

Designing *Looped in*:

Using qualitative research in the development of an online tool to support interpersonal communication on HIV

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Background

People living with HIV are powerful advocates and educators in the fight against stigma. But taking on this role can lead to experiences of 'educators' fatigue' and is impacted by the nature of interactions and relationships involved. During summer 2018, we utilised a community-based research approach to explore the types of information sharing that people living with HIV would find most beneficial to be supported. From these insights, we developed a prototype for an online tool for people living with HIV to share information based on the key relationship types discussed.

Looped in is a website that allows individuals to curate the information presented on a custom webpage. Users first choose from content that has been sorted based on key relationship types (e.g. family, sexual partner, employer). The tool then gives users control over what content they share, the order that it appears in, and how the final output is delivered (e.g. URL, PDF). The tool aims to empower people living with HIV by aiding interpersonal communication, supporting challenges of misinformation and discrimination in their everyday lives.

An evidence-based process has been used to develop the tool to make sure it is useable and useful to a diverse group.

Methods

In November 2018, we conducted group based activities in Manchester with people living with HIV to evaluate the *Looped in* concept and prototype. Nine participants were divided into two groups, alternately participating in two 30 minute activities: a guided usability test of a mobile prototype of the website and a group review of four use case storyboards. Both groups were then brought together for a 30-minute semi-structured discussion about the overall experience and the *Looped in* platform itself.

Storyboards were chosen to evaluate the service concept in order to quickly illustrate potential applications and features of the platform. We chose to use scenario-based communication, an established approach to practicing user-centred design for human-computer interaction [1],

in order to allow for the various features of *Looped in* to be contextualised in familiar ways. Visuals were added to provide further explanation and to improve comprehension for a broad range of participants [2], who may have various levels of technology experience and confidence. Storyboards have been shown to successfully foster dialogue with broad audiences through their perceived simplicity and accessibility [3].

Participants were purposively sampled by the hosting HIV community support organisation to reflect the gender, age, and ethnic diversity of its user base. Each participant was given a £10 Amazon voucher for their time.

Results

Storyboard 1



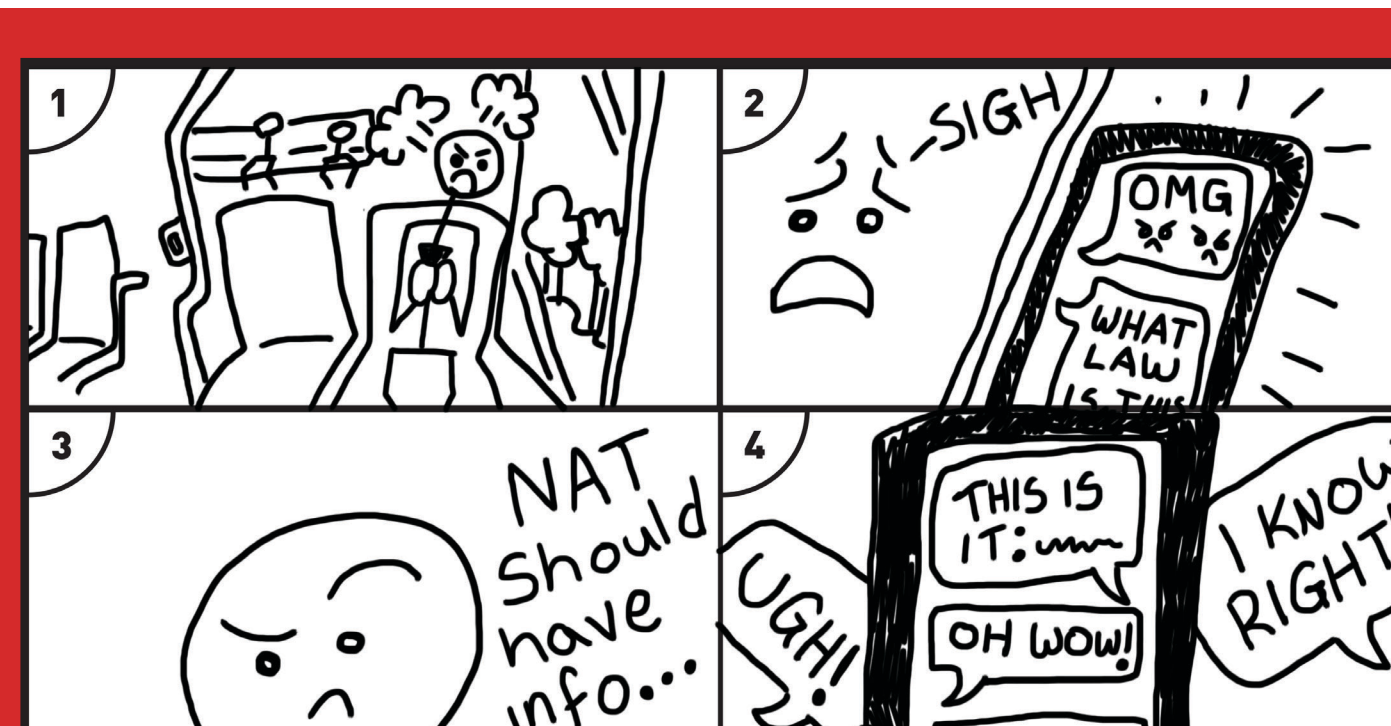
Using *Looped in* to create a custom PDF to support in-person conversations with family following disclosure

