Emotion and Experience in Negotiating HIV-Related Digital Resources: "It's not just a runny nose!"

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ABSTRACT

While digital technologies are increasingly being used to provide support and diagnoses remotely, it is unclear whether they offer adequate emotional support and appropriate messages in navigating complex, stigmatised and sensitive conditions that can have a momentous impact on people's lives. In this paper, we investigate how and why people access existing HIV resources, and their experiences of using these resources through a survey with 197 respondents and an interview and think-aloud study with 28 participants. Our findings indicate that many HIV-related resources do not address the anxiety-provoking reasons for access, reinforce stigma and neglect to provide important information and emotional support. We finally discuss potential ways of addressing these issues in the current environment where more sexual health services are being delivered online.

CCS CONCEPTS

• Human-centered computing~User studies

KEYWORDS: Remote testing; information interaction; emotion; emotional support; HIV; health management

1   INTRODUCTION

The amount of health information online and new technological advances in biomedical information, services and devices enabling remote testing and diagnosis is increasing; this means that more people than ever before are making health-related decisions without contact with health care professionals. These online resources have the potential to be life-changing by empowering people to develop the self-confidence and coping skills needed to manage health problems. Online provision of self-care can address difficulties of reduced access to clinical settings due to cutbacks in health services, but it also has the potential to cause distress and harm.

The use of self-tests to diagnose or monitor conditions is now commonplace with technologies such as pregnancy tests, and blood glucose monitors for diabetes management. Recently, new diagnostic tests for Human Immunodeficiency Virus (HIV) have emerged and are providing opportunities for people to test and receive HIV test results remote from traditional health services [2]. Information about and options for accessing traditional health services are also available online from different sources, along with advice about what treatment or testing options are available to people. However, there is little research into how people perceive the information and support they get from accessing online resources for HIV to make choices about testing and accessing care [41,61]. Furthermore, it is unclear whether existing online and digital resources offer appropriate information (i.e. timely and useful information and resources for testing support, services and interventions based on user needs) and emotional support to people.

In this paper, we focus on identifying the emotional and informational support needs of people when interacting with HIV-related digital technologies around the time of testing. While we started the study with the aim of exploring information structure and support in HIV-related digital resources, emotional support emerged as a focus from our studies: participants' emotions were heightened when perusing HIV-related resources and describing their experience of them. Here, we use the term "emotional support" to include the provision of information in a reassuring, encouraging and trustworthy manner that provides a subjective perception of feeling accepted and respected [13,31]. This study is unique in investigating how

people interact with online resources and make sense of the information and in its focus: we identified a rich picture of emotions around accessing HIV-related online resources, influenced by factors such as information structure, people's previous experiences, context, knowledge and beliefs. There is a dearth of literature on how people make their choices in terms of how and where they test for HIV since self-tests have been available. We reflect on our findings to provide directions for developing this area of research in HCI. Our findings will inform the development of a self-testing app and an online results and management pathway, linking people testing for HIV remotely to information, support and, if necessary, specialist services.

2   BACKGROUND

Much prior research has focused on the exploration of people's everyday engagement with health information and the process of making sense of this information [1,21,35,56]. Sensemaking, the cognitive act of understanding information, is a process of developing a sophisticated representation of information to serve a task, for example, decision-making and problem-solving [56]. There is a renewed interest in sensemaking due partly to the information explosion on the Internet and web based tools that have made it much easier for users to access this information [57]. Information acquisition and use have been postulated to be significant predictors of people's intentions to seek HIV testing - decision making in the context of HIV information behaviour has included information exposure, use, and experience [39]. However, the emotional states of individuals in relation to other factors (e.g., individual goals, tasks, or situations) when seeking information are often ignored in the literature [32]. This is despite the fact that "emotional cues" are increasingly recognised as intrinsic to information seeking which should also focus on people's emotions and affective experiences [22,44]. Emotional barriers have proved to be significant in limiting access to health information since emotions affect the situation, task and goal of seeking information and vice versa [16,22]. People react emotionally to information which impacts on understanding, internalization, learning, and coping [44]; indeed information processing capacity has been shown to diminish under stress [12]. Emotions can often interfere with clarity of thought in undertaking a task or support, or conversely can encourage particular goals [58]. In each case, these factors modify and are modified by people's information seeking behaviours [16]; further, these factors vary depending on the type of information being sought and what the reasons for and experience of searching are.

Significant emotional aspects including stigma and fear surround the HIV context. Thus, information behaviour research in this context should account for emotion [27]. People who believe themselves to be at risk of HIV infection may choose to avoid distressing information when it conflicts with their beliefs [4,10]. Others avoid diagnostic information that might help them determine the implications of symptoms [10].

Recent work in HCI has focused on how people choose to use digital tools for self-care including monitoring, home testing, information for health concerns and managing activity (e.g., in pregnancy, diabetes, etc.) [9,43,46,47,60]. However, there has been little scrutiny in the area of HIV, especially before diagnosis; HIV is still viewed as stigmatised [48] and has a different set of constraints – where people are making sense of a potentially disruptive condition with health and social implications.

Online interventions for HIV prevention, testing, treatment and care have the potential to reach and engage at-risk populations [34]. They can help people make informed choices about when to test and which test to use, provide information and help them in making sense of their results, and help link them to services. Additionally, the possible anonymity afforded by online applications could break down the barriers to prevention and testing for HIV [3], allowing people who would not otherwise test to do so. Some of these advances are already being integrated with existing services (online or otherwise) [3]. Despite an increase in online HIV-related information and resources, we lack an understanding of how people use the Internet to make decisions about accessing testing and care. It is likely that this information could be particularly useful for those who are isolated from traditional means of support (e.g. family, friends, community-based organizations) due to socio-geographical or medical circumstances.

2.1   Why HIV?

Despite a decline in incidence and improving health outcomes, HIV continues to be a major public health issue; worldwide, 36.7 million people live with HIV, with 2.1 million newly diagnosed in 2016 [65]. HIV weakens people's ability to fight infections and diseases by targeting the immune system. While HIV is incurable, taking antiretroviral therapy (ART) medication is effective in conferring an almost normal life expectancy if accessed soon after acquiring HIV, making it a treatable long-term condition. Late diagnosis of HIV is associated with a much poorer prognosis and inadvertent transmission [17]. ART can also stop onward transmission of the virus. Thus, identifying people with undiagnosed HIV in a timely

manner, and ensuring early access to treatment and engagement with care, has major individual and public health benefits.

However, public knowledge of HIV remains poor and negative attitudes towards those living with HIV persist. This means people continue to be reluctant to get tested, or disclose their HIV status, due to HIV-related stigma and fear of discrimination [26,36,66]. In addition to stigma (both experienced and anticipated (in case of being diagnosed with HIV) [23]), various barriers to HIV testing and care persist, such as low-risk perception [14,23,34], inaccurate assessment of HIV risk [15], fear of a positive HIV diagnosis [34], fear of disclosure and accessibility of health services [15,62], inaccurate knowledge about treatment and prognosis [34], and the presence of mental health issues [45]. These misconceptions can also be compounded by racism, homophobia and other prejudices. A significant percentage of people who perceive themselves at risk of HIV frequently do not access sexual health services and testing, whereas the majority of people who are tested in the UK are low risk [11]. Further, people experiencing multiple stressors related to social, physical, and affective context (e.g., friends and family support, housing, mental health status) are significantly more likely to have delayed testing, especially in the absence of social support, stable mental health, and self-efficacy to engage in protective health behaviors. [45]. Thus, despite people living with HIV having a near-normal life expectancy if they are diagnosed early and take effective treatment, a diagnosis of HIV or even the fear of it can cause people to feel anxious, depressed and socially isolated and can have a significant impact on quality of life [54].

