AIDS Care

Psychological and Socio-medical Aspects of AIDS/HIV

ISSN: 0954-0121 (Print) 1360-0451 (Online) Journal homepage: www.tandfonline.com/journals/caic20

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To cite this article: Georgina Gnan , Jane Vosper, Caroline Foster, Janet Seeley, Victor Musiime, Sarah Fidler, Graham Frize & Michael Evangeli (2026) "If there was no stigma around it, I would tell people": perspectives of UK youth living with perinatally acquired HIV, their social networks and healthcare professionals on HIV status sharing, AIDS Care, 38:6, 1268-1281, DOI: 10.1080/09540121.2026.2614346

To link to this article: https://doi.org/10.1080/09540121.2026.2614346

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Published online: 21 Jan 2026.

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AIDS CARE
2026, VOL. 38, NO. 6, 1268–1281
https://doi.org/10.1080/09540121.2026.2614346

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"If there was no stigma around it, I would tell people": perspectives of UK youth living with perinatally acquired HIV, their social networks and healthcare professionals on HIV status sharing

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ABSTRACT
Sharing one's HIV status with others is complex for youth with perinatally acquired HIV (PAH). However, the support from sharing one's HIV status may assist with HIV-related challenges. This study explored barriers and facilitators of HIV status sharing among UK-based youth living with PAH. Drawing on semi-structured interviews with ten youth with PAH, ten members of their social networks and five HIV professionals, this study examined the complex relational nature of disclosure. The data were examined using thematic analysis. While many youths expressed a desire to be open, sharing was shaped by stigma, cultural silence, familial secrecy, fear of rejection and lack of HIV education. Facilitators included emotional readiness, peer support, increased knowledge and positive prior experiences of disclosure. Social network participants often saw themselves as supportive, although professionals tended to focus on potential emotional risks. This study underscores disclosure as a process requiring ongoing support and suggests that empowering youth with education, skills and confidence is key. It identifies the need for better professional guidance and disclosure interventions co-designed with youth to support health and well-being. The findings have implications for stigma reduction, education and psychosocial support, contributing to improving the quality of life for youth with PAH.

ARTICLE HISTORY
Received 19 October 2025
Accepted 5 January 2026

KEYWORDS
HIV; disclosure; status-sharing; perinatal HIV; qualitative

SDG KEYWORDS
Good health and wellbeing; Reduced inequalities

Introduction

Approximately 1.7 million young people aged between 10 and 19 years live with HIV globally. Many of this population have perinatally acquired HIV (PAH; UNAIDS, 2021).

Many stressors faced by youth born with HIV include those experienced by all people living with HIV. These include lifelong medication adherence (Mosha et al., 2024), sexual and reproductive health decision-making, anxiety about onward HIV disclosure (sharing one's HIV status with others; Evangeli & Wroe, 2017) linked to HIV-related stigma (Perger et al., 2025; Robinson et al., 2023), managing relationships, and some hospitalisation and pain (Mofenson & Cotton, 2013).

However, youth living with PAH experience additional challenges. This can include experiencing multiple caretaking transitions and losses due to parental illness or death (Lowenthal et al., 2014), negative parental disclosure attitudes, and anxiety about revealing their mother's (or other family members') HIV status (Hogwood et al., 2013). The rates of viral suppression in youth with HIV are variable and often associated with poor antiretroviral therapy (ART) adherence (Rakhmanina et al., 2024). There is also evidence of lower levels of well-being in youth living with PAH than in their HIV-unaffected peers (Dessauvagie et al., 2020).

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Sharing one's HIV status with others has the potential to facilitate positive outcomes in relation to these challenges. Sharing one's status may improve ART adherence, and the fear of sharing is commonly cited as a barrier to adherence (Audi et al., 2021; Buchanan et al., 2012) in youth living with PAH. There is evidence of less medication hiding and higher CD4 counts being associated with onward disclosure (Calabrese et al., 2012). Sharing may also improve engagement in care among people with PAH, as has been shown in a wider HIV-positive population (Ostermann et al., 2015). Furthermore, sharing may improve well-being through increased social support (Nöstlinger et al., 2015), and enhanced social self-competence (Wiener & Battles, 2006). As sharing one's status may be an avenue to improving youth well-being, it is important to understand what the barriers and facilitators to sharing are and how to support youth in making decisions about sharing their status and helping build their confidence.

While a small number of qualitative studies have explored youth experience of disclosure (e.g., Audi et al., 2021; Buchanan et al., 2012; Callen et al., 2022), research on barriers and facilitators is limited. Furthermore, there is a lack of research exploring views on HIV sharing from the perspective of friends, family, partners, or health professionals.

