurrent formative research activities included (1) focus group discussions (FGDs) investigating factors influencing AYA care engagement, (2) a discrete choice experiment on incentive delivery preferences<sup>22</sup> and (3) a phased HCD process. AYAs were recruited from three high-volume Ministry of Health facilities with HIV youth-centres serving AYAs aged 10–24 years.

### HCD study design

Our HCD approach included four iterative phases: discover, define, develop through a co-creation workshop and deliver, guided by the Design Council's Double Diamond approach<sup>24 25</sup> described in more detail below. Our study design and reporting were informed by the proposed guidelines for health research involving design.<sup>26</sup>

### The design team

The design team comprised AYA workshop facilitators, the research team, and a design expert. The lead youth facilitator (28 years old) and two co-facilitators (24–26 years) comfortable discussing their HIV status with other youth were selected among adolescent HIV peer leads and collaborators from the study health facilities. Consistent with HCD mindsets,<sup>27</sup> the AYA facilitators (two male, one female) demonstrated good group facilitation skills, flexibility, optimism and creativity. The research

team included individuals from Kenya and the USA with expertise in paediatrics, adolescent sexual and reproductive health, HIV medicine, nursing, public health, social science and qualitative research; the design expert was from the USA with extensive experience conducting HIV research and design work in SSA. All team members were compensated for their role and are co-authors. Team composition was driven by the goal to blend content expertise with in-depth understanding of local communities. Co-creation was guided by AYA workshop participants.

### Design team training

Led by the design expert, the design team engaged in collaborative HCD training, preparation and implementation over 7 months prior to the workshop. Biweekly didactic trainings were held over Zoom from July 2020 to October 2020. Topics included A4A study aims; HCD concepts, analysis approaches and practical application of HCD as a research tool; codevelopment of workshop objectives and activities; facilitation skills; adolescent health and HIV; confidence, and team building. Three practical, in-person trainings among Kenya-based team members covered practice workshop activity facilitation followed by full team debriefs. Importantly, this fostered formal reflexivity as the design team discussed their perspectives on the HCD questions prior to working with the AYA participants in the workshop.

### Study procedures

#### Discover phase (March 2020–April 2020)

Drawing on: (1) knowledge and experience from delivering patient engagement and other HIV interventions in the region, (2) existing data from prior studies conducted by this research team and (3) extant literature, the research team mapped out key insights related to the A4A-proposed interventions: E-NAV, IP-NAV, CCT.<sup>28 29</sup> The team systematically brainstormed and documented answers to the questions: ‘what do we already know?’ and ‘what do we need to learn more about?’ to formally reflect on perceived areas of strengths and potential gaps in how the interventions might improve AYA HIV treatment engagement. The areas identified for further learning represented design opportunities for exploration in the Define phase.

#### Define phase (April 2020–September 2020)

Building on the discover phase, the research team identified specific design challenges (HCD research questions).<sup>30</sup> Through discussion, we generated 18 ‘how might we...?’ questions targeting anticipated intervention effectiveness gaps.<sup>30</sup> Using grouping, rating and ranking according to significance and relevance of knowledge gaps, the research team selected six initial core questions to address during the workshop (table 1). In consultation with the design team, including the AYA workshop cofacilitators, the HCD expert developed participatory design activities for each question to engage AYAs in

discovery, ideation and co-creation during the workshop and created facilitation guides for each activity. She drew on underlying qualitative, participatory and design methods to create activity options tailored to the design opportunities and context (table 1). The Kenya-based design team reviewed activity options, selected the most preferred, and ensured contextual and cultural appropriateness. Example activities included journey maps, role plays, storytelling and ‘tomorrow’s headlines’ (table 1). The facilitators internally pilot tested and refined activities before the workshop. Questions and activities were influenced by FGD and DCE work through overlap of research team staff conducting data collection and analysis and iterative discussion of results as they were available.

#### Develop phase (October 2020–December 2020)

Our primary co-creation activities to improve the eNAV, IP-NAV and CCT interventions were conducted during a 4-day design workshop held in October 2020. Specifically, the design workshop aimed to (1) build empathy and understanding around engagement and viral suppression between the study team and AYAs; (2) co-create solutions to anticipated HIV retention challenges through adapting the planned A4A study interventions and (3) identify AYA-led priorities to which the study should respond, iterating on the discover and define phases. The HCD workshop was AYA-led with adult co-facilitator support.