The number of online HIV resources has increased. Existing mHealth prevention and management initiatives for HIV include support for getting tested using tailored messages to reduce barriers to HIV prevention [51], social marketing interventions to increase testing uptake using promotional prevention messages [25], test result notification, and support for adherence for anti-retroviral therapy (ART) and management [42,61]. Although men who have sex with men (MSM) and people of Black African ethnicity are at higher risk of HIV than other populations in the UK, 29% of the total HIV diagnoses made in sexual health services in 2016 were in "non-high risk attendees" [1]. Digital resources can reduce barriers to care and enable people to enter and remain in the healthcare system; however, online resources need to reach a diverse population. Finally, it is important that people with a reactive (initial unconfirmed positive) result engage with care as soon as possible to access support and treatment or, if they test negative and are at high-risk of HIV, to access

behavioural and biomedical interventions (e.g. pre-exposure prophylaxis (PrEP, medication taken before sex to prevent acquisition of an infection) or post-exposure prophylaxis (PEP, a course of medication given to people who have potentially been exposed to HIV within the previous 72 hours)). This is important from both an individual and a population perspective. To do this, individuals need to be provided with the right information and support, at the right time, in a format that is accessible and empowers them to take action.

2.2 Digital interventions for HIV

Recent work in HCI has explored many traditionally sensitive areas but, with a few exceptions (e.g., [6,8,9, 30,61,67]), has ignored HIV and other aspects of sexual health and sexually transmitted infections (STIs) [28]. Recently, research has emerged on uptake of self-testing for HIV [2,18,19], medication adherence, and support for tracking personal health information [9,33], but barriers affecting adoption of such technologies have largely been ignored. Marcu et al. [36] propose empathy-driven design strategies to identify and work through factors, often related to stigma and marginalization, which would lead to rejection of sexual health related technologies in daily life. Studies of MSM who have never tested for HIV [34] found that many would use an over-the-counter rapid HIV test [34,62] even when few held strong testing intentions.

Digital resources for HIV need to provide support and information based on people's needs. However, recent reviews of apps and websites for HIV found a dearth of resources that supported people's HIV-related information needs [42,61]. To our knowledge, no user studies have been conducted to investigate end user needs for information and support around the time of testing for HIV. Singh et al. [61] divided people's search for resources and needs for HIV-related support into three broad categories: pre-diagnosis, diagnosis (HIV positive) and post-diagnosis: in this paper, we focus only on pre-diagnosis needs, which we define as people's needs prior to and immediately after testing.

Pre-diagnosis needs include searching for information, support and resources for HIV prevention, safe sex and to assess people's risk of HIV. Examples include accessing information following a one-off risky sexual encounter: on symptoms, routine testing options, and seeking local testing sites or remote testing kits. **Table 1** has details of available tests including the setting, times to receive results, window periods (time between infection with HIV and the ability of a test to detect it) and linkage to care after results.

Table 1: Characteristics of different types of tests (self-tests, self-sampling, and point-of-care tests in clinic).

Type of test	Setting	Time from testing to receiving results	Window period	Contacted for links to care
Self-sampling	User choice	2-7 days (depends on post)	1 month	If positive result
Self-testing	User choice	0-15 mins (depends on test)	2.5-3 months	No
Point-of-care tests	Clinic or community	1 – 15 mins	2.5-3 months	Yes

HIV self-tests have been available in the UK since 2014 and raise new challenges in terms of providing support and links to care to those with potentially positive results [24]. Point-of-care tests are rapid tests (often the same as self-tests) used in clinical or community settings by healthcare providers.

3   METHODS

A series of studies (see **Table 2**) were designed to explore the information and support needs of people looking for HIV testing and treatment options using digital resources. Studies were approved by the UCL Research Ethics Committee (ref: 5632/001). The survey introduction stated that participating in the survey implied consent for the data being used in the study. No identifiable information was collected. Participants in the other studies had the choice to do one or both interview and think-aloud studies; all participants did both. Written informed consent was obtained for both these studies. The details of methods and participant recruitment for each study are presented in the sections relevant to the particular study below.

Table 2: Summary of studies conducted.

Studies	Participants	Context	Tools
1. Online Survey	197 members of the public	Online	Survey questionnaire
2. Think-alouds	28 members of the public	Face-to-face	Semi-structured topic guide
3. Interviews	28 members of the public	Face-to-face	Semi-structured topic guide

3.1   Study 1: Survey

An initial online survey (Study 1) was conducted to explore people's experiences of accessing sexual health services and information about sexual health, how they use online resources to find information about STIs and HIV, testing

and/or treatment options available to them, and specific apps or websites they had used. The survey was hosted on *LimeSurvey,* an online survey tool. Survey data was anonymised and no identifiable information was collected. Recruitment procedures included social media advertising, word of mouth, and snowballing approaches. Participants were entered into a prize draw for a £50 voucher. We used descriptive statistics to analyse the data.

3.2   Studies 2,3: Interviews and Think-aloud studies

We recruited participants by using social media, by approaching community organisations, on the notice boards and email lists of local bookshops, and through word of mouth and snowballing approaches. A website was created with study details. We did not restrict participation based on sexuality or ethnicity as pre-diagnosis HIV-related resources are important for all populations; however, we prioritised recruitment of men who have sex with men (MSM) and people from Sub-Saharan Africa as they are disproportionately affected by HIV. A voucher of £15 was given to participants as a token of appreciation for participating. The think-aloud and interview studies together took 70-105 minutes. We recruited 28 people to the studies (10 women, 18 men). Our sample included 16 men who have sex with men (MSM). Of the women, 9 women identified as heterosexual while one identified as bisexual. In terms of ethnicities, we recruited five Black Africans, three Asians or mixed race, 16 were white British, three were other white and one was other. 6 of the 28 participants were people living with HIV. The think-aloud and interview studies were conducted face-to-face at the UCL campus or in public places of participants' choice. Study 1 findings informed the focus of, and topic guides for, studies 2 and 3.

The studies were conducted by the first author (FA - HCI researcher). The second author (clinical academic) was present at all studies. The analysis was led by FA following Braun & Clarke's six steps for thematic analysis [5]: Audio recordings were fully transcribed. FA immersed herself in the data by listening to the recordings before final analysis. As part of initial code generation, the transcribed files were annotated in Nvivo. Resulting transcriptions and annotations were printed out and cross-analysed (on a large wall, later mindmaps and Nvivo) to generate another iteration of themes. Themes were discussed with all authors and reviewed for fit with the transcribed/annotated data, before finalising and writing up.

3.2.1 Think-alouds: The think-aloud study aimed to elicit people's perceptions of information and support associated with browsing HIV-related resources during a complete

user journey from contemplating testing, ordering a remote test online or choosing a clinic for testing, doing a test and getting their HIV results remotely. Participants were not asked to actually do the tests. Studies were video and audio-recorded.

Before starting the think-aloud, participants filled in a pre-test demographic and background information questionnaire. Participants were given simple open-ended scenarios (e.g., recent exposure to HIV: what would you do / search for?) as a starting point for the think-aloud study so that they did not need to disclose their own personal information if they did not want to. Based on the scenarios, we asked participants to complete tasks using a provided laptop or phone or their own if they preferred. Participants were asked to describe their thoughts and experiences while browsing. We observed how they found information on assessing risk, methods of preventing HIV and testing, and searching for online self-testing and self-sampling kits. If they did not encounter certain resources, for example a self-test site, we directed them to explore a related resource. We did not ask for emotional reactions or whether the resource met their needs – only for what they would do next.

3.2.2 Interviews. The interviews were semi-structured; we asked participants questions around their views on existing online HIV information and testing resources and in what situations they had used these in the past. We then asked them how these could be improved and whether they addressed their needs. The purpose of the study was to identify user requirements and features that people felt would improve provision of HIV online interventions and digital tools for testing. In this paper, we focus on their experiences of accessing resources pre-diagnosis of HIV.

Table 3: Participants' characteristics for Study 1

	Ethnicity Group by Gender					Total
	White	**Black**	**Asian**	**Mixed**	**Other**	
Female	78	4	14	4	0	100
Female to Male Transgender	1	0	0	0	0	1
Male	51	14	18	8	1	92
Male to Female Transgender	1	0	0	0	0	1
Non Binary	1	0	2	0	0	3
Total	132	18	34	12	1	197

4 STUDY 1 FINDINGS

197 people answered the survey. Participants' characteristics are summarised in **Table 3**. The median age

of participants was 31 (IQR 26-28). Nearly 58% of respondents lived in London, 30% outside London, within the UK, six percent outside the UK and six percent did not say where they lived. Over half of respondents reported spending more than four hours a day accessing the internet. All respondents had internet access as the survey was online.