Many of the barriers to sharing are about the anticipated reactions of people surrounding the individual living with HIV. As disclosure is inherently a social process, it could be particularly meaningful to explore HIV-sharing from multiple perspectives. It is the people in an individual's social network who will be the ones providing support after sharing. These individuals may have insights into what they think is helpful or unhelpful in relation to sharing, especially around what information they feel is important, and what ways of sharing could potentially lead to a positive reaction.

The objective of this study was to further understand the sharing process and provide insight into the reasons behind low levels of disclosure. This is a crucial step towards supporting youth living with HIV in making decisions about sharing their status. The study aimed to understand youths' experiences and perspectives of barriers and facilitators to sharing their status, as well as the perspectives of their social network, including friends, family, and partners, in addition to health care professionals.

Materials and methods

Design and setting

This study used a cross-sectional qualitative design, involving semi-structured interviews. Data were drawn from a feasibility study of an intervention aimed at supporting youth in making decisions about sharing their status (HIV Empowering Adults' Decisions to Share – UK/Uganda Project (HEADS-UP); Evangeli et al., 2020). While data were collected in both the UK and Uganda, this study focuses exclusively on the UK findings due to the availability of qualitative research expertise and resources that enabled more in-depth data collection and analysis in that setting.

Participants

Participants were recruited from four National Health Service (NHS) sites in specialist urban HIV clinics for youth living with HIV, and one HIV charity, between September 2019 and June 2020. A sample size of approximately 25 (ten youth aged 18–25 years with PAH (YP), ten people in their social network (SN; e.g., friends, family, partners), and five professionals (Pr) working with youth with PAH) was determined prior to the initiation of data collection, as this was expected to be sufficient to achieve thematic saturation. Youth with PAH were included if they (i) were aged 18–25 years, (ii) were living with PAH, (iii) had knowledge of their own HIV status, and (iv) were able to give informed consent. Youth were excluded if they had (i) current serious mental health problems, (ii) moderate to severe learning disability/executive functioning difficulties, (iii) current serious physical health problems with life expectancy < 12 months, (iv) inability to understand or communicate in English, and (v) current participation in other psychosocial intervention/support research. Friends, family, and partners of youth with PAH were able to take part in the study if they were (i) aged 16 years or over; (ii) friends, family, or partners of people aged 18–25 with PAH; (iii) aware of the HIV status of the youth with PAH; and (iv) able to give informed consent. Participants were excluded if they were unable to understand or communicate in English. Professionals (healthcare

professionals and peer support workers) were included if they had current or recent involvement in caring for people aged 18–25 with PAH.

Ethics

Ethical approval was obtained from NHS and University ethics committees (IRAS:252582). Written informed consent was obtained from all participants.

Procedure

Youths with PAH were identified by clinicians and representatives of an HIV charity. PAH status was ascertained using the following criteria: HIV diagnosis before 15 years, evidence of parental HIV+ diagnosis/maternal death consistent with HIV, no other risk factors for behavioural acquisition. Youths who consented to participate were asked whether they could identify any friends, family members, or regular partners who they thought might like to participate. A young person was asked to discuss the project with them, and if they were willing, they contacted the researcher to go through the consent process. Professionals working with youths with PAH were identified by the research team, attempting to sample across a range of clinics and support organisations.

The participants participated in semi-structured interviews, either face-to-face ($n = 2$) or via Zoom ($n = 23$). Participants' payments of £20 were made to non-professional participants.

The research team generated interview guides in collaboration with the project advisory group, which comprised health professionals in HIV care, academics, youth living with HIV, and representatives from an HIV charity. Separate interview guides (available in the supplemental materials) were designed for (i) youth living with HIV, (ii) their support networks, and (iii) professionals. The interview questions addressed perceived barriers and facilitators to sharing, advice about sharing, and what could help youth make decisions about sharing. For youth, the questions included, "What are the reasons why you sometimes do not share your HIV status with others?" "What has helped you to make decisions about sharing your status?". For their social network, questions included, "What do you think are the main reasons youth born with HIV share their status with others?" and "What is helpful if someone is sharing their HIV status with you?". For professionals, questions included, "What advice do you or other professionals give youth about sharing their HIV diagnosis with others?" "What is helpful for youth if they decide to share their status?"

Care was taken to avoid leading or closing the questions. The interviews were conducted by the first author, who was trained using role-play techniques by the final author (an experienced Clinical Psychologist with experience working with adults living with HIV). All the interviews were recorded and transcribed. The interviews lasted between 25 and 50 min.

Analysis

Reflexive thematic analysis (Braun & Clarke, 2019) was used to generate themes and sub-themes.

The first author transcribed all interviews. The final author listened to several interviews and read their transcripts. The initial codes were generated by the first author. The second author reviewed and added codes for the five interviews, and the second and final authors reviewed all initial codes. Discrepancies between authors were resolved through discussion, and further revisions were made until an agreement was reached. Themes and subthemes were developed and reviewed based on the initial codes. These themes were defined and named.