#### Participant selection

HCD workshop participants included (1) purposefully sampled AYAs willing to participate and discuss their HIV status and (2) peer navigator implementers of the e-Nav and IP-Nav interventions, who were also AYAs openly on ART. The first group were drawn from the three study clinics and AYA study FGD participants. We purposefully sampled for variation in gender, age and childbearing history.<sup>31</sup> Trained research staff members contacted eligible participants by phone or at clinic and conducted verbal informed consent procedures for interested AYAs and assent for caregivers of AYAs <18 years old.

#### Data collection, real-time analysis and documentation

Workshop facilitators led the design activities, which were adapted in real-time based on participant feedback (online supplemental appendix A : workshop agenda) and yielded visualised outputs (e.g., pictures, collages, etc) (online supplemental appendix B: photo images of workshop activities). On completion of each activity, facilitators fostered large group discussions using activity-specific guiding questions to support reflection, articulation of design or prototype-refinement ideas based on the activity results and synthesis, written on flip charts. Participants wrote down their thoughts on the most important take-away from each activity (participant insight statements). A qualitatively trained researcher took workshop ethnographic field notes.<sup>32</sup>

**Table 1** Overview of human-centred design extant knowledge, planned research questions and design activities

Discover	Define	Develop		
Extant Insights from prior research and experience	Key research questions (How might we...?)	Workshop design activity	Participatory method underlying activity	Purpose of activity/expected activity outcomes
<ul style="list-style-type: none"> <li>▶ Peer influences are powerful.</li> <li>▶ Building trust between AYAs and navigators is essential.</li> </ul>	How might we facilitate peer navigators to be influential with AYAs they are supporting?	The Ideal: Participant create visual composite representations of qualities AYAs value in others (sexual partner, healthcare worker, parent, friend).	Analogy <sup>27 52</sup>	<ul style="list-style-type: none"> <li>▶ Revealed preferences.</li> </ul>
<ul style="list-style-type: none"> <li>▶ Threats to effective electronic peer support delivery: access, content, voice tone, delivery frequency.</li> </ul>	How might we provide consistent peer support for AYA who have limited phone access or are in boarding schools?	Role plays: Participants write and act out short dramas responding to provided scenarios. Allows for creativity, emotion, humour and movement to explore topics and generate creative solutions.	Storytelling <sup>53-55</sup>	<ul style="list-style-type: none"> <li>▶ Sense-making.</li> <li>▶ Empathy development.</li> <li>▶ Creative problem solving.</li> </ul>
<ul style="list-style-type: none"> <li>▶ Potential differences in preferences around cash transfer between age groups/ other AYA characteristics.</li> <li>▶ Funds amount needs to cover transport, be motivating but not excessive.</li> </ul>	How might we structure incentives to best motivate AYAs to stay in HIV care and be virally suppressed?	Incentives prototypes: Present prototypes (models) of incentive delivery to AYAs. Discuss preferences on key prototype features.	Rapid, iterative refinement <sup>27 50 56</sup>	<ul style="list-style-type: none"> <li>▶ Co-creation of improved intervention models.</li> </ul>
<ul style="list-style-type: none"> <li>▶ Care engagement influenced by marital status, childbearing, age.</li> <li>▶ AYAs are not a homogenous group</li> </ul>	How might we structure the intervention to respond to needs of specific groups (pregnant, age groups, gender)?	Experience (Journey) Map: Small groups create a step-by-step storyboard and context for: A health facility visit for AYAs living with HIV.	Narrative synthesis. <sup>53-55</sup>	<ul style="list-style-type: none"> <li>▶ Empathy development.</li> <li>▶ Sense-making.</li> <li>▶ Revealed preferences.</li> <li>▶ Prioritisation.</li> </ul>
<ul style="list-style-type: none"> <li>▶ AYAs need providers who are understanding and supportive of the unique needs of adolescents, yet not all providers are trained/well trained/experienced in youth friendly service provision</li> </ul>	How might we empower AYAs to interact with providers to meet their needs?	Tomorrow's headline: Participants draw hypothetical news stories on what positive change has been realised and how it was realised	Visioning <sup>27 50</sup>	<ul style="list-style-type: none"> <li>▶ Creative problem solving.</li> <li>▶ Prioritisation</li> </ul>
<ul style="list-style-type: none"> <li>▶ Social network influence among AYAs which may affect care engagement.</li> </ul>	How might we support AYAs to engage with their social networks to support HIV care engagement?	Building a bridge: Participants voluntarily relate a challenging time and connect the people who helped them to planks of a bridge built to cross a river.	Storytelling, Mapping. <sup>55 57 58</sup>	<ul style="list-style-type: none"> <li>▶ Sense-making</li> <li>▶ Empathy development</li> <li>▶ Social network mapping</li> </ul>
<ul style="list-style-type: none"> <li>▶ Voluntary disclosure supports care engagement.</li> <li>▶ AYAs face stigma and other difficulties with status disclosure.</li> </ul>	How might we provide navigation support that allows AYAs to disclose safely and to support and strengthen adherence when disclosure is not possible?	Disclosure vignettes: Facilitators read out realistic but fictional short stories then elicit participant reactions.	Case studies. Narrative synthesis. <sup>27 54 55 57</sup>	<ul style="list-style-type: none"> <li>▶ Revealed preferences.</li> <li>▶ Prioritisation</li> <li>▶ Creative problem solving</li> </ul>

AYA, adolescent and young adult.

