

# Experiences of initiating rapid antiretroviral therapy among people newly diagnosed with HIV in East London: A qualitative study

R Dhairyawan, A Milner, J Thornhill, L Kwardem, N Matin, C Orkin, K Deane

## Corresponding author:

Dr Rageshri Dhairyawan

Barts Health NHS Trust,  
London, London, UK

Queen Mary University of London, SHARE Collaborative,  
London, UK

Email: [Rageshri.dhairyawan@nhs.net](mailto:Rageshri.dhairyawan@nhs.net)

Telephone number +447980723753

## Co-authors:

- Dr Adrienne Milner  
Brunel University London, Uxbridge, UK
- Dr John Thornhill  
Queen Mary University of London, SHARE Collaborative,  
Barts Health NHS Trust,  
London, UK
- Longret Kwardem  
4M Network of Mentor Mothers, London, UK
- Dr Nashaba Matin  
Barts Health NHS Trust,  
London, UK
- Professor Chloe Orkin  
Queen Mary University of London, SHARE Collaborative,  
Barts Health NHS Trust,  
London, UK
- Dr Kevin Deane  
The Open University,  
Milton Keynes, UK

**Word Count: 2994 words**

**MeSH terms: HIV, Anti-retroviral Agents, Qualitative research**

**Funding statement:**

This work was supported by the British HIV Association grant number 5020.

**Competing Interests Statement:**

RD has received grants from the British HIV Association and speaking honoraria from Gilead and ViiV.

JT has received grants from the British HIV Association and Gilead and speaking honoraria from Gilead.

NM has received support from ViiV for conference registration fees.

CO has received grants from ViiV, Gilead, MSD, GSK and Astra Zeneca, and speaking honoraria from Gilead, ViiV and MSD. CO is Chair of the Medical Women's Federation.

**Contributorship Statement:**

RD and KD are responsible for the overall content as guarantors.

RD designed the study, carried out and analysed the interviews and drafted the manuscript.

AM reviewed the study design, carried out and analysed the interviews and reviewed the manuscript.

JT reviewed the study design, advised on the running of the study and reviewed the manuscript.

LK reviewed the study design, advised on the running of the study and reviewed the manuscript.

NM reviewed the study design and the manuscript.

CO reviewed the study design and the manuscript.

KD designed the study, supervised the research and drafted the manuscript.

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## **Abstract**

### Objectives

We aimed to explore the experiences of people who initiated rapid antiretroviral therapy (ART) within seven days of HIV diagnosis, as part of routine care in London.

### Methods

Using purposive sampling, 18 in-depth, semi-structured interviews were conducted between December 2020 - September 2021 with people who started rapid ART at Barts Health NHS Trust. Participants aged 22-69 years included 15 cisgender men and 3 cisgender women. Five identified as heterosexual and 13 as gay and bisexual and other men who have sex with men. Ethnic identities: 6 White Non-UK, 5 White UK, 3 Black Caribbean, 2 South Asian, and 2 East Asian. Interviews explored feelings about the new HIV diagnosis, attitudes to rapid ART including barriers to and facilitators of starting. Thematic analysis of transcribed interviews was undertaken.

### Results

Four themes were identified 1) being offered rapid ART is acceptable 2) it's a way of taking control of their health 3) the need for information and support and 4) an individualised approach to care. Reasons for starting included getting well, staying well, and reducing the likelihood of passing on HIV. Facilitators included being given comprehensive information about treatment and managing potential side-effects, and a supportive clinical team. Support specified included a non-judgemental attitude, approachability, reassurance, encouragement and information about peer support. Most participants expressed they could not understand why people would not begin treatment, but suggested needing more time to decide and denial of diagnosis as possible barriers.

### Conclusions

To our knowledge this is the first qualitative study exploring the experiences of people initiating rapid ART in the UK. It was deemed acceptable to an ethnically diverse, predominantly male sample of people newly diagnosed with HIV. Future research should include strategies to recruit a more gender diverse sample and those who declined, or stopped rapid ART.

## **Key messages**

- **WHAT IS ALREADY KNOWN ON THIS TOPIC.** High uptake rates of rapid ART (started within 7 days of HIV diagnosis) have been reported in a variety of settings. Qualitative studies have found a range of barriers to and facilitators of uptake.
- **WHAT THIS STUDY ADDS.** This is the first qualitative UK study to focus on the experiences of people starting rapid ART as part of routine care. We found that rapid

ART was acceptable to an ethnically diverse, predominantly male sample of people newly diagnosed with HIV in London.

- HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY. We recommend an individually tailored approach to care when offering rapid ART as well as information, counselling and peer support.

## Introduction

Since 2015, the World Health Organisation has recommended people living with HIV should start antiretroviral therapy (ART) regardless of CD4 count<sup>1</sup>. However, pathways to ART initiation can be protracted, resulting in unnecessary barriers to ART access<sup>2,3</sup>. In settings with prolonged waiting times for ART, there are high rates of disengagement<sup>4,5</sup>. In 2017, the World Health Organisation recommended rapid ART, defined as initiating ART within seven days of a HIV diagnosis<sup>6</sup>. Potential benefits of rapid ART include improved clinical outcomes such as reduced time to viral suppression, fewer tuberculosis and severe bacterial infections and greater engagement in care<sup>[7-10]</sup>. The latest ART guidelines from the British HIV Association (BHIVA) are the first to mention rapid ART outside of the context of primary HIV infection in the UK<sup>11</sup>. However, they focus on ART offered on the same day as HIV diagnosis (not within seven days), recommending it when an individual wishes to, is ready to start, and it is clinically appropriate, as long as information on the potential advantages and disadvantages are given.

Literature looking at rapid ART has found high uptake rates, in a variety of settings<sup>8,9,10,12,13</sup>. Qualitative studies in the United States (US), Eastern Africa and South Africa show various barriers to and facilitators of uptake among people living with HIV and their healthcare professionals<sup>14-23</sup>. Barriers include time to adjust to the new HIV diagnosis, shock, denial, fear of domestic violence, anticipated side-effects and logistical issues. Facilitators such as wanting to improve health, a sense of agency, the benefits of viral suppression and provider knowledge and attitudes have been reported<sup>14-23</sup>.

In the UK, high uptake has been demonstrated in an urban population of gay and bisexual and other men who have sex with men (GBMSM)<sup>24</sup>. However, beyond this there is a lack of evidence on the uptake of and experiences of people starting rapid ART in the UK. This article reports findings from a qualitative study aiming to explore the experiences of people who started rapid ART within seven days of diagnosis, and the barriers to and facilitators of rapid ART initiation.

## Methods

In 2019, Barts Health NHS Trust launched the East London Immediate ART (ELIA) pathway offering rapid ART within seven days of HIV diagnosis (Supplementary Figure 1). Barts Health NHS Trust serves a population in East London with a high UK HIV prevalence of between 5.7 - 11.8 cases /1000 people aged 15-59 years<sup>25</sup>. This includes communities with complex social and healthcare needs, due to the impacts of poverty, systemic racism, insecure immigration status and homelessness. During the first two years, approximately 180 individuals were offered rapid ART with 87% of individuals taking up the offer<sup>26</sup>. Of those offered rapid ART, 26% were female, 51% were GBMSM, 45% were White (UK and non-UK) and the median

age was 34 years. Of those that didn't start rapid ART, some waited for baseline blood results and initiated ART more than seven days after diagnosis.

Between December 2020 – September 2021, 18 in-depth semi-structured interviews were conducted with people who started rapid ART through the ELIA pathway. A purposive sampling approach was used to ensure a wide range of participants with different background characteristics including gender, age, ethnicity and sexual orientation. Participants were identified by the clinical team from the patient log and given information about the study. For patients who indicated interest in participation, the study team provided more information about the study, and on agreement arranged an interview time.

All interviews were conducted by RD and AM. RD is a British Asian, female doctor. AM is a white, queer, female social scientist and has a PhD. Both RD and AM are experienced researchers and were supervised for this study by KD who specialises in qualitative methods. None of the study participants were previously known to either RD or AM. RD works at Barts Health NHS Trust as a HIV clinician. Throughout the process, she reflected with AM and KD on her position as both a clinician and researcher, and how this may affect her approach to the interviews and analysis. She did not approach any potential participants or interview any participants that she had previously had any contact with as a clinician.