Quality, reflexivity and positionality

Quality standards were used to inform the study (Elliott et al., 1999). The analysis was grounded in examples, and credibility checks of the first author's coding were conducted by the second and final author. Reflexivity was maintained through reflexive journaling and repeated discussions among the first, second, and final authors. Additionally, reflexivity related to the first author's identity and life experiences was

maintained throughout the study. The first author is a white, 28-year-old (at the time of the study) who was not living with HIV, identified as LGBTQ+, and grew up outside the UK. Prior to this study, she worked with marginalised groups but did not have experience working with people living with HIV prior to this study. Following the guidelines for owning one's perspective (Elliott et al., 1999); the first author kept a diary to reflect on the influence of personal thoughts and values on the collection and interpretation of the data. The first author wrote memos to explore the reflections, ideas, and concepts arising from the data. This allowed for data comparisons and was vital in linking each stage of coding to the final development of conceptual categories.

Results

A total of 25 interviews were conducted and analysed. The sample included ten youth living with PAH aged 20–25 :7 males, 3 females; ethnicity: 8 Black, 1 mixed, 1 white (YP), ten people in their social networks: one sibling, three partners, six friends; ethnicity: 8 Black, 2 white (SN), and five professionals working with youth with PAH (Pr): one peer support worker, one clinical psychologist, one nurse, and two medical doctors; ethnicity: 4 white, 1 Black.

Seven themes were identified. These are shown in Table 1.

Theme 1: Family influence / community context

Secrecy within the family

HIV is often treated as a family secret, and even siblings not living with HIV often do not know their status. Two professionals pointed out that parents were very resistant to letting their child know their diagnosis. In addition,

> Parents don't want to disclose their own status. I think they feel terribly guilty maybe, that it was them that caused them to have the HIV in the first place." (Pr10)

Parents were described as having a "huge influence on whether they share" and professionals thought that not talking about it at home can mean that youth struggle to adjust and "then it doesn't come naturally for them to share".

Secrecy within the family was also a common theme among the youth,

Table 1. Themes and subthemes identified.

Themes	Subthemes
Family influence / community context	*Secrecy within the family*
	Cultural influence
	Not wanting to share mothers' status
Lack of knowledge and education about HIV	*Misinformation and lack of education*
	Knowledge as power
Practicalities of sharing	*Is there ever a right time?*
	Knowing how to share
	Including facts when sharing
Status acceptance and feeling ready to share	*Positive attitudes towards HIV / status acceptance*
	Feeling ready to share
	Feeling confident and resilient
	Activism – sharing to destigmatise
	Preparing for reactions
Social support	*Social support*
	Peer support
Perceptions of others	*Stigma and Fear of rejection*
	Trust
	Previous experiences
Navigating personal choice and emotional consequences	*Your choice – Not wanting or needing to share*
	Effect sharing could have on others
	Effect of keeping a secret / relief of sharing

> You know families sometimes don't even discuss it. It's like shamed upon … The only thing that's discussed is, take your meds. That's the conversation. That's not healthy. (YP05)

Many described being given direct instructions about not sharing their status with others (e.g., certain family members) or not sharing at all. "It's not that I wouldn't want to share, it's just my mum and dad don't want me to share to be honest." (YP12).

Youths also talked about the importance and benefits of open communication, explaining that if they talk about it within their family and their siblings are aware that it is a more open discussion, they feel more able to share this information with other people.

> Imagine how much easier it would be if … you're talking to your mum and dad about HIV, about how it made you feel … Now if that person feels uncomfortable talking about it at home, do you really think they're going to be talking about it outside? (YP07)

Cultural influence

Several participants across all three groups talked about secrecy around HIV in the context of cultural influences. Although some participants felt that sharing was generally acceptable, they felt that it was not in their community:

> I'm from [country in Africa], literally the HIV capital of the world. And that philosophy is don't talk about it, don't bring it up at dinner. (YP05)

The reluctance to talk about HIV has been attributed to fear due to misconceptions. The fear of HIV in some communities was described as "a revulsion that is irrational". One youth pointed out that in their culture, "A lot of people think it's a punishment, which it's not," while a social network participant described, "Well from the background that I'm from … if you hear they have it, it's like, ok that's it, they're dying."

Some participants felt that these negative beliefs were "a generational thing" and implied that they themselves did not feel those cultural pressures, as they were from a "generation of accepting and tolerance and understanding," (SN22).

Not wanting to share mothers' status

A common theme for youths and professionals was that sharing for those living with PAH "is not just about them disclosing their status, it's about them disclosing their parent's status as well" (Pr06). One youth said, "I mean in my head I don't mind, but then … . my mum tries to keep it so much a secret so I feel like if I were to tell someone it would probably go around without her knowing." (YP09).