To assess participant workshop experience and acceptability, we conducted a 10-question, anonymous, individual participant survey self-administered on a tablet computer at workshop conclusion.

**Deliver phase (December 2020–April 2021)**

Informed by conclusions drawn from the first three HCD phases including FGD and DCE results, the full design and trial investigator teams reviewed and brainstormed trial adaptations, prioritised actions and noted concerns not addressed by the trial but critical to share with other stakeholders. High-level trial adaptation decisions were made through dialogue and trial investigator team

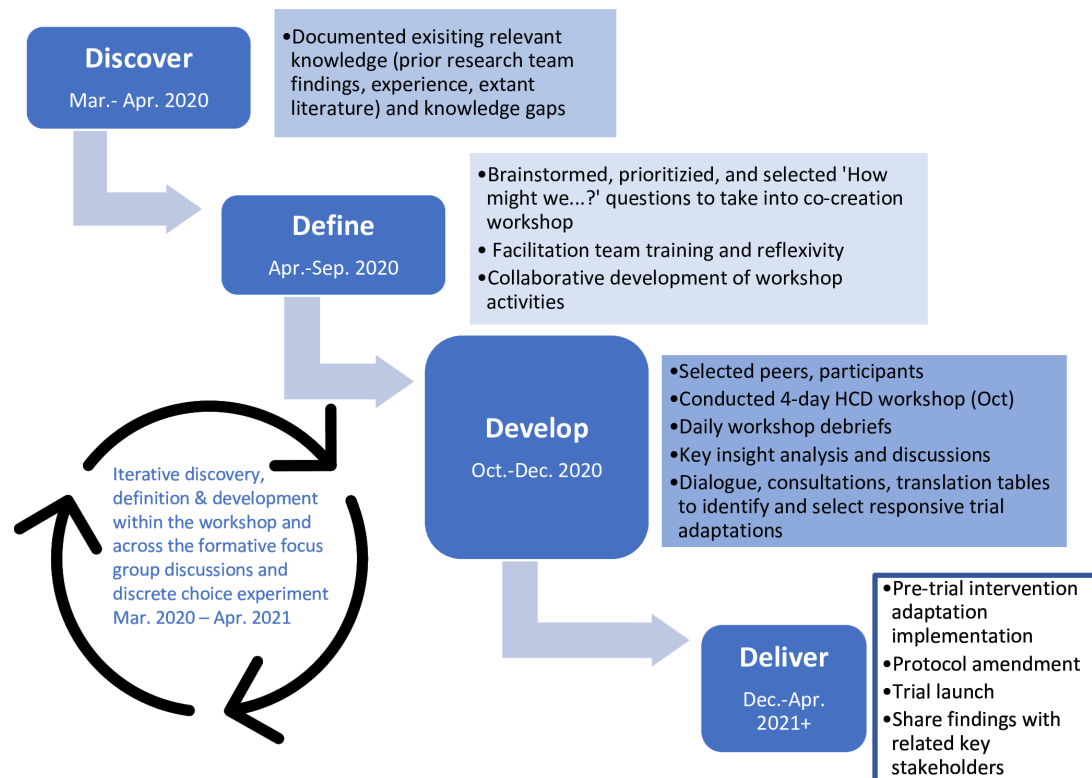
consensus, led by principal investigators. Modifications are being tested, in the A4A trial that started in 2021 and will conclude in 2024 (figure 1). Peer navigator HCD participants were among the trial intervention implementers, allowing for ongoing reflection and iteration on intervention standard operating procedures and delivery during formal Navigator debriefs, refresher trainings and administrative study reviews.