Eleven interviews were conducted over the telephone, five over Zoom and two in person. The use of Zoom and telephone was due to the COVID-19 pandemic which made in-person interviews impractical due to social distancing requirements. All participants were interviewed on their own. The study team conducted a quality review of the data emerging from the first five interviews to ensure that the mode of interviews was gathering data of sufficient quality and depth. All interviews were conducted with a pre-prepared interview topic guide devised by the study team that had been piloted with two persons living with HIV (Supplementary Figure 2). The interview guide was developed with the socio-ecological model of health as a conceptual framework<sup>27</sup>. This guided both the questions asked and also the background to the study, as the team wanted to know what people from diverse backgrounds and communities experienced. The interviews explored participants' feelings about the new HIV diagnosis, attitudes to ART initiation, barriers to, and facilitators of accepting rapid ART, and recommendations for future improvements. The interviews lasted between 30-45 minutes. A debrief was conducted after each interview between the interviewer and KD to discuss emerging themes and any unanticipated methodological or ethical concerns. No participants required repeat interviews and none dropped out of the study. Participants were reimbursed for their time with £30 gift vouchers.

All interviews were recorded and transcribed, and managed in Nvivo Version 12. Transcripts were analysed using a reflexive thematic approach<sup>28</sup>. The first three interviews were open coded independently by RD and AM to produce a coding framework for the remainder of the interviews<sup>29</sup>. Following the standardisation of all codes, RD, AM and KD developed the core themes, which were then refined in consultation with the broader study team. Ethical approval was granted by Camden and Kings Cross Research Ethics Committee (20/LO/0390). Participants were given an information sheet and consent form in advance of the interview and time to ask questions. Participants provided verbal consent, which was recorded and

transcribed or written consent. The study was funded by a BHIVA Research Award 2019, reference 5020.

## Results

### Participant characteristics

The sample of 18 participants had a median age of 34 (range 22-69 years; median age of men = 33 and women = 41 years). Time from diagnosis to interview ranged from 2-22 months. All participants were still taking ART at the time of interview. Table 1 has more details.

Table 1. Participant demographics

Demographic		n (total N = 18)
Gender	Cis-male	15
	Cis-female	3
Sexual orientation	GBMSM	13
	Heterosexual	5
Ethnicity	White Non-UK	7
	White UK	5
	Black Caribbean	2
	South Asian	2
	East Asian	2

Our sample was representative of the ELIA cohort with regards to age, but women, people from Black ethnic groups and heterosexuals were under-recruited.

Through our analysis, four themes were identified.

#### 1. Being offered rapid ART is acceptable

Being offered rapid ART within seven days of HIV diagnosis was deemed acceptable in retrospect, using Sekhon's theoretical framework of acceptability<sup>30</sup>. Many participants viewed it as the next step after diagnosis, particularly if they felt unwell. Most expressed they could not understand why people would delay treatment, as it is potentially lifesaving and means that they can lead a "normal life". One participant acknowledged that having regular check-ups meant their life span could even be extended, as any illnesses would get picked up early. However, some said that delaying treatment could be understandable, as the HIV diagnosis, its implications and information about treatment could be overwhelming. Patients were also making a decision to start lifelong treatment, so this may require some time for consideration. When asked about why people may not accept rapid ART, needing more time to decide, "to get comfortable with the diagnosis", denial of diagnosis and not wanting to live were suggested.

Table 2. Theme 1: Being offered rapid ART is acceptable

Participant demographics	Quote
White UK GBMSM aged 26-35yrs	<i>"I've kinda dealt with it a bit more pragmatically – I've seen there's a problem that needs to be fixed, and I think that just comes from the way that I work. I just saw it as a problem that needed sorting."</i>
White non-UK heterosexual woman aged 36-45yrs	<i>"Why you wouldn't? You've got a sickness that you know is gonna kill you if you don't take the treatment. You've got research over the years that this treatment can help you have a normal life – maybe a better life because you are checked every six months."</i>
White UK GBMSM aged 26-35yrs	<i>"So, I do get the hesitance because there is a lot to take in. Before you start on meds, you might want to just get comfortable with what's going on, before you then put this thing in. You are introducing something that's gonna be part of your daily routine...potentially the rest of your life, so I understand why people might be a bit hesitant at the start."</i>
White UK GBMSM aged 26-35yrs	<i>"So, like, there was never really anything to think about. It was like, I don't know, when you go to the hospital and you've got a broken leg, you don't have to think about whether or not you want your leg put in a cast, they just do it because that's what you need. So, it was kind of like that. I was just sort of like 'yep, fine, let's like... give me my tablets, let me go, I'll do it'."</i>
Black Caribbean heterosexual man aged 46- 55yrs	<i>"Starting treatment is like what you'd say in my language, is like a no-brainer."</i>