Theme 2: Lack of knowledge and education about HIV

Misinformation and lack of education

Participants talked about the lack of information and understanding about HIV in the general population, attributing this to poor education in schools, being ""misinformed," and it being something that is "not widely spoken about". A professional attributed negative attitudes and consequences of sharing one's status with the lack of HIV education: "it's through ignorance really about transmission … .people's misconceptions, that's the route to the stigma really isn't it" (Pr01). One youth agreed with this, saying, "the fear is because they don't know." (SN18).

The negative image of HIV was seen as being "something that could hold someone back from letting it out." (SN21). While a general lack of information and knowledge about HIV was discussed frequently, some participants also pointed out how little youth living with HIV knew themselves.

Knowledge as power

The idea that "knowledge is power" was common. "I feel like you become more confident as you know information about what you're actually dealing with." (YP08).

> If I know the information about it, I'm more likely to share it. If I don't know the information, how can I share that and how can people feel confident in what I'm saying, if I'm not confident in what I'm saying myself. (YP05)

It was felt that other people being more aware about HIV would also help with sharing: "Because to someone who knows about HIV, if you tell them, it's not really that big of a deal" (YP09). A friend added, "If people are educated about it, it becomes less of a discrimination against it doesn't it." (SN24).

Theme 3: Practicalities of sharing

Is there ever a right time?

Many talked about the importance of finding the "right timing" to "catch someone in the right headspace". "It was probably a perfect time because I don't feel like it was too soon or too long into the relationship." (SN18). However, others pointed out "Is there even ever a right time, I don't know" (SN19) and "the longer you leave it there's kind of, not a deceit element, but I think sometimes people feel like, why didn't you trust me" (SN22).

One aspect considered to help determine the right timing was waiting until you know someone well and can trust them, "and know the information is not going to be used as a weapon against you" (SN22). The sentiment was similar from youths, "it's just the worry of her finding out too late, and then breaking the trust … she might say if you didn't tell me about this is there a lot of other stuff you haven't told me about?" (YP13). Professional participants agreed, saying it can become a "heavy secret" (Pr01) and sharing too late "shakes the foundation of the relationship" (Pr10).

Knowing how to share

Another common theme was how difficult it was to know how to share information and where to start. The consensus was, "you want to do it face-to-face" (SN20) and find a private, quiet space to tell someone so that no one else could overhear. Other suggestions included sharing when "they haven't had lots to drink." Some people talked about wanting to share with others one at a time, while others wanted to share with the whole group to get it over with.

One person talked about taking it step-by-step, first revealing that they take medication, "I would then openly take my medicine in front of them and they'd be like what are you taking that for [and I would tell them]" (YP02). Others also talked about "testing the waters" and "gauging what a person thinks" by introducing a conversation about HIV without revealing their status. A professional participant said this, "could give them the idea whether it's possible or not that they would respond well … if they're like oh yeah it's disgusting I wouldn't go near them with a barge pole, or if they're like well you know it's treatable now." (Pr10).

Some youth talked about having someone there for support and encouragement when sharing, such as a family member "for ease of mind" or "if they're feeling nervous." Participants from all three groups talked about the possibility of taking someone to the clinic to share with them in a facilitated discussion, where they would be able to ask health professionals questions. However, one young person said, "I feel like it's just easier and more sincere if it came from the person themselves" (YP16). A professional pointed out that in some situations external support is more important than in others, "we have to think about safety concerns as well around partners, particularly if there's a violent history." (Pr06).

The idea that different sharing methods may be appropriate for different people is common. Participants said it "depends who they are disclosing to" (Pr01), and to make sure to "cater it to each person" (YP08).

> Personalise it … so like for example my first friend, he's a very blunt guy, he's very straight forward right – throw him facts and he's ok … then there's your other approach which is more for the emotional response, that's when you tell them a story. (YP05)

Another important consideration was to be conscious of your tone and to stay calm, not making it seem terrifying when sharing. A youth described it as,

> if I come in with an attitude where I'm like really nervous then they'll also be really nervous. But if I'm really relaxed and I'm like yeah I'm HIV positive and they're like oh you don't seem that bothered by it and I'm like yeah, I'm not bothered by it, that's the thing, there's nothing to be bothered by, it's perfectly fine. (YP16)

Including facts when sharing

Participants felt it was important to pass on knowledge about HIV to people with whom they share their status, to help them understand and cope with this new information, "If you just say I have HIV and don't give them information, they might panic." (SN18).

A common suggestion to help inform the person they were sharing with was to signpost people to trustworthy websites for more information or to take information leaflets or diagrams, in case "in the moment you get choked up". A professional suggested, "sometimes reading something or watching a video they might find that easier and then they can answer any questions afterwards" (Pr01). One youth partner explained how this helped them.