(1.1) "And I think that having something official with you when you do that [talk to another person about HIV] just gives it that bit more of... like... you can believe me it's not just made up. It's kind of like here are all these resources and documents that are telling you what I'm telling you."

Participants commented that *Looped in* would allow them control over what information was shared and the tone of the communication. As it was produced by NAT, participants felt that the information provided would be trusted as it was coming from a respected organisation (1.1). Participants also discussed the importance for information to be written in accessible and approachable language that encourages empathy (1.2). Lastly, participants highlighted the importance for the information selections within *Looped in* to be customisable. This feedback supported our initial concept for *Looped in* to have information sorted by key relationship types.

(1.2) "I don't want to leave her worried... a message that I would want for her is that your daughter is okay, she just needs your support. She wants you to understand."

Storyboard 2



Using *Looped in* to share specific information on legal rights to a friend group chat after being discriminated against at a job interview

Rather than asking friends for support, participants wanted *Looped in* to work as a tool to help them address the issue with their employer themselves. *Looped in* could help those who may not feel comfortable confronting an employer. It could also allow employers to quickly learn and adopt legal workplace standards without being confronted with legal action (2.1). Employers may also use *Looped in* to educate their employees. This discussion informed the legal content within *Looped in*.

(2.1) "Most of the time I've been in situations where... they really don't know. They're tripping over themselves, getting it wrong, not realizing what the parameters of it are, so you want to... give them good information, so that they copy it. They take it, download, update, so they're training, rather than beating them up and going to a lawsuit. You know? So [that's what] I want that app to do for me in that situation."

Storyboard 3



Using *Looped in* with a match from an online dating website to share HIV information over WhatsApp

Participants noted that disclosure to a romantic and/or sexual partner was a very personal concern, requiring an approach specific to those involved (3.1). The tool could be used in ways other than through text messaging, such as a support after an in-person conversation with a partner or through an online dating website's messaging system. Most participants felt they would wait to build a relationship with another person before sending them information about HIV, but that *Looped in* would be useful when they did (3.2).

(3.1) "I think it's a completely personal choice really. Would I do it? I'd say I'm quite traditional, I'd probably say not straight away that I would use [Looped in]... but again it's just personal."

(3.2) "I would definitely send additional information from the tool... and that information would happen at some point [in the relationship]."

Storyboard 4



Using *Looped in* to address an issue within a community group by sending information to a community leader

This scenario resonated with all participants (4.1). One participant noted that educating others is an empowering experience (4.2). Participants also said the *Looped in* would have been useful in past experiences of disclosure within workplaces to inform multiple people easily and as a resource when dealing with ignorance within the workplace.

(4.1) "So this tool would be very nice for groups. People, like in the church, community groups, in schools, GPs..."

(4.2) "When I was first out, to send a message around to the group [about my HIV status], it was a power to me. And ever since I was diagnosed I've been wanting to, wanting to educate. For me this tool is the power to educate, and I think that's important."

Design Implications

UX testing and group discussions presented various design considerations. These should also be considered within the development of future online platforms serving users living with HIV and can be summarised as follows:

Avoid Logins

Participants noted that many HIV information sources were safeguarded by online accounts, requiring users to remember a login for each service/platform. This was viewed as a nuisance and potential barrier to accessing a service.

Responsive Digital Design

The mobile-first but responsive design of the prototype so it can be accessed from various devices was highly valued by all participants.

Importance of Customisation

The ability to customise information to put together outputs unique to various relationships is important. In this way, the user has agency and is empowered by the selection of the information they choose to share.

Distribution Formats

The different output formats were seen as being valuable for different situations and audiences, mainly relating to how the recipient would prefer to access and read the information.

"I guess it depends on the person and how technology, how up to date with technology they are. So if my mother, say I was talking about it with my mother, I know she would want to read it from paper, so I'd then print it off, whereas my nephew would be, oh just send me the link and I'll have a look at it, so really person-focussed. But having that ability to print it off I think is key."

Conclusion

Our study helped validate both our initial concept and prototype for *Looped in*, an online tool to support people living with HIV through individualised information sets. Participants felt that the tool would be useful and accessible in their own lives, and they supported the further development of online interpersonal tools to help educate others about HIV. *Looped in* has since been further developed and will be released as an online product in 2019.

References

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