

# Discursive Disclosures

Sharing HIV status via  
networks of care



## What's the research about?

Research has found that people living with HIV (PLHIV) who share their HIV status with others are more likely to seek treatment. Health and social care professionals therefore understand that status disclosure is an integral part of HIV care and further prevention. However, disclosure can mean different things to different people and depends upon personal experiences and social circumstances. To improve the support we provide to PLHIV, we wanted to find out more about the relationship between the settings of care PLHIV encounter and the anxieties they experience around disclosing their HIV status. We did this by researching how people talk about their HIV status. This means we asked PLHIV and those who provide them with care and support for their stories around their experience of disclosure.

## What did we find out?

Overall, PLHIV find it difficult to share their HIV status. A lack of up-to-date knowledge places a burden onto a PLHIV when they disclose their status and this can be a barrier for them to seek treatment. But our research found that PLHIV's experiences of status disclosure change in different types of social settings and reflect shifting models of health and social care. We found the following settings created different experiences of status disclosure for PLHIV:

### Clinical Settings

Models for HIV care have shifted in the past twenty years. Previously, PLHIV received all their medical care from an HIV clinic. Now, services are integrated into general healthcare models such as GP surgeries. This has changed how PLHIV experience disclosure in clinical settings.

**First disclosure:** A person's first experience of HIV disclosure is when they are diagnosed. All PLHIV respondents noted that this was a devastating experience and they often remembered the exact phrasing of their initial diagnosis. Clinicians therefore view this as an important moment to discuss the benefits of disclosure because how a PLHIV experiences their diagnosis can have lasting effects on how they interact with their status in the future.

"It's really hard, but unless we as health professionals feel that we can make HIV a lot more destigmatised and normalised then part of that is not making it closeted either."

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**Multiple disclosures:** Accessing medical services in different settings means that PLHIV respondents had to repeatedly disclose their status and often had to advocate for their own treatment. This is because there is often less time for clinicians to respond to the general health and wellbeing needs of PLHIV, which both PLHIV and clinicians felt was very important in managing the condition.

“Visits are just shorter. You now get 20 min, and within that 20 minutes they just look at your health around that one thing and that’s it.”

**Restricting disclosures:** PLHIV participants overwhelmingly felt frustrated that they seemed to know more about HIV than their GPs. Their GP tended to refer them to specialist clinics for every health issue, which made them lose confidence and feel that they were a ‘complicated case’. This affected research participants’ decisions whether to disclose their HIV status in clinical settings, what type of medical care they would seek out, or sometimes even prevented them from seeking medical care at all.

“Say I get a chest infection, the first thing she’ll do is pick-up the phone to my HIV specialist clinic and get their ok to treat me the correct way. So that’s me feeling a little bit vulnerable then.”

## Third Sector Settings

The third sector provides services for the overall health and wellbeing of PLHIV, including confidential support services and social settings. They are therefore an important site of disclosure that our PLHIV research participants experienced differently from medical settings.

**No need to disclose:** Overall, PLHIV research participants found that they did not feel the need to actively disclose their HIV status in third sector settings of HIV care. This removed feelings of guilt and responsibility that they felt sharing their status elsewhere. Through removing the need to disclose, participants found that they could come to terms with their diagnosis more easily and did not feel as affected by stigma around HIV.

“It isn’t always that you were not disclosing, it’s that it’s just not relevant.”

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**WAVERLEY**  
**care** Positive about HIV, Hep C & Sexual Health in Scotland

**Disclosing publicly to help others:** Many of our research participants who had received support from third sector services wanted to 'give back' in the form of outreach, for example peer-to-peer support or public speaking. This meant they had to disclose their HIV status publicly. Research participants who did this felt that it was beneficial to their overall sense of wellbeing. However, this did not impact their desire or ability to disclose in other social situations.

"There's not once that I have spoken in public and I've not had complete support by the people I've been speaking to. But that's because that was in a safe space. There are still parts of society that you don't really want them knowing your status. That is genuine fear."

## Social Settings

Much of the support around HIV disclosure provided in clinical and third sector settings is designed to help PLHIV in their everyday social lives – with friends, family, colleagues, etc. This was another type of setting that PLHIV experienced disclosure differently.

**Providing support:** Overall, PLHIV research participants found that they would often have to provide emotional support and information to the person they were disclosing their HIV status to. This was because of a general lack of awareness around HIV. They therefore often felt an emotional burden around sharing their status, which was expressed as a reason not to disclose.

"I don't have any friends now that aren't HIV [positive], I don't have them in my life anymore. It's easier that way than it is having to tell them. And then having to answer all these questions, it's like Question Time. You're sitting there, people bombarding you with questions."

**Fear of stigma:** PLHIV research participants also generally expressed a fear of social stigma from disclosing their HIV status. This fear came from both their own experiences and others' negative stories about disclosing their status. This contributed to some PLHIV respondents choosing not to disclose their status in their social lives.

"It doesn't affect or shouldn't affect our relationship, unfortunately in some cases it does. [So] they'll only find out after I'm dead."

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## What will we do with this research?

This research shows that PLHIV have varying experiences of disclosure, depending on the setting in which disclosure takes place. In clinical settings, there is a clear need to ensure PLWH have enough time to discuss their health needs with clinicians, while increased HIV education to GPs is also required. Waverley Care will incorporate these findings into our services targeting HIV education and awareness in clinical settings. We will also use these findings to influence policy affecting PLWH.

PLWH experienced third sector services as safe spaces to disclose. Waverley Care will use this finding to seek resources to sustain such spaces.

Stigma continues to prevent PLWH from disclosing to both people within their lives. This demonstrates the need for continued anti-stigma campaigning targeting the general public. Waverley Care will use this finding to support calls for a public health campaign raising awareness of HIV across Scotland - tackling outdated myths.

## Tweetable extract:

Research finds people living with HIV find it difficult to share their HIV status, and this can be a barrier for them to seek treatment. Read more here:

<https://www.waverleycare.org/fdasdjcnakjdhckhadhcdcs>

This research was carried out by Wren Wilson at the University of Edinburgh, with support from Waverley Care's Research and Communications team.