> She made me a booklet with basically everything I need to know … her journey through it, diagrams explaining it all, she told me about U = U … so she made it easy for me. I don't feel like I had any other way to react but to be understanding of it. And like respectful. (SN18)

Theme 4: Status acceptance and feeling ready to share

Positive attitudes towards HIV / status acceptance

Youths and professionals talked about overcoming their feelings of shame and accepting their status before sharing. Being born with HIV was considered to make it easier to accept their status, as youths can say to themselves, "it wasn't my fault" (pr06) or "it's not like I did something and then I got it." (YP15).

Once they accepted their status, the participants felt that it was easier to share. "Because I found it easier to accept I feel like ok I'm comfortable with telling people about it.." (YP15). Another youth felt that not only did acceptance facilitate sharing, but "if you have accepted who you are then someone's reaction won't affect you."

Feeling ready to share

The importance of feeling ready before sharing was highlighted by all three groups. They warned, "you can't catalyse the readying process" and "don't rush it, share when you feel you are ready."

"It's your HIV, it doesn't belong to anyone else so don't feel pressured" (Pr10).

It was also advised to go for it as soon as you feel ready, "if you feel like the time is right to do it, do it. Don't hold back on yourself because that's gonna affect you, like inside." (YP13).

Feeling confident and resilient

Confidence was described as making "you feel more open to say it, and talk about it" (YP11) and helping "to shrug off negative comments or attitudes about HIV and not take notice" (YP15). Youths felt they were able to cope by having a "this is me, if you don't accept me then that's your issue" (YP16) attitude and "it's probably better off that they are not your friends anymore" (YP19) if someone responded negatively.

Activism – sharing to destigmatise

All three groups talked about youth being open about their status despite the abuse they may receive to educate people and actively fight stigma, normalise having HIV, and show that it is "not some burden" (YP14) they have and that "you can live with HIV and live well, just like anyone else" (Pr03). Changing attitudes were thought to only really work if more people were open about their status, to "break down the taboos and the stigma" (SN22).

> I guess if everyone started telling people that they had HIV and it's not really a big deal then it doesn't really become that much of an issue to anyone in general. It definitely reduces the kind of negative thoughts that people have around it. (YP16)

Sharing was also thought to help other people living with HIV: "we've got to help more people out here by talking about it, you know." (YP08).

Preparing for reactions

Participants felt that, to be able to share, youths had to be prepared for the reactions they might face. It was suggested that "you need to be ready for any kind of reaction" (YP16) or to "expect the negative and if you

get the positive then great" (SN26). One professional talked about going through different scenarios to help prepare and make sure to provide them with resources to manage any situation after sharing. A youth's partner felt it was important not to "worry youth that oh it might not go well, but preparing them for that. I'd say the best thing is for them to know where their next steps lie beyond the initial disclosure" (SN22).

Even if people initially had a less than positive attitude, participants felt it important to give people time to react and process it, and they will probably "come around". Some participants felt that "a lot of people would be willing to support someone with HIV" (SN23) and said, "usually I've heard good things" (Pr01). However, one professional felt that "rejection happens quite a lot actually … and actually it has a big knock on effect on their ability to adhere to medication, and their sense of their self-worth and things like that" (Pr10). Therefore, preparing for different reactions was deemed important, and "the issue of safety is the overriding consideration. Because once you put it out there you can't take it back" (Pr01).

Theme 5: Social support

Social support

Both having and seeking social support have been described as facilitators of sharing. Youths felt that they could share if they had close friendship groups and open-minded friends. Although some talked about social support leading to sharing, others talked about wanting to share that support so that they did not have to go through things alone.

The idea of having support for taking medication was common among the youth. "I used to hide myself to take my medication … but when I told her, she's got comfortable around it. Now she even tells me, have you taken your medication … that little support it really helps, like I'm so glad I did tell her as well" (YP13).

A young person's partner also felt it was helpful to be able to discuss things "just having someone else there so you're not in your own thoughts all the time. And maybe someone other than your parents to speak to, to get a different perspective" (SN18).

Peer support

Almost all participants talked about the importance of receiving support from other people living with HIV, community-based support, or simply being around other people living with HIV. Peer support (often through camps or support groups) was described as helping them feel less alone, being able to connect with others, feeling more like they could talk about it, and gaining confidence. A youth talked about having friends who are open about their status being "a mixture of like being inspired by them and also just realising that sometimes this isn't a huge deal so I can tell people if I wanted to" (YP16).

Youths talked about being given information at camps that they did not learn in school, where they were only taught about "how bad it is".