Sixty-five percent (128/197) had previously tested for HIV on at least one occasion; 28% (34/122 (6 missing data)) of these had tested within the last year. When asked where they were last tested for HIV, only two reported having ordered a self-sampling kit online and two reported using a self-test purchased via the internet.

Of the 197 people who completed the survey, 114 sought information and resources for HIV online. 108 of these (94.7%) reported using websites to access this information and only 8 (7%) reported using smartphone apps. Table 5 below shows the proportion of people seeking information about HIV online, and what they were looking for.

While 40% of people reported using websites or apps for online dating or to look for sexual partners, only 5% reported using an app or website to calculate their risk of HIV, most using official or NGO websites (e.g. NHS choices, CDC, Terrence Higgins Trust).

Table 4: Accessing information on HIV online. Note: Common responses were explicitly included in the survey; an 'other' field was provided to add any missing options.

What people look for	Participants (%)
How to get tested for HIV	25.4
Safe sex & how to avoid HIV infection	20.3
Their risk of HIV	22.7
Symptoms of HIV	31
Health consequences of HIV	42.4
What it would mean to be infected with HIV	41.6
Concerned they had symptoms indicating they may have HIV	10.6
Looking for information on PrEP as they wanted to date someone with HIV	<1
Searching for prevalence of HIV in the area their partner was from	<1
Finding clinic locations, opening times	<1
Searching for 'how HIV works' and information about antiretroviral therapy	<1

4.1 Design of further studies using survey results

The first study (online survey) informed the design and scope of the further studies - a think aloud and interview study. Based on the survey, we created scenarios and focused the content of the think-aloud to investigate how people navigate the online resources available. Further, we

explored whether participants could find the information they were seeking and whether they were able to link the information into informed decisions about testing, treatment and care. We used the interviews to focus on their previous experiences, perceived barriers to information needs, how they felt when accessing the resources and how the resources could be improved.

5 STUDY 2 & 3 FINDINGS: NEEDS FOR INFORMATION AND EMOTIONAL SUPPORT

Our studies revealed various needs for information and emotional support while using HIV-related digital resources. Six themes were identified: (i) Finding "trusted sources for information", (ii) information presentation to alleviate anxiety and fear, (iii) stigmatising narrative is disempowering, (iv) fear of testing and its outcome, (v) choosing a test is daunting, and (vi) HIV-related apps and sense of control. We present here the themes in detail. Participant identifiers for studies 2 and 3 are denoted by P#.

5.1 Finding "trusted sources for information"

As with the findings from Study 1, a major factor in selecting which resource to use for information was trust – people selected websites based on whether they had heard of the provider and whether they trusted the provider to give appropriate information (official or non-governmental organisation (NGO) websites). In the UK, this meant that the *National Health Services* (NHS) website (*NHS Choices)* or HIV charities' sites such as the Terence Higgins Trust (a leading HIV charity) were the most often chosen for information. MSM also commonly chose the GMFA (Gay Men Fighting AIDS) website for information. The majority of participants did not trust promoted or sponsored links that were displayed by Google. P27 said, *"I would normally go with reputable organisations or sites, so probably NHS website".* P11 did not want to use the information from a site he did not recognize even though it felt more accessible and easy to understand: *"[Organisation name] - short and punchy [information] - but I don't know them, I'm not sure."*
People in Studies 1 and 2 were more likely to choose UK based resources as they felt that the information would be more related to their needs. P27 said, "*Sometimes you do get some American ones pop up, but I tend to keep it to the UK, because it's relevant to where you're living and what you want to do."* P11 felt that the evidence provided on UK and other sites (e.g., American) was different: "*that it's not a UK government thing does make me question the background of it, not necessarily the accuracy ... like how it's transmitted in the US, I wonder how relevant that would be to me: needles*

and syringes is high up whereas, that's fairly low down in transmission risks in the UK."
Out-of-date resources were also not trusted. For example, P11 said, *"I do notice it was last updated in 2014..."*

5.2 Information presentation to alleviate anxiety and fear

As shown in the previous section and **Table 4**, people searched for HIV-related information for specific reasons; however, the structure of HIV-related online resources were not perceived as reflecting people's aims. Participants felt that resources were "*text-heavy"* and "*top-loaded*", and the amount of information was overwhelming.
Participants felt that the important information on what test or treatment they needed should be highlighted early in the process. They expressed strong feelings about not being able to find the information that they needed quickly. P12 exclaimed, *"I think the NHS digital platform is like disgusting! It's good to have this level of information, but the reason people go to a site like this is to find out immediate information."* P20 had similar thoughts: *"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, but the links are further down. You're stressed and want to get to the point right away"*
Participants thought that the information was presented like a textbook or patient pamphlet, describing it as "*passive*" and "*not engaging*". P16 explained, "*... it's almost written like, I have ten minutes to spare, so maybe I should read about something on HIV testing [...] as if I'm sitting at home and I'm worried [...] and I want to go and get tested for a cold and that's not how it works. You're sitting there in extreme anxiety inducing uncertainty and I want answers now and I want to be reassured. It's not, 'ooh I've got a runny nose...'"*
Participants felt that it would be better for websites to be more tailored to their needs, like other e-commerce websites. P12 said, "*...think about someone's customer journey on a website [...] replicate it like an online service like having it be accessible and understanding of the customer [needs]."*
Participants felt that if they knew what they were looking for, online resources should make the information and resources needed easier to find/ access. Many found that when they were looking for testing options, online resources did not capitalize on their intentions. Instead, they often had an approach of giving users more information about HIV even when they had specific aims and information or resource needs. P13 explained, *"Anyone*

who's gone to the trouble of clicking on, 'how do you catch HIV?', should be left with a clear call to action, [...] on how to test … and regularly."

Some participants were frustrated by the unnecessary information they had to navigate before getting to the resources they were after. P12 said, *"people don't need to be educated before they ask for a test. If they think they need a test, they need a test."* Providing unnecessary information meant that people who were motivated to test and were looking for information about their choices could lose the impetus or motivation for testing. P16 explained, *"'when should I get tested', that's the wrong question because I might already be wanting to get tested - I feel like that should be later [after giving options for testing]. In fact, I feel like that's more of a disincentive to get tested..."*

However, participants felt this oversight could be addressed easily: *"in case they think they contracted it [HIV] [...] - even having a button that's just 'Get Tested'. That's first, because that's why people are coming to the website and it's the first thing they want to do."* In addition, online resources could encourage motivated users, at high risk of HIV, to test regularly and give them information about that and biomedical interventions (e.g. PrEP).

At other times, participants did not need generic information but specific recommendations based on their experience. Participants felt that searching for high-risk behaviours or having put themselves at risk should automatically highlight the option to get emergency HIV prevention medication, PEP. P14 said, *"it's quite logical if somebody is searching for signs of HIV, if they think they've put themselves at risk [...] It should be obvious on a [public] health funded website to suggest PEP."*

Participants shared stories of their own panic and desperation when they felt they had put themselves at risk and how websites had directed them to testing options rather than PEP. P16 said, *"[PEP] was something I didn't know about in the past [...]. I ended up going to A&E because I found out about it at the last minute. I felt I had been [exposed to HIV] and was really upset and paranoid as I had this sudden four to six-week window of uncertainty and felt completely unable to do anything about it …"*

Since not everyone is aware of PEP, the question about when (how recently) the risky exposure occurred should be highlighted upfront before people can order tests. For example, on the NHS funded website where people could order a self-sampling kit, the question of PEP did not come up before people could order the kit. PEP could prevent HIV if administered early (within 72 hours). P11 commented on this saying, *"[PEP] needs to be dealt with upfront... it would have to be a very early triage question around whether or not*

PEP was going to be beneficial in that particular circumstance (to prevent HIV)."

