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How do people experience negotiating HIV-related online and remote testing resources?

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Background

• Advances in digital health and novel diagnostic technologies are creating new opportunities.

• Increasing proportion of information provision and testing occurring online/remotely.

• HIV self tests have potential to reach undiagnosed fraction, but linkage to care and surveillance are critical.

• Unclear whether existing information about accessing testing, interpretation of results and future management, meets people’s needs.
Aim

To explored how people access online HIV resources for information and testing, and their experiences of using these resources and HIV self-sampling and self-testing kits.
Methods

- Think-aloud and semi-structured interviews
- Community convenience sample
- Recruitment via social media
- UCL ethics
- Transcripts analysed using thematic analysis
Methods – user journey

1. **Search online**
2. **Order test**
3. **Prepare for test**
4. **Do the test**
5. **Getting result**
6. **Next steps**

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HIV and AIDS

**Overview**

HIV (human immunodeficiency virus) is a virus that attacks your immune system and makes you more likely to get infections and certain types of cancer. AIDS (acquired immune deficiency syndrome) is a condition that happens when your immune system is damaged by the HIV virus.
Results

• 28 participants

• Demographics:
  • Median age: 30  IQR: 35-49
  • 36% (n=10/28) female
  • 57% (n=16/28) MSM
  • 18% (n=5/28) Black Africans
  • 21% (n=6/28) people living with HIV
  • Mixed experience of previously accessing online information and using self-sampling or self-testing kits
Seeking reassurance
“I don’t like the way it’s written. Although the language is plain, I feel it’s not understanding enough. I wouldn’t say it should be emotional, [...] but I ... get frustrated. It says things that I might have, or things that might have happened. But the links are further down. You know you’re stressed and want to get to the point right away, I guess.”

P20, Other White MSM
Impetus
“The free sampling is great, but with the walk-in centre you have the panicky impulse. .... You go and do it. They [self-sampling kits] arrive three days later, ... By then I think, oh, I won't do that now. Anyway, I've got to send it back and wait. I think I've still got one on top of my fridge somewhere. It doesn't fit with how people live.”

P7, White British MSM
Preparedness for result
“... it’s potentially life changing news and you don’t want to be doing that with the wrong person in the wrong environment. There should be a sort of ... personal sort of booklet and/or pamphlet just to kind of hit that message home. More information or a video with an example of someone who has been diagnosed as positive and what their next steps were, and have it as reassuring as possible. ....... More a personal touch to it because otherwise you’re left with these bits of plastic and clinical things around you and literally not a resource around you that you can sort of feel connected to.”

P24, White British MSM
Cognitive dissonance
Cognitive dissonance

“Literally they say wait for two minutes then open this page to read your result.... this is not a pregnancy test and while sometimes terrible, the solution [of pregnancy test] is almost known before you take the test so you come in feeling, if this is a positive test I'm going to do XYZ ...”

P16 White Other MSM
Lack of support
“someone tells you [your] results, you’re literally not listening, because all you’re just hearing is like, shit, HIV, shit! ....Then you start questioning, wow, will I never get married, have children...? [...] your mind just goes so far, [...] But then if someone just keeps telling you, keep calm, it’s going to be all right; it’s not the end of the world, like there is options, there is... you can have a perfectly normal life... that rings in your mind, even if you’re thinking about all these worst scenarios possible .... and then by the time you’re now actually calmed down, you now start to remember these words: there’s options, there’s medications; people lived long lives with this.... You cannot just finish, and it’s like, oh... Someone will just jump off a building.”

P26, Black African WSM
Conclusion

• Participants highlighted the importance of situation and emotion on their needs and experience.

• Many HIV online testing resources do not consider the emotional and/or social contexts in which people are seeking information.

• They fail to address people’s anxieties about HIV testing and fail to provide appropriate information to inform testing, interpret results and or support receiving reactive results.

• There is a need for innovative, fit-for-purpose approaches to support and inform decision making and testing.
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