Several youths pointed out that it was easier to be open about their experiences with their friends living with HIV than with their friends who were not living with HIV. One person said, "Like for me I only started really talking about HIV after I went to camp. It just wasn't so taboo, because everyone had it, and everyone had their own story and information about it and whatnot. So that burden gets lifted off" (YP05).

Theme 6: Perceptions of others

Stigma and Fear of rejection

HIV stigma is a prominent barrier to sharing information. A social network participant added, "It just seems so unfair that they are scared to open up about their own identity just because of what others think … the stigma overrides the feeling of wanting to share." (SN25). Professionals said, "they have one of the most ill-understood and stigmatised conditions" (Pr01) and that issues people living with HIV face are "all down to stigma" (Pr 10). A young person stated, "if there was no stigma around it, I would tell people." (YP14).

Fear of rejection was frequently discussed. Many youths talked about worrying about how people would react if they knew their HIV status. They worried that people wouldn't want to "hang around" with them

anymore or that they could "lose everyone around them", that they may be excluded and discriminated against. Some felt that there was a risk of rejection regardless of how well they knew someone.

Their worries included a "fear of being betrayed by their friends" or a fear of knowledge of their status being passed on to others, and a "fear of losing control of who finds out" "(YP15). Although they did not think their friends would tell anyone else, they felt that they could not know for sure. As a result, one youth said, "I don't really get too close to people." (YP13). Professionals and youths talked about the risk of someone "exposing them" on social media.

Participants also talked about not wanting to be looked at differently or being judged, worrying that people would not take them seriously or would think "they're not worthy of being loved" (SN19).

One youth talked about rejection having the potential to affect someone's mental health: "if he doesn't want to see me because of something I can't control. That's when that helplessness comes in, and that's when depression can come in etc. That can be where the slippery slope begins. Just from a bad reaction" (YP05).

Trust

All social network participants talked about trust and had close relationships when they were asked why they thought their friend/sibling/partners shared with them. "You have to wait for the right people to be able to share something like that with them. First see if they can be trusted" (SN24). "If they told you it means they trusted you, and letting that out, is like, letting something huge out. It's really a big deal" (SN26). Trust among social network participants was described as knowing that it would not be shared with others, having a special bond, and being able to tell each other everything. "If you also share some stuff with them then they feel safer to share their information with you, it's like a two way thing, you share, they share" (SN26).

Trust was a common theme among youths living with HIV as well, with most saying they would only share with close friends, "real friends", people they've known a long time, or people they know they can trust. A professional added,

> when a young person has been seeing someone for several months and they seem sensitive, receptive, compassionate, thoughtful, intelligent, rather than vindictive, impulsive, hot headed or likely to become violent, then it is best not to leave it too long before sharing with a partner. (Pr01)

Previous experiences

Participants talked about previous experiences that affected their decision to share. Most youths talked about only having positive experiences. Several said that as the first sharing experience went well, they then "built more confidence" and felt they could share with others.

Some have highlighted that it is easier each time you share. One youth talked about how having shared before helps you gauge "which kind of people it's ok to tell, which people don't care and which people you shouldn't tell" (YP16). None of the youths spoke about their negative experiences. However, professional participants described their patients' negative experiences of sharing, which can lead to them "not then going to start telling other people because you're going to be worried about other people finding out." (Pr06).

Although having shared with someone before may help people with their next sharing experience, as one professional participant pointed out, "of course disclosure is a process, it's not a fact that is isolated in time. So you disclose one day, and the next day and the day after that. You have different questions and different things coming up" (Pr01).

Theme 7: Navigating personal choice and emotional consequences

Your choiceN – ot wanting or needing to share

All groups pointed out that it was a person's choice of whether or not they shared. Several youths said they simply did not want to share and did not feel like it was a big issue.

It was also highlighted that there was no need to share friends. "You should never ever feel pressured to tell someone if you don't want to. Some people might not trust anyone, and that's fine as well." (YP16).

Interviews also revealed that it is their choice whether they share how they acquired HIV or not: "Some people feel quite strongly that they want other people to know, I've had it since birth, it's not down to my own behaviour. And then I think that inspires a bit of like sympathy in the person that's hearing it … but some people really don't want people feeling sorry for them either." (Pr10).

When it came to the idea of sharing with a sexual partner, people felt it was more important and responsible to share, "so that the person knows they need to be protected" (YP11). "When it comes to partners it's a bit different … the least you can do is tell them about the condition so you can't pass it on" (YP13). Three professionals felt it was important to share with an intimate partner for other reasons: wanting to be honest, wanting your partner to know you intimately, and not keeping anything from them.

Effect sharing could have on others

Some participants described not wanting to make people panic or worry about them. "A patient said I don't want people to feel sorry for me. I want the relationship to continue with the same power between us. I don't want someone to have to always be worrying about me, asking me how I am. I want things to be the same, just that they'll know this about me" (Pr10). Others felt that not wanting to be a burden could be a way of sharing. "If they've been carrying this and it's quite a heavy weight for them, for them then to kind of share it, to give it to somebody else they sometimes, they feel like they don't want that person to then have to carry it." (Pr06).