## 2. Rapid ART is a way of taking control of their health

Participants expressed viewing HIV as a serious diagnosis, and ART life-saving. Therefore, taking rapid ART was a way of taking action quickly to regain control of their health, and avoid becoming unwell. Several participants had been unwell for months, so the diagnosis gave them an explanation for their symptoms and a way of resolving them. Asymptomatic participants saw rapid ART as a way in which they could stay well. Some participants knew of people who had died from HIV, so this reinforced their view that ART could prevent this happening to them. Participants took comfort in the fact it was offered so quickly and that their healthcare needs were being prioritised and taken seriously. Reasons for starting

included the desire to get well, stay well, to reduce their likelihood of passing on HIV and to live “a normal life” again.

Table 3. Theme 2: Rapid ART is a way of taking control of their health

<b>Participant demographics</b>	<b>Quote</b>
White UK GBMSM aged 26-35yrs	<i>“I have always had the thought process that this medication was life-saving, and so therefore I just need to take it.”</i>
Black Caribbean heterosexual man aged 46- 55yrs	<i>“You know, there’s only one way and it’s to start treatment. If you go the other way then you’re gonna get sicker, you’re gonna mess your life up.”</i>
White UK GBMSM aged 26-35yrs	<i>“I mean, I was very happy to be offered it on the day. I took comfort I think in knowing how quickly everything was being responded to.”</i>
White UK GBMSM aged 26-35yrs	<i>“Like the fever just came and went and came again so it was really, really, really upsetting. Really annoying, and I just wanted something that can get rid of it already, so I was really, really happy that the doctor provided a treatment and ... after several days I started to feel better.”</i>
White non-UK GBMSM aged 20-25yrs	<i>“I mean of course like with, with any sickness, you start with treatment as soon as possible for your wellbeing, right?”</i>
East Asian GBMSM aged 26-35yrs	<i>‘I know that this treatment can help so that I have some hope. I know that I will be better’.</i>

### 3. The importance of being offered information and support

Many participants felt that receiving comprehensive information from the healthcare team was a facilitator to starting and staying on rapid ART. This included information on how treatment worked, managing potential side-effects, how to access peer support and counselling. The majority wanted everything explained to them by the healthcare team at initial appointments. Those that didn’t, found it overwhelming. They preferred to take the clinicians’ advice and to read information in their own time.

The importance of a supportive clinical team, who were approachable, non-judgemental, encouraging and reassuring was emphasised. Many said that being able to ask questions and having them answered promptly, helped. Some participants also said that seeing an improvement in their symptoms and blood tests (particularly the HIV viral load) encouraged



them to continue treatment. They also appreciated advice on whether or not and how to share their diagnosis with others, and how they could access support for this if required.

Most participants said that they valued being offered peer support and counselling. However, preferences about the timing of when these were offered varied, with some preferring them immediately after diagnosis, and some months afterwards, when they felt more ready. This suggests that the offer should be made regularly from diagnosis onwards. Some participants also talked about attending peer groups for people newly diagnosed with HIV, where they found comfort in hearing other peoples’ narratives.

Trust in the healthcare team was seen as an important facilitator to starting rapid ART. Many said that they had been encouraged to start rapid ART by their care team, and that they had trusted in the advice they were given.