5.3 Stigmatising narrative is disempowering

All participants agreed that HIV-related stigma persists and is a complex phenomenon. P22, a person living with HIV, explained, *"I know a lot of people [...] would put their status on an app like Grindr [dating app for MSM] and they receive anonymous hate from that. Because a lot of gay identity or LGBT identity is kind of internalised with HIV stigma. And people really act out against those living positively."*

Participants commended the choice in testing options, but felt that some of the rhetoric needed challenging and should not be reinforced by community and government organisations. P13 said, *"This is the wrong information to give - 'There are home-testing kits you can use if you don't want to visit any of these places' - that is not the point! Why don't they want to visit? It should say, 'if you're concerned about visiting, let us give you more information about the services these places provide and the comfort, security, information, knowledge and care that you can get.' "*

Most participants felt that the narrative around HIV self-testing was negative rather than empowering and reinforced stigma that it was something to be shameful of, which is a betrayal of what people especially in the MSM community believe and have campaigned for. They felt that HIV self-tests were being advertised as if HIV was something shameful, to hide. P16 said: *"I think that what [HIV self-testing narrative] is encouraging is dangerous. It's encouraging disconnection [...] a change of perspective that you should want to do that at home and in privacy which encapsulates the stigma. This is exactly why you want to do it in the presence of others, to know that it's okay. They use #knowyourstatus: all the discourses that LGBT people would have fought for and purged but in an insidious exclusionary way [...] as opposed to in the public sphere where you should be able to exist as a proud, out, positive, person."*

However, some participants found the information provided online reduced stigma, and allowed them to access information they would not otherwise feel able to. *P5: I think just how they've made them like really stigma-free is the most important thing, because the HIV campaign that everyone remembers is the you're going to die of AIDS one, even though that hasn't been true for a long time. So just emphasising that it's treatable and not something to be ashamed of is important and, it's not the end of the world or really embarrassing or to hide. It's not something that you don't want to know."*

5.4 Fear of testing and its outcome

People spoke about the fear of testing and possible positive outcomes. P26 explained, *"I'm HIV-positive, [...]But before I found out, I wouldn't have been keen [to test], because I'd be like, 'ooh, [what] if I am!' - so that kind of fear."* Many felt that the result could be one that people were not mentally prepared for. P12 commented, *"… a lot of people know now that HIV isn't a death sentence but that doesn't take away from the shock of it."*

Given the possibility of a potential positive result, participants felt home tests should make people aware of the fact that they may need support or to be in a supportive environment when doing the test. P13 said, *"My first test: the first question they asked when they told me that the HIV test was possible on the spot was, 'Are you here with somebody who can give you support if the answer is not the one you are hoping for?' And I thought what a wonderful question to ask. [...] I can't imagine the terror of getting a positive result and not knowing what to do. That would be irresponsible!"*

Some participants were reluctant to do the test at home due to lack of support. P19 said, *"The thing that would prevent me from doing the test at home, specifically for HIV, [...], is crap, now I've actually got this result and I'm at home, by myself, with no counselling or care around that, in a way that I don't think matters for any other disease [...]. Whereas I think the stigma around HIV is that it's such a momentous thing that it's going to impact you forever.. the idea of finding out that information at home without being surrounded by medical professionals, [...] is the biggest barrier to getting somebody to do the self-test at home."*

5.5 Choosing a test is daunting

People decide to test, how they are going to access testing, and the type of test they are going to use, based on their own past experiences, circumstances, knowledge of testing and confidence [3]. It has been acknowledged in the sexual health literature that testing for HIV is not one size fits all and different testing interventions suit different people according to the barriers [18]. Participants suggested that in addition to recentness of testing, frequency and inter-test intervals could be used to tailor testing recommendations. P11 said, *"I think there's a gap here: [...] there's two different people that will be testing regularly. Those who are the 'worried well', who will test regularly, they don't even have to; and those who test regularly as a matter of good practice. [...] you can have lots of regular sex and you might want to test every three to four months, certainly more than twice a year. Then there are those people who are testing with [a particular] reason, [they] fall into other categories and other*

time periods – and then there is frequency and time between tests."

While the choice in testing options is to be encouraged, there is a lack of guidance for people in making choices based on factors such as testing frequency. Previous literature in sexual health has highlighted that people who are testing routinely might benefit from self-sampling kits being sent to them regularly or on subscription [18]. Even within the groups of people who want to test due to a one-off risky event, there are those who will be testing for the first time, and need more information and support, and those who have tested before. Other complex aspects need to be disentangled to assess whether someone chooses to self-test or self-sample including the '*window period*' (the time taken between someone being infected and the infection being detectable by the test) for that particular test, and the time taken to get the result. Online resources can provide cumulative information on these aspects, aiding decision making rather than leaving people to make decisions without understanding all the aspects involved.

The other issue that participants encountered was a lack of recommendations from the NHS or other providers about which test to get. The recommendation on the NHS site was considered confusing by some people: "*It's important to check that any test you buy has a CE quality assurance mark and is licensed for sale in the UK, as HIV self-tests available from overseas can be poor quality."* P26 commented, *"That's not very helpful! I have to just go to a shop and say, do you have a self-test kit, and that if it's CE-marked…"* Also, since self-testing is not funded by the NHS, cost is a barrier. *P26 said, "would I pay £30 when I can just go get it free [in clinic or self-sampling]? Not everybody has £30. "*

Self-tests came up when the participants searched online for testing and they questioned how they would find out other relevant information. Self-tests were available on Amazon and other commercial sites which did not include the contextual information about testing that the vendor's site included. *"But if I found out I may be at risk, how am I supposed to know this information [about PEP, window period, free tests]? … I'm literally going on Google and clicking on whatever page I see first and they're telling me I have to pay £30 … I have only £10. What am I going to do?"*

Fear of testing, housemates or others in the family finding out or losing the momentum to test were factors that participants mentioned as barriers in choosing a self-sampling or self-testing kit. **Table 1** shows time to get results for each of the tests. P7 said, *"I know that if I go to [the clinic], I'd have an instant test, and I don't have to spend a week worrying and I'm given to periods of depression, [...]. Free sampling is great, but with the walk-in centre you have*

the panicky impulse- you go and do it. By the time [self-sampling kits] arrive I think, oh, I won't do that now. 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."

Participants felt that if using self-sampling these barriers could be addressed by following up people who did not engage after ordering tests, and suggesting different methods of testing proactively. However, for self-tests, there was no way of following up with people unless they chose to engage.

Most participants felt that HIV resources are disproportionately targeted towards MSM, who accounted for 54% of new diagnoses in 2016 [7]. . P11 said, *"We shouldn't overlook the fact that a lot of this should be targeted at the non-MSM community, which is still responsible for 50% of the diagnosis. [...]those groups would only get tested for HIV when testing positive for another trigger condition such as chlamydia. Use those as a trigger to test for HIV, without necessarily the stigma that occurs, especially in the non-MSM communities. "*

5.6 HIV-related apps and sense of control

Most participants did not use an app for HIV information. In our study, HIV-related apps were predominantly used by people living with HIV – a topic that is out of scope for the present paper. Most participants were reluctant to use exclusively HIV-related apps just for information or testing due to possible speculation by others and potential stigma. P10's reason was, *"because people might know that I'm having this app so I'm not going to risk it because in my circle of friends, getting HIV is not very common – it's very prejudiced "*. P26 agreed with this: *"If like I have a friend who had an app on HIV, I'd be like, why do you need this? Like are you at risk or something?"*

A few participants accepted that an app might be able to meet the needs for personalisation better than websites. P20 said, *"I do think that apps are more personable now... if you have an app that's something you'll go to, it's going to be more connected or tailored if you need to know any information"*. P12 had a suggestion, *"I don't think having an NHS branded app on your phone would be an issue for most people."* A couple of participants mentioned being interested in risk calculator apps that could make insightful suggestions about their risk and testing / treatment options and be updated by the latest research. P24 said, *"With an app, the layout could be really useful if you wanted to find out whether you were at risk: it's like describe your situation, and all the sexual activities and say no protection and then it says okay so what are your results, and then tells you what to*

do next there, where and how to get tested, [...], it covers a lot of grounds."