Effect of keeping a secret/relief of sharing

Most participants spoke about wanting to be honest, and the toll that not sharing could have on youths. They discussed not wanting to have to hide or "keep a dark secret," not wanting "to have shadows" or to feel like they are leading a "double life," a "secret life" or "living a lie." They didn't want to feel guilty for lying, or to have to make up excuses when people ask questions about their medication or having to hide their medication; they wanted to be open and "live a free life." One youth said that lying had become "exhausting" and another said lying stopped you from being "the true you, your true self" (YP15).

> "Sometimes you just want to let it out. Like you can't keep those types of things in forever, because you just get into you, it's like a cup full of water, and once it's all full up some of the water spills out and eventually they will want to talk about it" (SN20).

Once they had shared, people talked about a weight off their shoulders, feeling much happier, feeling relieved, and being able to know them fully. One social network participant described it as a "release. You have someone else to talk to now so you're not in your own thoughts all the time." (SN18). Other youths said, "I had to tell someone, it was kind of driving me a little bit mad" (YP08); "it was affecting me. I was getting bitter inside because, you know, I've got this big thing; I can't hide myself" (YP13).

Some felt that not sharing was getting in the way of accepting their status: "I don't want to be just hiding my whole life; you know, I want to be able to embrace it." (YP15). They also felt that sharing can help avoid feeling down or improve their well-being; "I just feel like it's inherent in our human nature, we're always creatures that like to communicate … we always like to express ourselves, we always like to be received and responded to, and when we're not and when we are unable to we just feel really like negative or down on ourselves" (SN25).

Discussion

This study offers a novel exploration of the barriers and facilitators of HIV status sharing among UK-based youths living with PAH, drawing on the voices of youths themselves, their social networks, and professionals.

Examining three perspectives contextualises the decision to share an HIV status as a dynamic, relational process, rather than a fixed individual choice. Notably, the inclusion of social networks and professional participants revealed both an affirming and contradictory understanding of the sharing process.

Youths described disclosure decisions as deeply personal and heavily influenced by emotional readiness, prior experiences, and perceptions of others' attitudes. Many expressed a desire for honesty and connection; however, these motivations were often complicated by anticipated stigma, familial secrecy, and not knowing

how to share. By contrast, social network participants tended to focus on trust and emotional bonds, often positioning themselves as safe and supportive recipients of disclosure. This contrast reveals a discrepancy between how youths perceive the potential risks of disclosure and how recipients view their trustworthiness. These findings align with recent qualitative research on youth living with HIV in Zimbabwe, where stigma, discrimination, and inadequate HIV knowledge were identified as prominent barriers to disclosure (Khan et al., 2023).

Professionals expressed more cautious attitudes towards disclosure. Their insights may have reflected an accumulation of difficult or negative experiences shared by people living with HIV, which may more frequently be reported than positive experiences and may have contributed to a more protective or even pessimistic framing of the disclosure process. PAH selection bias towards those with disclosure experience and who feel comfortable in peer and research settings may have excluded young people with previous negative experiences from the study, but whose experiences were represented by their clinicians. Professionals were more likely to emphasise concerns about safety, rejection, and the potential negative impacts on adherence or mental health. While these concerns are valid, this tendency may inadvertently reinforce stigma by overemphasising risk over opportunity and underplaying youth agency and resilience.

Stigma has emerged as a central cross-cutting barrier to sharing. Anticipated stigma is strongly linked to secrecy, fear, and self-protection, consistent with the findings of previous studies (Fei et al., 2025; Hogwood et al., 2013). The participants described stigma as isolating, strengthened by family norms, or cultural silence around HIV. These dynamics are well aligned with models of shame and social threat, which conceptualise shame as a powerful inhibitor of social connection, leading individuals to shut down and withdraw as a self-protective strategy (Gilbert, 2000). Youths frequently spoke about not "getting too close to people" or avoiding relationships due to their fear of disclosure.

A pervasive theme across all groups was the lack of knowledge about HIV, both in the wider society and in youths with PAH themselves. The participants described a significant gap in HIV education, contributing to persistent myths about transmission and a continued sense that HIV is a forbidden subject. Importantly, even youths living with HIV reported knowledge gaps regarding their own health. This lack of understanding has contributed to both internalised stigma and uncertainty about how to share their status accurately or confidently. Recent research has found that even when they do know about U = U, youth remain worried about transmitting HIV to their sexual partners (Ibrahim et al., 2024). Subjective difficulty in HIV sharing in this population has been reported in many previous studies (Hogwood et al., 2013) and is consistent with the low levels of HIV sharing reported among youths living with PAH (Evangeli et al., 2024). Both youth and social network participants expressed that increased knowledge made disclosure easier and improved their confidence. This finding highlights the need for enhanced education at multiple levels. Disclosure interventions using educational techniques have been shown to increase HIV sharing in other populations of people living with HIV (Schulte et al., 2021).