**Data analysis**

**During workshop analysis**

After each workshop day, the full design team held structured debriefs over Zoom lasting approximately





**Figure 1** HCD phases, key activities, timeline. HCD, human-centred design.

1–1.5 hours. These sessions included (1) General reflections and ways to improve the workshop in subsequent days, (2) For each activity: rapid review of activity-related data; documentation of high-level insights guided by questions such as ‘What seemed important?’, ‘What surprised you?’, ‘What confirmed what you already knew?’, ‘What was consistent?’, ‘What was confusing or conflictual?’, (3) Rapid identification of design opportunities using brainstorming, affinity clustering and dialogue,<sup>33</sup> (4) Reflection on emerging AYA-led priorities requiring further exploration and (5) Agreement on subsequent day agenda revisions to ensure responsiveness to emerging priorities and design insights. While priority ‘How might we...?’ questions guided initial activity plans, insights and priorities for intervention adaptations were not restricted to specific activities or questions. Key insights, new questions and trial adaptation ideas were informed by the entirety of the workshop activities and dialogue, including ongoing empathy development throughout. Debrief results were summarised in a report. Initial findings were shared with AYAs during the workshop for feedback and refinement.

#### Postworkshop analysis

Postworkshop, the full design team held two analysis sessions over Zoom lasting approximately 2 hours each. Rapid thematic analysis was conducted through iterative workshop data review, dialogue and affinity mapping.<sup>34</sup> Clustered themes were categorised to elucidate higher level insights. Results were compared with ethnographic field notes for confirmation and identification

of omissions. Results and interpretation were influenced by FGD and DCE results through overlap in study staff across data collection activities and formal discussion. Thematic insights were documented in translation tables applying abductive thinking<sup>35</sup> to systematically identify trial intervention adaptations and linking in-workshop results.<sup>36</sup> The research and facilitation teams iteratively contributed adaptation ideas for each of the key insights through in-person meetings and asynchronous contributions to a document over approximately 2 months.

#### Patient involvement

Patients were involved in the design and conduct of this research. Two cofacilitators (24–26 years) comfortable discussing their HIV status and AYAs on HIV care and treatment at study facilities were actively involved in codesign activities and iteration of patient retention interventions in the study. The two AYA cofacilitators were actively involved in conducting the HCD workshop, data analysis and reporting, and disseminating findings from the workshop to the study team and health facilities.

## RESULTS

### Overview

Workshop results and intervention adaptations are reported by the three AYA trial interventions that include E-Nav, IP-Nav and CCT for ease of interpretation.

**Table 2** Example thematic insights and trial adaptations (abbreviated translation table)

Key research questions (how might we...?)	Key workshop-derived insights	Trial action/adaptation
How might we facilitate peer navigators to be influential with AYAs they are supporting?	<ul style="list-style-type: none"> <li>▶ AYAs wanted to feel appreciated, not judged.</li> <li>▶ AYAs valued having a peer navigator who could ‘walk with them’ by sharing empathetic experiences.</li> <li>▶ AYAs wanted to engage on topics other than HIV.</li> <li>▶ AYAs valued professional appearance.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Pretrial navigator training adapted to emphasise empathy and storytelling, and professional appearance during visits.</li> <li>▶ Peer navigator training included sexual reproductive health and relationship education modules with appropriate referral options.</li> </ul>
How might we provide consistent peer support for AYAs who have limited phone access or are in boarding schools?	<ul style="list-style-type: none"> <li>▶ AYAs go through trusted adults to access phones or communicate through in-person visits.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Modified study protocol to include AYAs with no mobile phone access in the control arm, which allowed them to be eligible for re-randomisation to one of the more intensive interventions including IP-Nav and CCT.</li> </ul>
How might we structure the intervention to respond to needs of specific groups (pregnant, age groups, gender)?	<ul style="list-style-type: none"> <li>▶ Confidentiality and privacy are paramount. AYAs preferred untraceable messages sent in coded language that avoid words like ‘HIV’, ‘viral load’</li> <li>▶ Concern about too frequent communication.</li> <li>▶ AYAs have personal preferences: each one would like engagement responsive to those preferences.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Modified study text messaging architecture to ensure messages sent were not traceable.</li> <li>▶ Harmonised message content with AYA preferences for coded language</li> <li>▶ Study protocol changed to reduce planned message frequency.</li> <li>▶ Peer navigators trained to assess and respond to individual-level messaging preferences (eg, option booster communication if desired).</li> </ul>
How might we empower AYAs to interact with providers to meet their needs?	<ul style="list-style-type: none"> <li>▶ AYAs wanted to increase their own skills in interacting with clinic-based, adult healthcare workers.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Enhanced the peer navigator training with role plays on self-management skills for capacity building AYAs to interact with clinics and providers to meet their needs.</li> </ul>
Inductive priority that arose during workshop: How might we improve the required AYAs experiences of transition to adult HIV services?:	<ul style="list-style-type: none"> <li>▶ Transition from adolescent to adult services is a significant area of concern and possible disruption.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Even though outside study scope, training on transition integrated into peer navigator intervention sessions.</li> <li>▶ Findings, including suggestions for peer-group transition and early awareness of transition shared with facility-level stakeholders.</li> </ul>

AYA, adolescent and young adult; CCT, conditional cash transfer; IP-Nav, in-person patient navigation.