Some participants felt that existing and popular apps could and were doing more to provide information about testing and treatment. P24 said, *"on the odd occasion where you sign into Grindr [dating app for MSM], there's an initial popup ad, I have seen links to information about PEP. which is useful and reassuring: they're getting better at it."*

6 DISCUSSION

The aim of our studies was to investigate the needs around developing an online pathway for taking people from seeking information on HIV, to testing, results management and engagement in care. In this paper, we have presented insights into how people approach and identify HIV-related information and digital resources online around the time of testing for HIV. In doing so, this paper highlights mismatches between the design of current resources and people's emotional and informational needs when seeking information and testing. We have identified several needs that arise due to the complexity and stigma associated with HIV, including the context and emotion driving people to seek information on HIV in the first place. This study reiterates the particular importance of designing for real user needs (establishing why people may be searching online, why they may visit a site and what information they may need to find quickly) in health information systems where the interaction has high emotional import: many health information resources currently do not address people's emotional needs and urgent goals. While our analysis has focused on the emotional support needs linked to technology use for HIV, our results have implications for other STIs and can be used as a starting point for technologies for other complex, stigmatised conditions. Even more broadly, our results have implications for the design of resources for self-testing and self-management in other health conditions, where people need to make a choice of intervention or treatment, or simply access information and are worried or face emotional barriers.

This analysis has focused on providing information and support in HIV-related digital resources, including websites (for information and ordering tests), remote tests, getting results remotely and immediate options for support. Our findings show that people do not receive appropriate emotional support during their journey to find information about HIV, test and receive results online or remotely. Further, people felt concerned both about the risks of self-testing for HIV remotely with the current information and support resources available, and the time taken for a kit to arrive and to receive results when using a self-sampling kit.

These could act as major barriers to people accessing these resources. While there has been some HCI research investigating needs from technology for people living with HIV in personal informatics and behavioural intervention apps [9,36], these interventions are aimed post-diagnosis of HIV. From this perspective, our study is unique:

1. we look at the needs from technology for people prior to and immediately after testing for HIV to support information seeking and make decisions regarding testing, prevention and engagement with services.
2. we focus on the general population with significant input from at-risk populations. This inclusive approach is important as, although MSM and heterosexual Black Africans have higher rates of HIV than the general population, a higher proportion of non-Black African heterosexuals are diagnosed late [7]. In addition, if technological resources only target certain high-risk populations, others may be deterred from testing, and normalization of HIV testing and HIV as a condition will not occur. The relationships between participants' backgrounds and the local culture, context of use, and technology available, warrants further research.
3. we focus on the emotional needs that are rarely well addressed in online resources that provide information and resources related to HIV.

Here, we discuss four specific aspects that have design implications and opportunities for further research, and highlight how these inform or extend existing principles of information design and information seeking.

6.1 Purposeful design of early interactions

A recurring theme of our studies was that people accessed resources based on specific purposes – often with already formed intentions or motivations to test, to look for specific avenues of treatment, or for advice based on their experience. People found it difficult to get support as resources were structured in a way that was incongruent with people's mental models and reasons for accessing the resources. Many reported having been in a situation where they were anxious (following a perceived risk event), uncertain and desperately searching for the right resources for help. These initial phases were characterized by frustration because people did not find information that they were looking for. Even when websites had the relevant information, it was not highlighted or did not facilitate or signpost people to enable them to act on the information.

Some research in public health has focused on the need to provide information on biomedical or other interventions before offering those interventions to people who may be unfamiliar with them [37]. However, in our study people felt there was a need to find a balance by offering the interventions upfront and linking them to information - such approaches can engage both users who have some knowledge of the intervention as well as those for whom this information is novel. Also, as more interventions become available and people are searching for options, there will be more responsibility on the designers of the resources to structure information in a way that highlights the most immediate and urgent actions with links to information as needed to avoid information overload. Literature on information seeking behaviour in health acknowledges that users can disengage very quickly with websites due to design issues that place the burden of making sense of information solely on the user [49]. However, even basic presentation differences can affect outcomes [32]. This resonates with our results where the generalized nature and tone of the resources, and the lack of immediacy or suggestion for action, diluted or even dissipated people's impetus to act. Designing resources for purposeful interactions is therefore imperative to engage users. One way to do this is to design resources using plain language design principles [52] and tailor resources to specific user needs. Another is supporting goal directed activity, as in the persuasive technology literature, by providing obvious cues to actions that people can take, (e.g., clicking on a button to order a test) so that they can act on their already formed intentions [40] or trigger an action [20]. This maps to the "cues to action" concept of the Health Belief Model [38,55] which attempts to explain how individuals might try to avoid ill health. In our case, the behaviour (e.g,, HIV testing/ interventions/ information search) is influenced by multiple factors including perceived risk of contracting HIV and its severity, and cues to action are considered central to changing behaviour such as taking a decision to test or safer sex [38].

6.2 Need for emotional support throughout the process

Keeping people engaged in the process and encouraging them to test or get treatment is a vital endpoint of the pre-diagnosis path from accessing information, support and resources. We found that emotional needs were present throughout the process. Technological interventions need to respond to psychological aspects of evaluating options, considering the process of HIV testing and individual needs for support. Fear of testing for HIV or of receiving a positive result is a major barrier to testing [19] as is self-efficacy (another concept in the health belief model), as a mediator for dealing with the process/ result [45]. It is important for technologies to recognise what HIV testing means to the individual [19]: the implications of a positive result can be significant within their inter-personal, societal

and cultural contexts. The need for empathy and acknowledgement of emotional aspects of a health condition as a key mediator for persuasive messages in health promotion has been previously highlighted as a way to engage people [10]: in this paper we argue that it is important to address emotions at every stage since people can disengage at any stage of the process. For example, one participant in Studies 2,3 had made the decision to order a test but it remained unused on the fridge due to loss of impetus to test by the time the test arrived. While with self-sampling there is some linkage into care, people might disengage even after doing a test, especially if the test is positive [18]. This is particularly critical for HIV because its sensitive nature and associated stigma means that people accessing help may already feel unsupported and stressed [36], and failure to engage with care in a timely manner can have severe adverse health consequences, as well as facilitate transmission to others.

Some participants suggested that online or digital resources could be designed for support along with diagnostic tools such as self-tests. For example, they might include a virtual agent to support people when preparing to conduct a self-test or to overcome the isolation of remote testing, or an app that links people who use self-tests into care or provide more information and direct links to healthcare resources, positive peer user stories, hotlines or forums. Currently, available self-tests do not provide the required support [42,61], and this is a worthwhile aim for future research.

6.3 Addressing different expertise and patterns of use

HCI research has found that seeking and using online health information is complex as it needs to cater to a range of users across systems [49,50]. Based on the responses in our studies, we identified that people had different attitudes to testing and sexual health. Those with past experience of sexual health and testing helped people to negotiate resources. It is therefore important that resources are optimized so that those testing for the first time are also able to negotiate them and are signposted into clinical services, if appropriate. We identified people in our studies as: (i) those who regularly test as good practice or due to high risk behaviours, (ii) those who test in response to a one-off event (for diverse reasons such as antenatal screening, a risky sexual encounter or opportunistically as part of a health check-up), (iii) the worried well who regularly test, and (iv) first time testers. Similar user groups for self-testing in MSM have been identified in other research [18] with the additional category of those who live in a high-risk area: this did not emerge in our research.

Different information and interventions could be signposted for each of these user groups. For example, a regular tester could be signposted into subscribing for regular self-sampling kits, appointment reminders for clinics or biomedical interventions if they were perceived as high risk. Currently, the big e-commerce websites offer options such as setting up reminders and subscriptions and health applications can learn from their success. On the other hand, first time testers reported needing more information and support in making decisions about testing, not just for HIV but also for other STIs, and to facilitate access to primary prevention strategies (e.g. PrEP and PEP) available within a clinic-based setting. A positive experience of first-time testing could help to establish healthy testing habits [68]. Similarly, if someone was searching following a high-risk encounter, a face-to-face clinic appointment might be the best option, where they can also be given PEP if appropriate. While the need to "tailor prevention messaging" to at-risk groups has been highlighted in public health literature [37], our studies highlight the need to tailor the many mainstream resources that could be (necessarily) aimed at anyone in need of testing to their needs (incl. digital literacy, past experience of testing or exposure to information, risk perception). Building websites that guide users in making testing/ treatment choices and have seamless online-offline pathways, could improve existing solutions in making resources available to a large proportion of the population.