Table 4. Theme 3: The importance of being offered information and support

<b>Participant demographics</b>	<b>Quote</b>
White non-UK GBMSM aged 20-25yrs	<i>“They gave us a lot of literature explaining what HIV meant especially to young people, support services and the viral load and the explanation for all that. So yeah, it’s all been quite good, there, there wasn’t a lack of information.”</i>
White UK GBMSM aged 26-35yrs	<i>“What would have helped is just being told what to start with. I remember getting that list of all the meds, and I was just like, ‘I have no idea what you want from me, um, in this situation.’ I appreciate the information, and it was helpful, but... I just said, ‘Give me what will help.’”</i>
White UK heterosexual woman aged 56-65yrs	<i>“Seems like all the people that I’ve met are lovely, you know, caring and gentle and considerate. And trustworthy, I don’t feel that you know, anybody is going to be sort of you know, underhand in any way, I feel quite comfortable with it all.”</i>
White non-UK heterosexual woman aged 26-35yrs	<i>“So, yeah, probably the first thing is communities – that one is just quite helpful because you can see then that it’s other people who have the same issue, or same. You can talk with them, even, you know, you don’t talk, for example. In my case, I didn’t talk – I was just listening...”</i>
White UK GBMSM aged 26-35yrs	<i>“There was no judgement. I found it a very open environment and a safe environment.”</i>
White UK GBMSM aged 26-35yrs	<i>“She was just so nice to me when she told me. She offered me all the help that I wanted. She checked on me three or four times within the first couple of months and then again six months down the line, she</i>

	<i>just called me and I didn't ask her to. She would just call out of the blue and just ask me if I was alright, how I was doing, and that was really nice."</i>
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#### 4. Providing an individualised approach to care

An individualised approach to care was mentioned as being important to several participants. For example, one said that initially his HIV viral load was quick to drop, but then took a while to get to undetectable levels. He requested more frequent monitoring until the viral load was undetectable. Recognising his worry, the healthcare team agreed to the extra blood tests, which he was grateful for and alleviated his anxiety. Another preferred few tablets and was offered a switch to one pill, which they accepted. Participants recommended that the healthcare team should ask the individual what they needed.

Some participants did not want to be given a choice on which rapid ART regimen to start, preferring to be told by the healthcare team which they thought would be best for them. This could be regarded as being too paternalistic in approach for some people, so again an individualised approach should be taken. Indeed, some participants expressed that they wanted a choice.

There were also differences in attitudes to the peer support worker offered. Some participants preferred to see someone from a similar sociodemographic background to them, with regards to gender, age or sexuality. The last quote in Table 5 from the White UK GBMSM aged 46-55yrs demonstrates this well. This may make them more likely to continue with peer support. Participants who reported negative experiences of peer support said they did not feel like they had life experiences in common with the worker they were allocated. However, some participants had no preference. This suggests participants should be offered a choice where available.

Table 5. Theme 4: Providing an individualised approach to care

<b>Participant Characteristics</b>	<b>Quote</b>
East Asian GBMSM aged 26-35yrs	<i>"Different people have different ways of dealing with their problems. I mean generally that's how you should be approached. You see the individual... you tailor to their needs."</i>
South Asian GBMSM aged 20-25yrs	<i>"Actually, I was a bit bad with my medication when I first started, like just being consistent with it. So then once they realised that they, instead of giving me two pills they gave me a brand-new pill which was all of them put together one smaller pill, which I take now. Just one pill a day and it's so easy."</i>
White UK GBMSM aged 26-35yrs	<i>"So, they were really great coz they allowed me to come back like more regularly. I was like 'well, can I come back in three weeks or something? So, they</i>

	<i>allowed me to come back in three weeks as opposed to three months, just because that's what I wanted."</i>
White UK GBMSM aged 46-55yrs	<i>"I think it's really important that I relate to them. The person I spoke to had come from a similar way that they contracted it and they'd also got that same attitude towards it 'cause they'd lived through all the horrible adverts of the 90s and we could laugh at those things and certain things."</i>

## Discussion

In this qualitative study of people who initiated rapid ART, within seven days of diagnosis as part of routine care at Barts Health NHS Trust in London, we found rapid ART was deemed acceptable. Using thematic analysis of 18 semi-structured interviews, four themes were identified. These were that 1) being offered rapid ART is acceptable 2) it's a way of taking control of their health 3) the need for information and support and 4) an individualised approach to care.

The participants found that being offered rapid ART was acceptable in retrospect, meeting the component constructs of 'affective attitude', 'intervention coherence' and 'self-efficacy' in Sekhon's theoretical framework of acceptability<sup>30</sup>. Qualitative studies in the US, Eastern Africa and South Africa<sup>[17-19]</sup> and uptake rates reported in the UK also found rapid ART to be acceptable<sup>27</sup>. Like participants in the US study, our participants viewed rapid ART as the logical next step after diagnosis and found reassurance in the speed of the response to diagnosis from healthcare providers<sup>18</sup>.