Examples of trial intervention adaptations resulting from the workshop are described below, highlights in [table 2](#).

Twenty-two participants engaged in the 4-day workshop ([table 3](#)). Co-creation activities yielded specific recommendations for improving planned interventions, critical principles to employ across interventions, and identification of additional AYA HIV treatment engagement priorities (online supplemental appendix B: photo images of workshop activities).

**Table 3** Participant characteristics (n=22)

	Males (%)	Females (%)	Total (%)
Age group (years)			
14–17	4 (36.4)	4 (36.4)	8 (36.4)
18–24	7 (63.6)	6 (54.5)	13 (59.1)
25–27		1 (9.1)	1 (4.5)
Participant role			
Clinic patient	7 (63.6)	7 (63.6)	14 (63.6)
IP or E-navigators	4 (36.4)	4 (36.4)	8 (36.4)

IP, in-person patient navigation.

### Workshop results and proposed adaptations for trial interventions

#### Electronic navigation

The proposed E-Nav intervention involved electronic communication (SMS messages, phone calls) to provide peer support for AYA engagement in HIV care. The code-sign workshop revealed that AYAs preferred less frequent communication than initially planned. AYAs concerns included message fatigue and competing school demands. We modified the study protocol, reducing communication frequency between E-Navs and AYAs from weekly to every 2weeks for the first 2months of intervention assignment, then monthly, with an option for additional sessions as desired by the individual participant.

AYAs emphasised that confidentiality and privacy were critical to navigator communication acceptability. AYAs desired text messages that: (1) were not traceable, eliminating the possibility of accidental or intentional discovery of the message origin and (2) used coded language (eg, avoided words such as ‘HIV’, ‘viral load’, ‘clinic appointment’). Further, through conversations about the importance of AYAs being seen holistically, beyond the lens of HIV, AYAs expressed a desire to receive messages related to life priorities and events outside of

HIV. For example, encouragement if they performed poorly on a test at school or sending birthday wishes. We revised the HCD workshop agenda to include participants creating actual messages e-Navigators might send to participants covering the range of topics and types of language they might appreciate. Additionally, we modified our text messaging architecture to ensure messages sent were not traceable and harmonised message content with preferences.

Our original trial eligibility criteria excluded AYAs without access to mobile phones, (eg, in boarding schools where phone access is curtailed) because of seemingly critical logistical barriers to the phone-delivered E-Nav arm. However, workshop findings demonstrated the exceptional characteristics and circumstances of AYAs who have limited access to mobile phones, underlined the importance of including them and problem solved options for engaging them such as youth-led connections to trusted boarding school educators with phones or communicating during permitted phone access windows. However, it was noted that delivery of E-Nav would remain limited in this subgroup as biweekly or even monthly communication would be impossible. Our study protocol was modified to include AYAs without mobile phone access, starting them in the control arm which allowed them to be eligible for re-randomisation to IP-Nav or CCT.

#### In-person navigation

The proposed IP-Nav involved in-person sessions with peer navigators to influence retention and adherence behaviours among AYAs. Acknowledging that not all peer navigators will necessarily be influential to all AYAs, the workshop identified opportunities to improve positive peer navigator influence. Codesign workshop participants highlighted the importance of feeling appreciated and having non-judgemental navigators who are vested in the preferences, experiences and goals of AYAs. They also desired empathetic navigators who can 'walk with them'; and are open about sharing their lived experiences with HIV treatment. Additionally, they preferred navigators who can comfortably discuss health topics other than HIV, such as sex and sexuality, family planning, life skills and relationships. They also expressed a strong preference for navigators who demonstrate a high level of personal hygiene and neatness. Many participants expressed a desire to have IP-Navigators share informal recreational time in addition to specific HIV counselling (eg, playing a sport together or meeting caregivers/dependents). However, some older participants strongly preferred limited interaction time to accommodate busy schedules.

In response, the pretrial peer navigator training modules were modified to further emphasise active listening skills, facilitation skills, motivational interviewing, support discussion of non-HIV or health-related interests and sexual reproductive health and relationship education modules with appropriate referral options.