6.4 Ensuring messages do not reinforce stigma

A recent study reviewing existing HIV-related web and smartphone apps found that while many apps are available, very few provide the functionality and information required to support the needs of people seeking information on HIV [61]. Self-sampling and self-testing are convenient and even necessary in the current climate as services are under pressure and cost-cutting is imperative within health services. Self-testing/ sampling allows people to test privately and has the potential to normalise testing, facilitating access by those who may not otherwise test, leading to earlier diagnosis and subsequent care. However, our findings indicate that the discourse surrounding it is also potentially disempowering - HIV-related stigma, which people have campaigned to end, is reinforced by messages where people are encouraged to 'test in private' as if it is something to be ashamed of [33]. The downsides of private screening include no direct linkages to support services such as linking to care. People may justify risky sexual behaviour in the absence of counselling in case of a negative result, while a positive one could potentially lead

to self-stigmatisation, depression, self-harm or even suicide. HIV testing is something that needs to be encouraged. Additionally, even if a test is done in the privacy of the home, if positive, it always needs to be confirmed; users testing negative may have other needs.

Self-testing has the potential to overcome barriers and increase the proportion of people who know their HIV status and start timely treatment; however, participants in our study objected to the rhetoric around it as being something to hide. They felt that it was more about promoting self-testing as a matter of user choice (empowering) and not suggesting that it's important that it's private (stigmatising). One way of reinforcing the empowering and supportive aspects of self-testing could be through open community sharing of information and experiences [64], peer [29] and online social networks [63]. Recent studies on the role of social networks in HIV testing behaviours have found that some social network characteristics and functions such as network-mediated information acquisition about HIV is associated with ever testing and repeat testing [63] and peer support is associated with recency of HIV testing in black MSM [59]. Thus online social and support aspects of HIV information seeking and decision making in this context are valuable, and though they did not emerge in our study, need further investigation.

One limitation of our first study is a lack of diversity as the survey was online with opportunistic sampling. However, it was exploratory and designed to inform studies 2,3. In the subsequent studies, we attempted to recruit more inclusively with a focus on high risk groups with the proportion of MSM (57%) recruited similar to the proportion of new diagnoses of HIV in 2016 who were MSM (54%) [7]. However, we still did not manage to recruit all groups including more heterosexual men.

7 CONCLUSIONS

In this paper, we have focused on identifying people's emotional support needs when interacting with HIV-related digital technologies around the time of testing. Our findings show that many online HIV-related resources are not designed to address the emotional reasons for access, reinforce stigma and neglect to provide important information and emotional support. While technologies for diagnosing, and medications for preventing, HIV are advancing rapidly, the human facing aspect of these technologies is not as developed: there is a need for innovative, tailored and fit-for-purpose technology that provides emotional support while providing information and supporting decision-making. In order to provide

effective remote/online care, and to empower people to make informed decisions, we propose that resources need to be designed in a way that: 1. Aligns with people's mental models and reasons for accessing the resources; 2. Acknowledges and supports the emotional needs of people; 3. Is personalized to different levels of knowledge and experience of HIV and testing for HIV; 4. Ensures messages are supportive and not reinforcing stigma.

The findings reported in this paper are being used to inform the development of a self-testing app to read the results of an HIV test and link them to an online results, management and care pathway including offering support and next steps for people with potentially positive results. In addition to existing digital interventions on promoting self-testing (discussed in the background section) which are valuable [25], we aim to address user needs for testing and post-testing linkage to care to provide tailored information and suggest next steps and advice on safe sexual behaviours and repeat testing even for people testing negative.

REFERENCES

[1] Ann Blandford and Simon Attfield. 2010. Interacting with Information. Synthesis Lectures on Human-Centered Informatics 3, 1: 1–99. https://doi.org/10.2200/S00227ED1V01Y200911HCI006

[2] M Brady, G Carpenter, and B Bard. 2016. Self-testing for HIV: initial experience of the UK's first kit. 22nd Annual Conference of the British HIV.

[3] M Brady, W Howells, C James, D Edwardes, B Bard, and G Carpenter. 2017. HIV self-testing: Feasibility and acceptability of a large scale national service. HIV Medicine 18: 5. https://doi.org/http://dx.doi.org/10.1111/hiv.12512

[4] Dale E. Brashers, Judith L. Neidig, and Daena J. Goldsmith. 2004. Social Support and the Management of Uncertainty for People Living With HIV or AIDS. Health Communication 16, 3: 305–331. https://doi.org/10.1207/S15327027HC1603_3

[5] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. Qualitative Research in Psychology 3, 2: 77–101.

[6] Johanna Brewer, Joseph "Jofish" Kaye, Amanda Williams, and Susan Wyche. 2006. Sexual interactions: why we should talk about sex in HCI. In CHI '06 extended abstracts on Human factors in computing systems - CHI EA '06, 1695. https://doi.org/10.1145/1125451.1125765

[7] Alison Brown, Colin Campbell, Cuong Chau, Sara Croxford, Maciej Czachorowski, Jennifer Davidson, Valerie Delpech, Rachel Glass, Luis Guerra, Viv Hope, Gwenda Hughes, Georgina Ireland, Peter Kirwan, Maeve Lalor, Louise Logan, Sema Mandal, Holly Mitchell, Hamish Mohammed, Anthony Nardone, Eamonn O 'moore, Claire Reynolds, Ruth Simmons, Bhavita Vishram, John Were, and Dominik Zenner. 2016. HIV testing in England: 2016 report. Retrieved April 28, 2017 from www.gov.uk/phe

[8] Adrian Bussone, Simone Stumpf, and John Bird. 2016. Disclose-It-Yourself: Security and Privacy for People Living with HIV. In CHI EA '16: Proceedings of the 2016 ACM annual conference on Human Factors in Computing Systems Extended Abstracts, 1–4.

[9] Adrian Bussone, Simone Stumpf, and George Buchanan. 2016. It Feels Like I'M Managing Myself: HIV+ People Tracking Their Personal Health Information. In Proceedings of the 9th Nordic Conference on

Human-Computer Interaction (NordiCHI '16), 55:1–55:10. https://doi.org/10.1145/2971485.2971542

[10] Rose G. Campbell and Austin S. Babrow. 2009. Health Communication The Role of Empathy in Responses to Persuasive Risk Communication: Overcoming Resistance to HIV Prevention Messages. Health Communication 16, 2: 159–182. https://doi.org/10.1207/S15327027HC1602_2

[11] Soazig Clifton, Anthony Nardone, Nigel Field, Catherine H Mercer, Clare Tanton, Wendy Macdowall, Anne M Johnson, and Pam Sonnenberg. 2016. HIV testing, risk perception, and behaviour in the British population. AIDS (London, England) 30, 6: 943–52. https://doi.org/10.1097/QAD.0000000000001006

[12] Sheldon Cohen, Gary Evans, Daniel Stokols, and David Krantz. 1986. Behavior, health, and environmental stress. Plenum Press.

[13] J. R. Dale, S. M. Williams, and V. Bowyer. 2012. What is the effect of peer support on diabetes outcomes in adults? A systematic review. Diabetic Medicine 29, 11: 1361–1377. https://doi.org/10.1111/j.1464-5491.2012.03749.x

[14] J. Deblonde, P. De Koker, F. F. Hamers, J. Fontaine, S. Luchters, and M. Temmerman. 2010. Barriers to HIV testing in Europe: a systematic review. The European Journal of Public Health 20, 4: 422–432. https://doi.org/10.1093/eurpub/ckp231

[15] J. Deblonde, P. De Koker, F. F. Hamers, J. Fontaine, S. Luchters, and M. Temmerman. 2010. Barriers to HIV testing in Europe: a systematic review. The European Journal of Public Health 20, 4: 422–432. https://doi.org/10.1093/eurpub/ckp231

[16] Brenda Dervin and CD Reinhard. 2007. How emotional dimensions of situated information seeking relate to user evaluations of help from sources: an exemplar study informed by sense-making. In Information and emotion: the emergent affective paradigm in information behavior research and theory, Diane Nahl and Dania Bilal (eds.). Information Today, 51–84.