Most of the participants in our study could not understand why people would not start rapid ART. This is likely to be because all of our sample initiated rapid ART. When asked about why people may not start, participants felt it may be due to needing more time to decide, denial of diagnosis and not wanting to live. Other qualitative studies have shown more time to process the diagnosis, and denial are barriers to starting immediately<sup>[17-19]</sup>. Additional barriers cited in other qualitative studies, but not ours, include feeling too healthy to need medication<sup>17</sup>, fear of side-effects<sup>17,20</sup>, the stigmatising nature of attending clinic<sup>20</sup>, not understanding the benefits of rapid ART<sup>17</sup> and logistical issues<sup>18,19</sup>.

Many participants expressed that taking rapid ART helped them to feel more in control of their health at the time of a serious diagnosis. This suggests that rapid ART may help people feel empowered to be proactive about their diagnosis. Participants of a US study also reported this feeling of being in control and related this to a reduction in the anxiety of getting physically unwell<sup>18</sup>. The authors of this study felt that this mitigation in anxiety may even partially ease the psychosocial challenges of a HIV diagnosis. Another US study also reported that participants feared what would happen to their health if they did not start treatment<sup>19</sup>.

Being given comprehensive information, the quality of the relationship with the healthcare team and being treated as an individual were important facilitators of accepting rapid ART in

our study. In the US, qualitative studies found that clinical teams that were supportive, warm and encouraging, and skilled and knowledgeable were important<sup>18,19,22</sup>. In East African settings, participants also highlighted the need for individualised counselling and that the healthcare team were accessible<sup>17</sup>.

There were considerable strengths to our study. Firstly, to our knowledge, this is the first qualitative study examining the experiences of people initiating rapid ART in the UK. Due to the heterogeneity of the ELIA patient cohort, we were able to recruit an ethnically diverse sample, and a proportion of our sample was heterosexual. The study was initiated in December 2019, before the COVID-19 pandemic – as a study team we had to overcome several barriers related to this. These included swiftly adapting to carrying out Zoom and telephone interviews as in-person interviews were not possible, and pausing the study during redeployment of several clinical members of the team in the first and second waves.

Limitations included difficulties recruiting cis-women, trans and non-binary people. This was despite regular review of our recruitment strategies within the study team, which included cis-women and lived experience of HIV. Out of the eligible study population, more than two thirds were cis-men so there were fewer cis-women and even fewer (<5) trans and non-binary people to approach. It's possible that cis-women, trans and non-binary people may have preferred to meet the study team in person to discuss their potential involvement, rather than by phone or email. Barriers to recruitment in general may have included not being familiar with taking part in research, adjusting to the HIV diagnosis and stigma. We were unable to recruit people who had stopped rapid ART.

Our study has several implications. It suggests that rapid ART, starting within seven days of diagnosis, is acceptable and even desirable, offering a sense of empowerment and providing benefits along with other parts of HIV care. The BHIVA guidelines recommend as a good practice point that “the advantages and disadvantages of starting ART the same day as diagnosis are discussed with each person, including the lack of proven benefit for same-day ART in a UK or similar setting”<sup>14</sup>. We agree that informed choice is essential and believe that our study contributes to evidence for this.

We recommend that clinics develop streamlined pathways to offer rapid ART within seven days of HIV diagnosis to eligible individuals within a package of support. This should include counselling and peer support. This package should be tailored to the individual depending on their needs at different stages after the diagnosis. People must be able to make an informed decision about whether to start ART, so providing comprehensive information about rapid ART and easy access to clinic staff for queries is essential.

Future qualitative research should include strategies to recruit a more gender diverse sample of participants, those who did not start or stopped rapid ART and to interview those that did start rapid ART several years later to explore how their attitudes to it have developed over time.

## Conclusion

To our knowledge this is the first qualitative study exploring the experiences of people initiating rapid ART, within seven days of HIV diagnosis in the UK. Starting rapid ART was acceptable to an ethnically diverse, predominantly male sample of people newly diagnosed with HIV. Findings emphasise the importance of a tailored approach to care, the quality of the relationship with the HIV clinical team, and the need to provide comprehensive information, counselling and peer support when offering rapid ART. Further research should look at strategies to recruit a more gender diverse sample, people who did not accept rapid ART, or stopped rapid ART.

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