The navigator training was adapted to encourage openness, empathy and equip them with the story-telling skills to share treatment experiences and challenges as learning points, and to emphasise the importance of professional appearance when meeting with AYAs. Based on prior peer educator experiences, the research team felt that encouraging external unstructured interactions outside of study procedures could be problematic in terms of maintaining professional boundaries and future scalability. Therefore, this recommendation was not adopted.

Additionally, participants preferred IP-Navigators of the same gender, particularly in boarding schools with gender-segregated environments that extend to visitors. AYAs preferred minimising IP-Navigator changes once assigned. Gender-matching was previously planned; We amended study procedures to avoid navigator switches whenever possible.

Across e-NAV and IP-NAV, the importance of navigators building trust with the AYAs and demonstrating themselves to be trustworthy arose. This included navigators supporting AYAs and in developing the skills needed to self-manage their HIV care, which was then included in Navigator training and re-emphasised during debriefs and annual trainings.

#### Conditional cash transfer

Realtime feedback on CCT prototypes largely endorsed the original plan including amount, delivery method and timing. However, two themes related to CCT arose. Some AYAs expressed a strong desire for confidentiality in who received the incentives, while others felt it was okay for their parents and guardians to know if they received an incentive. AYAs advocating confidentiality asserted, 'funds should be given under water' (ie, given in secret). Flexibility was consistent with the original study protocol, allowing incentives to be given either directly to the AYAs or to someone the AYAs designated. Caregiver notification was not required (though participants under 18 years had caregiver study consent which explained cash incentives may occur). In response to this topic, pretrial training materials around incentives further emphasised discretion. Additionally, there was a strong sentiment among HCD participants that viral suppression should not be incentivised, undercutting the study intent. Participants were concerned that: (1) missing an opportunity to receive an incentive would add shame and a feeling of punishment to the stress of having an unsuppressed viral load, (2) if friends knew they were in the study and were planning to use the extra funds in a social setting, not having the funds would reveal their unsuppressed status and cause social discomfort and (3) some viral failure may be outside of the control of the participant if related to drug resistance and would be unfair to withhold funds. Participants felt incentivising clinic visits would be more appropriate. The study team discussed

the HCD results with care and attention. Ultimately, it was decided that the potential benefit of improving viral suppression with incentives, supported by extant literature but untested in this population, was worth investigating. Measures to attend to the very real concerns of the AYAs included training and documentation procedures to ensure incentive distribution was private and not discussed among study staff members or outside of the study and incentives were based on a combination of viral suppression and clinic attendance; further, questions around confidentiality and shame were added to the post-trial FGDs around the participant CCT experience to continue learning and improve future CCT use.

### Principles to employ across interventions

#### Personalisation

Throughout the workshop, a strong theme around the desire to have interventions tailored to individual preferences as much as possible was present. For example: choosing cash or mobile money for CCT receipt, timing of SMS message receipt in e-Nav, and choosing optional additional interactions or content areas for discussion in IP-NAV. In response, we modified our study standard operating procedures to include flexibility when possible and the navigator training curriculum to build navigator capacity to explore AYA preferences.

#### AYA empowerment

Participants expressed a desire to improve interactions with clinic-based, adult healthcare workers. In response, Navigator training was revised to include assertiveness trainings and role plays on how navigators can build AYA capacity in patient-provider communication, expressing their challenges and asking targeted questions to better understand and self-manage their health.

### Emergent themes

#### AYA awareness of HIV status

During the workshop, AYAs emphasised the importance of being aware of their own HIV status. Specifically, they expressed concerns about not being informed of their HIV status and believed that healthcare workers and caregivers should be responsible for disclosing this information to them rather than leaving it for them to discover on their own. Knowledge of status is critical to a young person taking responsibility and garnering support. While facilitating disclosure directly was outside of the scope of the study as disclosure was an eligibility criteria to enrol, the study team included these findings in feedback presentations to the clinic on study results and revised the navigator training to include postdisclosure support skills.

#### Drug holidays

AYAs described 'drug holidays' as periods when they decide to stop taking their ART for certain durations and for reasons that include school schedules, stigma (fear

of others seeing them take their medication), peer pressure, visitors at home, food insecurity, a feeling of good health, 'no reason' and pill burden. The research team was aware of drug holidays but was surprised by how this term was widely applied to normalised non-adherence. Drug holiday assessments were added to navigator training and study intervention forms. Navigators were trained to provide non-judgemental support for AYAs who discussed drug holidays or intermittent medication adherence, as well as counselling around benefits for all AYAs (including the navigators themselves) to maintaining continual adherence.