[17] Public Health England. 2015. HIV in the UK – Situation Report 2015 Incidence, prevalence and prevention. Protecting and Improving the Nations Health 1, 1: 1–20. Retrieved September 3, 2016 from www.gov.uk/phe

[18] P Flowers, J Riddell, C Park, B Ahmed, I Young, J Frankis, M Davis, M Gilbert, C Estcourt, L Wallace, and L. M. McDaid. 2017. Preparedness for use of the rapid result HIV self-test by gay men and other men who have sex with men (MSM): a mixed methods exploratory study among MSM and those involved in HIV prevention and care. HIV Medicine 18, 4: 245–255. https://doi.org/10.1111/hiv.12420

[19] Paul Flowers, Claudia Estcourt, Pam Sonnenberg, and Fiona Burns. 2017. HIV testing intervention development among men who have sex with men in the developed world. Sexual Health 14, 1: 80–88. https://doi.org/10.1071/SH16081

[20] B J Fogg. 2009. A behavior model for persuasive design. In the 4th International Conference on Persuasive Computing, 40:1-40:7. http://portal.acm.org/citation.cfm?doid=1541948.1541999

[21] Shelagh K. Genuis. 2012. Constructing "sense" from evolving health information: A qualitative investigation of information seeking and sense making across sources. Journal of the American Society for Information Science and Technology 63, 8: 1553–1566. https://doi.org/10.1002/asi.22691

[22] Natalya Godbold. 2013. An information need for emotional cues: unpacking the role of emotions in sense making. Information Research 18, 1.

[23] Sarit A. Golub and Kristi E. Gamarel. 2013. The Impact of Anticipated HIV Stigma on Delays in HIV Testing Behaviors: Findings from a Community-Based Sample of Men Who Have Sex with Men and Transgender Women in New York City. AIDS Patient Care and STDs 27, 11: 621–627. https://doi.org/10.1089/apc.2013.0245

[24] Emma Harding-Esch, Anthony Nardone, Jo Gibbs, Lorna Sutcliffe, Pam Sonnenberg, Claudia Estcourt, Gwenda Hughes, Hamish Mohammed, Noel Gill, S Tariq Sadiq, and Catherine Lowndes. 2015. Can remote STI/HIV testing and eClinical Care be compatible with robust public health surveillance? In DH'15: proceedings of the 5th International Conference on Digital Health 2015: May 18-20, 2015: 129–130. https://doi.org/10.1145/2750511.2750517

[25] Ford Hickson, Keith Tomlin, James Hargreaves, Chris Bonell, David Reid, and Peter Weatherburn. 2015. Internet-based cohort study of HIV testing over 1 year among men who have sex with men living in England and exposed to a social marketing intervention promoting testing. Sexually transmitted infections 91, 1: 24–30. https://doi.org/10.1136/sextrans-2014-051598

[26] Randolph D. Hubach, Brian Dodge, Michael J. Li, Vanessa Schick, Debby Herbenick, William D. Ramos, Thea Cola, and Michael Reece. 2015. Loneliness, HIV-Related Stigma, and Condom Use Among a Predominantly Rural Sample of HIV-Positive Men Who Have Sex With Men (MSM). AIDS Education and Prevention 27, 1: 72–83. https://doi.org/10.1521/aeap.2015.27.1.72

[27] Heidi Julien and Ina Fourie. 2015. Reflections of affect in studies of information behavior in HIV/AIDS contexts: An exploratory quantitative content analysis. Library & Information Science Research 37, 1: 3–9. https://doi.org/10.1016/J.LISR.2014.09.001

[28] Gopinaath Kannabiran, Jeffrey Bardzell, and Shaowen Bardzell. 2011. How HCI talks about sexuality. In Proceedings of the 2011 annual conference on Human factors in computing systems - CHI '11, 695. https://doi.org/10.1145/1978942.1979043

[29] Lisa W. Kimbrough, Holly E. Fisher, Kenneth T. Jones, Wayne Johnson, Sekhar Thadiparthi, and Samuel Dooley. 2009. Accessing Social Networks With High Rates of Undiagnosed HIV Infection: The Social Networks Demonstration Project. American Journal of Public Health 99, 6: 1093–1099. https://doi.org/10.2105/AJPH.2008.139329

[30] Tassaneewan Laksanasopin, Tiffany W. Guo, Samiksha Nayak, Archana A. Sridhara, Shi Xie, Owolabi O. Olowookere, Paolo Cadinu, Fanxing Meng, Natalie H. Chee, Jiyoon Kim, Curtis D. Chin, Elisaphane Munyazesa, Placidie Mugwaneza, Alex J. Rai, Veronicah Mugisha, Arnold R. Castro, David Steinmiller, Vincent Linder, Jessica E. Justman, Sabin Nsanzimana, and Samuel K. Sia. 2015. Supplementary Information: A smartphone dongle for diagnosis of infectious diseases at the point of care. Science translational medicine 7, 273: 273re1. https://doi.org/10.1126/scitranslmed.aaa0056

[31] C P Langford, J Bowsher, J P Maloney, and P P Lillis. 1997. Social support: a conceptual analysis. Journal of advanced nursing 25, 1: 95–100. http://www.ncbi.nlm.nih.gov/pubmed/9004016

[32] Carolyn Lauckner and Gary Hsieh. 2013. The presentation of health-related search results and its impact on negative emotional outcomes. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems - CHI '13, 333. https://doi.org/10.1145/2470654.2470702

[33] Ramon Lee, Rosa R. Cui, Kathryn E. Muessig, Harsha Thirumurthy, and Joseph D. Tucker. 2014. Incentivizing HIV/STI testing: A systematic review of the literature. AIDS and Behavior 18, 905–912. https://doi.org/10.1007/s10461-013-0588-8

[34] Duncan A. MacKellar, Su-I Hou, Christopher C. Whalen, Karen Samuelsen, Travis Sanchez, Amanda Smith, Damian Denson, Amy Lansky, and Patrick Sullivan. 2011. Reasons for Not HIV Testing, Testing Intentions, and Potential Use of an Over-the-Counter Rapid HIV Test in an Internet Sample of Men Who Have Sex With Men Who Have Never Tested for HIV. Sexually Transmitted Diseases 38, 5: 419–428. https://doi.org/10.1097/OLQ.0b013e31820369dd

[35] Lena Mamykina, Arlene M. Smaldone, and Suzanne R. Bakken. 2015. Adopting the sensemaking perspective for chronic disease self-management. Journal of Biomedical Informatics 56: 406–417. https://doi.org/10.1016/j.jbi.2015.06.006

[36] Gabriela Marcu, Nadia Dowshen, Shuvadittya Saha, Ressa Reneth Sarreal, and Nazanin Andalibi. 2016. TreatYoSelf: Empathy-driven behavioral intervention for marginalized youth living with HIV. In Proceedings of the International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth 2016), 1–8.

[37] Omar Martinez, Elwin Wu, Ethan C. Levine, Miguel Muñoz-Laboy, M. Isabel Fernandez, Sarah Bauerle Bass, Eva M. Moya, Timothy Frasca, Silvia Chavez-Baray, Larry D. Icard, Hugo Ovejero, Alex Carballo-Diéguez, and Scott D. Rhodes. 2016. Integration of Social, Cultural, and Biomedical Strategies into an Existing Couple-Based Behavioral HIV/STI Prevention Intervention: Voices of Latino Male Couples. PLOS ONE 11, 3: e0152361.

https://doi.org/10.1371/journal.pone.0152361

[38] Marifran Mattson. 1999. Toward a reconceptualization of communication cues to action in the health belief model: HIV test counseling. Communication Monographs 66, 3: 240–265. https://doi.org/10.1080/03637759909376476

[39] Chrysta C Meadowbrooke, Tiffany C Veinot, Jimena Loveluck, Andrew Hickok, and José A Bauermeister. 2014. Information Behavior and HIV Testing Intentions Among Young Men at Risk for HIV/AIDS. Journal of the Association for Information Science and Technology 65, 3: 609–620. https://doi.org/10.1002/asi.23001

[40] Susan Michie, Stefanie Ashford, Falko F Sniehotta, Stephan U Dombrowski, Alex Bishop, and David P French. 2011. A refined taxonomy of behaviour change techniques to help people change their physical activity and healthy eating behaviours: The CALO-RE taxonomy. Psychology & Health: 1–20.