Current findings support and extend previous research on HIV disclosure among adolescents and youths (e.g., Audi et al., 2021; Buchanan et al., 2012; Wiener & Battles, 2006). While past studies have highlighted barriers, such as fear of rejection and lack of disclosure self-efficacy, this study adds depth by capturing how these barriers are socially embedded within families, communities, and healthcare systems. The decision to disclose was consistently framed not as a singular event, but as a process that must be supported over time.

Importantly, the study highlights a gap in guidance and resources for professionals on how to support youth in sharing their status. Professional uncertainty about how to support youth when they feel ready to share, how to prepare them for possible reactions, and how to provide support beyond a risk-based narrative was evident.

A key strength of this study is its triangulated approach, incorporating the perspectives of youth living with PAH, members of their social networks, and professionals. This multifaceted perspective is rare in the literature and offers a holistic understanding of the disclosure process.

However, this study had several limitations. The sample size was relatively small and limited to participants recruited from HIV clinics and a single charity, which may not reflect the experiences of all youth living with HIV, particularly those disengaged from care. The sample size also limits our ability to explore potential gender-based differences or other nuances. The professional sample was also small and may have been skewed towards those with more experience or interest in psychosocial care. We did not observe systematic differences in depth or openness between zoom and face-to-face interviews, but this remains a potential limitation, as remote interviewing may have reduced rapport for some participants.

The findings of this study underscore the urgent need for comprehensive education regarding HIV across multiple contexts. In schools, more inclusive and accurate sexual health curricula could reduce misinformation and stigma, creating a more supportive environment for youth living with HIV (CHIVA, 2022). Similarly, training for clinicians and medical students should incorporate modules on HIV-related stigma, psychosocial aspects of care, and emotional complexity of disclosure. These should move beyond risk management to include strategies for supporting youth with value-based decision-making around sharing, emphasising emotional readiness, empowerment, and the relational context. Guidelines and tools should be developed to help professionals offer structured, individualised support to youths who are considering sharing their status, including how to gauge readiness, rehearse disclosure, and prepare for different responses. These could include the co-location and integration of clinical peer and psychological support services, facilitated disclosure sessions, role-play, scenario planning, and written or digital materials for recipients of disclosure.

There is also a need for interventions and evidence-based guidelines that address HIV status sharing among youths with PAH. These should be co-produced with the youths themselves and their support networks, ensuring relevance and cultural sensitivity. Interventions that focus on reducing internalised stigma, building confidence, resilience, and communication skills while also creating opportunities for peer support may be particularly effective (Ferris France et al., 2023). Finally, creating safe, inclusive spaces for youth with HIV to connect and share their stories could help normalise HIV, reduce isolation, and promote thriving, not just surviving. This aligns with the global shift towards the "Fourth 95" (previously the "Fourth 90"), emphasising health-related quality of life and well-being as essential targets alongside diagnosis, treatment, and viral suppression (Frescura et al., 2022; Lazarus et al., 2016).

Acknowledgements

We would like to thank ViiV Healthcare UK, who funded the study, in particular, Chris Stainsby and Serufusa Sekidde. The participating sites were St. Mary's Hospital, London: Caroline Foster, Paula Seery, Hana Jayadel, Sara Ayers, Sarah Fidler; St. George's Hospital, London: Katia Prime, Lisa Hamzah; King's College Hospital, London: Elizabeth Hamlyn, Sally Hawkins; Chiva: Amanda Ely, Abi Carter; Heartlands Hospital, Birmingham: Claire Robertson, Gerry Gillian; and North Manchester General Hospital, Katherine Ajdukiewicz. We would also like to thank the advisory group members and all participants.

Author contributions

CRediT: **Georgina Gnan:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Visualization, Writing – original draft; **Jane Vosper:Caroline Foster:Janet Seeley:Victor Musiime:Sarah Fidler: Graham Frize:Michael Evangeli:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Writing – review & editing.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This study was funded by ViiV Healthcare UK Ltd., 980 Great West Road, Brentford, Middlesex, TW8 9GS, UK.

Ethics approval

The study was approved by the UK NHS Research Ethics Committee (IRAS:252582) and the Institutional Review Board at Royal Holloway, University of London, UK.

Consent to participate and publish

Written consent was sought from participants.

Data availability statement

Anonymised electronic data from the study are available in the Figshare data repository, freely accessible under the Creative Commons CC BY licence.

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