#### Importance of transition in AYA retention

Through 18 years of age, routine services at the health facilities are provided through a youth-friendly adolescent centre. When AYAs >18 years transitioned to the adult clinic, they described an impersonal, busier, setting with few peer interactions. The challenge of this transition was raised by participants and emphasised as a critical concern. During an added session on this topic participants expressed a strong desire for more support to help AYAs prepare emotionally and better understand how to navigate the adult clinic. Solutions included AYAs being informed about the need to transition prior to age 16 years and transitioning with a group of peers to ease the shift. While not an outcome of the A4A study, the research team opted to integrate training on transition and incorporate transition issues in Navigator intervention sessions. Further, the team shared these findings during feedback presentations to the study clinics.

#### Youth-led HCD workshop acceptability

Engaging AYAs as codesigners in a workshop-based approach was feasible and well-received by participants. Twenty-one of the participants completed the post-workshop survey, with 100% indicating the workshop met their expectations. The workshop content, mix of activities and quality of the facilitation team was rated 'outstanding' (means: 4.6, 4.4 and 4.4, respectively, on a 1–5 Likert scale). All but one participant reported they would recommend the workshop to others. Different workshop sessions appealed to different AYAs, with at least 20% of participants rating each of the eight main activities as one of their top three favourites. Elicited specific improvement suggestions included having more time for the workshop, an improved venue, reducing the amount of writing participants did and, most frequently, 'no changes' (n=10). The workshop produced results relevant to each of the study 'how might we...?' questions and allowed for participant-driven inquiry.

## DISCUSSION

An HCD approach cofacilitated by youth provided an acceptable and engaging opportunity for youth-driven inquiry, offering specific, unique solutions and key priorities and principles to improve care engagement intervention design pretrial.



Previous text message research with adult populations including pregnant women, lay health workers and men receiving medical circumcision<sup>37–40</sup> informed initial e-NAV design. Lessons from HCD yielded key modifications in our approach to delivering texting interventions to AYAs including altering our messaging architecture to ensure untraceable messages, tailoring message to include non-HIV life priorities, the use of coded language for confidentiality, and reducing message frequency. While consistent with considerations for AYAs text messaging in other research,<sup>41 42</sup> our HCD approach allowed for real-time creation of meaningful messages by youth, improving intervention face and content validity. Despite AYAs in boarding schools being described as higher risk groups for poor HIV treatment outcomes,<sup>43 44</sup> consistent with findings from other studies, we observed the impact of limited access to mobile phones as an obstacle to delivering patient retention interventions among them. Our design workshop problem solving identified specific, unique ways of engaging AYAs with limited phone access. While not all these solutions met trial intervention dose requirements, the HCD approach engaged research team empathy, reinforcing the importance of being as inclusive as possible and expanding eligibility criteria. Other m-health projects with AYAs should consider both creative solutions to phone access and potential limitations of m-health delivery in this key population.

Our study revealed that peer navigation might be most influential in improving retention when engagement with young people is based on mutual trust and extends beyond HIV-specific support. While unsurprising and consistent with extant literature demonstrating the impact of health provider empathy and confidentiality on adolescent trust,<sup>45</sup> this highlights that establishing and managing relational aspects of peer navigator interventions may be as important as peer navigator activities (eg, information sharing, accompanying to clinics). Further, our HCD approach allowed AYAs to lead the dialogue, specifying ways to demonstrate trust worthiness, such as supporting AYAs in developing self-management skills. Our findings also support increasing calls for patient-centredness of HIV care provision across interactions with the health facility, with attention given to patient-provider relationships, integration of medical and non-medical care, support for patient involvement in care and enhanced provider-patient communication.<sup>3</sup> AYAs highlighted that responsiveness to their personalised preferences whenever possible was important to them. For example, they preferred to decide the frequency of communication with navigators, the range of topics discussed and suggested incentive disbursement to be individualised. Both research trials and programmes seeking to engage young people might consider, where feasible, points of personalisation, how to discern preferences or offer choice, and respond to those choices within available resources or structures.<sup>46 47</sup> Adaptations emerging from the HCD process may signal important information to discern causal mechanisms in intervention

effectiveness. Therefore, documentation of adaptations in intervention delivery and future exploration of how these adaptations impacted outcomes may inform other youth-focused strategies.<sup>48</sup>

The iterative nature of HCD, length of interaction (4 days) building comfort, and explicit support for youth-led topics allowed key AYA priorities to emerge such as timing of adult to child status disclosure, support for AYAs status disclosure to others, successful transition from adolescent to adult services, and empowering AYAs to improve patient-provider interactions. Engaging AYAs as coresearchers along with the expansive, divergent nature of the HCD thinking allowed 'drug holidays', a culturally meaningful situation seemingly antithetical to a study focused on improving adherence, to arise for consideration in a way that would be less likely using other research methods.<sup>49</sup> AYAs demonstrated heterogeneity in their workshop activity preferences, with at least 20% of participants rating each of the eight main activities as one of their top three favourites. Likely influenced by AYA co-leadership in workshop planning, this demonstrates good fit between co-creation activities and the participant group. Additionally, it suggests the importance of variety in co-creation approaches to appeal to variation in participant preferences. From the research team perspective, valuable insights came out from each activity.

This work demonstrates an important research-based application of a phased HCD approach: formal, intensive and interactive reflection to document existing knowledge and gaps from relevant research settings and populations during the Discover phase, guiding the remaining phases. Much HCD guidance assumes limited extant knowledge of the topic and setting as HCD begins and, thus, encourages use of basic and very open-ended discussions and observations in the discover phase that may be either resource-intensive or limited in breadth and depth.<sup>50</sup> Many academic researchers familiar with a research topic tend to review extant knowledge informally, rapidly and with minimal stakeholder engagement during study planning and implementation, resulting in limited application of existing knowledge to inform intervention development. While this traditional approach may have sufficient value for a given process, our team's application of formal, iterative documentation, dialogue and review during discovery has distinct benefits. Our team's approach allowed for efficient yet thorough consideration of extant knowledge and prioritisation of knowledge gaps, systematic pairing of design activities with priority topics, and a structure to augment abductive thinking during solution generation. The study balanced drawing on past research and experience among AYAs in this setting to guide design questions with allowing for within study youth-driven inquiry. It also benefited from iteration between the study phases including knowledge from concurrent DCE and FGD research. The relevance of the knowledge documented in discover and the resulting questions generated in define were supported by the AYAs positive reception of the workshop topics,

broad learning about study areas of interest across ‘how might we...?’ questions, few but meaningful inductive workshop topics, and salient pretrial adaptations resulting from the develop phase. This systematic approach to discover would be appropriate for teams of researchers embedded in their study area, bringing significant past research and experience in the topic, and able to organise a committed review group.

Principled decision-making is necessary in applying HCD findings to research studies when not all insights can be accommodated. For example, the study implications of workshop participants’ guidance that viral suppression should not be incentivised would have removed a trial arm. While significant revisions may be appropriate, the research team applied evidence from other settings and theory to maintain the incentive arm. However, the empathy established during the HCD process around incentive-related concerns, namely that AYAs feel blamed for lack of suppression when it could be a resistance issue, led to the study instituting a process to flag and clinically review unsuppressed viral load results, as well as peer navigator training to avoid blame. Balancing study aims with design results is critical to HCD research, as is transparency with HCD participants. When inviting participants into an HCD research process, it is the facilitators’ responsibility to ensure that participants are advised that not all solutions will be adopted and that participants be given information to help them understand the scope of the research.<sup>26 33</sup> Future analysis of intervention effectiveness will explore the impact of recommended adaptations that were not possible to include through qualitative interviews and intervention satisfaction surveys.

### Limitations

While the broad HCD approach incorporated AYA-involved iteration on the study design across formative methods (ie, FGDs, DCE and HCD workshop) and over time (eg, HCD phases and peer navigator workshop participants working as intervention implementers which allowed ongoing reflection and adaptation during the trial), iteration on specific design elements by all AYA participants was limited to the 4-day workshop. The inclusion of both peer navigator intervention implementers living with HIV and AYAs with characteristics consistent with expected trial enrollees allowed for multiple intervention design perspectives. However, AYAs who were not peer navigators may have felt less knowledgeable or open to share their experiences. Workshop facilitators used small groups, anonymous individual sharing methods such as post-it notes, and other facilitation techniques to support equal participation. Participants were willing to openly discuss living with HIV, literate in Kiswahili or English, and able to create time to attend the workshop. They may have greater resource access than other AYAs who would benefit from HIV retention support. Study results may be applicable and informative for transferable settings with similar key characteristics such as

health systems, HIV epidemiology, research experience and youth population characteristics.<sup>51</sup>

### CONCLUSIONS

Compared with more traditional qualitative research methods, our youth-led HCD approach supported AYA-driven inquiry; specific, unique, real-time problem solving and solution creation; and rapid empathy cultivation, proving an acceptable, rapid and effective means of identifying intervention-tailoring opportunities pretrial. Findings highlight that interventions supporting AYAs retention in HIV care and services should prioritise flexibility and individualisation to respond to AYA preferences whenever possible. Attention to relational aspects of care interactions, confidentiality, episodic adherence interruptions and care transitions as youth age are paramount.

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