[41] Kathryn E Muessig, Cedric H Bien, Chongyi Wei, Elaine J Lo, Min Yang, Joseph D Tucker, Ligang Yang, Gang Meng, and Lisa B Hightow-Weidman. 2015. A Mixed-Methods Study on the Acceptability of Using eHealth for HIV Prevention and Sexual Health Care Among Men Who Have Sex With Men in China. J Med Internet ResJ Med Internet Res 1717, 414. https://doi.org/10.2196/jmir.3370

[42] Kathryn E Muessig, Emily C Pike, Sara LeGrand, and Lisa B Hightow-Weidman. 2013. Mobile Phone Applications for the Care and Prevention of HIV and Other Sexually Transmitted Diseases: A Review. Journal of Medical Internet Research 15, 1: e1. https://doi.org/10.2196/jmir.2301

[43] E D Mynatt, G D Abowd, L Mamykina, and J A Kientz. 2010. Understanding the Potential of Ubiquitous Computing for Chronic Disease Management. Health Informatics: A Patient-Centered Approach to Diabetes: 85–106.

[44] Diane. Nahl and Dania Bilal. 2007. Information and emotion: the emergent affective paradigm in information behavior research and theory. Information Today.

[45] Kimberly M. Nelson, Hanne Thiede, Richard A. Jenkins, James W. Carey, Rebecca Hutcheson, and Matthew R. Golden. 2014. Personal and Contextual Factors Related to Delayed HIV Diagnosis Among Men Who Have Sex With Men. AIDS Education and Prevention 26, 2: 122–133. https://doi.org/10.1521/aeap.2014.26.2.122

[46] Francisco Nunes, Nervo Verdezoto, Geraldine Fitzpatrick, Morten Kyng, Erik Grönvall, and Cristiano Storni. 2015. Self-Care Technologies in HCI: Trends, Tensions, and Opportunities. ACM Transactions on Computer-Human Interaction 22, 6: 1–45. https://doi.org/10.1145/2803173

[47] Aisling Ann O'Kane, Yvonne Rogers, and Ann E. Blandford. 2014. Gaining empathy for non-routine mobile device use through autoethnography. Proc ACM CHI '14: 987–990. https://doi.org/10.1145/2556288.2557179

[48] Carla Makhlouf Obermeyer and Michelle Osborn. 2007. The utilization of testing and counseling for HIV: a review of the social and behavioral evidence. American journal of public health 97, 10: 1762–74. https://doi.org/10.2105/AJPH.2006.096263

[49] Patrick Cheong-Iao Pang, Shanton Chang, Karin Verspoor, and Jon Pearce. 2016. Designing Health Websites Based on Users' Web-Based Information-Seeking Behaviors: A Mixed-Method Observational Study. Journal of medical Internet research 18, 6: e145. https://doi.org/10.2196/jmir.5661

[50] Patrick Cheong-Iao Pang, Karin Verspoor, Jon Pearce, and Shanton Chang. 2015. Better Health Explorer. In Proceedings of the Annual Meeting of the Australian Special Interest Group for Computer Human Interaction on - OzCHI '15, 588–597. https://doi.org/10.1145/2838739.2838772

[51] Pennpstar.org. 2017. Getting to Know Get Connected | Penn HIV | LGBT Public Health | PSTAR | Philadelphia. Retrieved December 30, 2018 from https://www.pennpstar.org/single-post/Getting-to-Know-Get-Connected

[52] plainlanguage.gov. Repurpose print material for the web | plainlanguage.gov. Retrieved December 26, 2018 from https://plainlanguage.gov/guidelines/web/repurpose-print-material/

[53] Public Health England. 2017. HIV testing in England: 2017 report.

Retrieved December 30, 2018 from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/759270/HIV_testing_in_England_2017_report.pdf

[54] Yangyang Qiu, Dan Luo, Rui Cheng, Yi Xiao, Xi Chen, Zhulin Huang, and Shuiyuan Xiao. 2014. [Emotional problems and related factors in patients with HIV/AIDS]. Zhong nan da xue xue bao. Yi xue ban = Journal of Central South University. Medical sciences 39, 8: 835–41. https://doi.org/10.3969/j.issn.1672-7347.2014.08.014

[55] Irwin M Rosenstock. 1974. Historical Origins of the Health Belief Model. Health Education Monographs 2, 4: 328–335. http://heb.sagepub.com/content/2/4/328.short.

[56] Daniel M. Russell, Mark J. Stefik, Peter Pirolli, and Stuart K. Card. 1993. The cost structure of sensemaking. In Proceedings of the SIGCHI conference on Human factors in computing systems - CHI '93, 269–276. https://doi.org/10.1145/169059.169209

[57] Daniel M Russell, Gregorio Convertino, Aniket Kittur, Peter Pirolli, and Elizabeth Anne Watkins. 2018. Sensemaking in a Senseless World. In Extended Abstracts of the 2018 CHI Conference on Human Factors in Computing Systems - CHI '18, 1–7. https://doi.org/10.1145/3170427.3170636

[58] R Savolainen. 2015. Approaching the affective factors of information seeking: The viewpoint of the lnformation search process model. In Proceedings of ISIC, the Information Behaviour Conference.

[59] Hyman M. Scott, Lance Pollack, Gregory M. Rebchook, David M. Huebner, John Peterson, and Susan M. Kegeles. 2014. Peer Social Support is Associated with Recent HIV Testing Among Young Black Men Who Have Sex with Men. AIDS and Behavior 18, 5: 913–920. https://doi.org/10.1007/s10461-013-0608-8

[60] Aneesha Singh, Nadia Bianchi-berthouze, and Amanda Cdec Williams. 2017. Supporting Everyday Function in Chronic Pain Using Wearable Technology. In Chi 2017, 3903–3915. https://doi.org/10.1145/3025453.3025947

[61] Aneesha Singh, Jo Gibbs, Claudia Estcourt, Pam Sonnenberg, and Ann Blandford. 2017. Are HIV Smartphone Apps and Online Interventions Fit for Purpose? In Proceedings of the 2017 International Conference on Digital Health - DH '17, 6–15. https://doi.org/10.1145/3079452.3079469

[62] Freya Spielberg, Bernard M Branson, Gary M Goldbaum, David Lockhart, Ann Kurth, Connie L Celum, Anthony Rossini, Cathy W Critchlow, and Robert W Wood. 2003. Overcoming barriers to HIV testing: preferences for new strategies among clients of a needle exchange, a sexually transmitted disease clinic, and sex venues for men who have sex with men. Journal of acquired immune deficiency syndromes (2003) 32, 3: 318–27.

[63] Tiffany C. Veinot, Ebony Caldwell, Jimena Loveluck, Michael P. Arnold, and José Bauermeister. 2016. HIV Testing Behavior and Social Network Characteristics and Functions Among Young Men Who have Sex with Men (YMSM) in Metropolitan Detroit. AIDS and Behavior 20, 11: 2739–2761. https://doi.org/10.1007/s10461-016-1296-y

[64] Tiffany Christine Veinot, Chrysta Cathleen Meadowbrooke, Jimena Loveluck, Andrew Hickok, and Jose Artruro Bauermeister. 2013. How "Community" Matters for How People Interact With Information: Mixed Methods Study of Young Men Who Have Sex With Other Men. Journal of Medical Internet Research 15, 2: e33. https://doi.org/10.2196/jmir.2370

[65] WHO. 2016. WHO | HIV/AIDS. WHO. Retrieved April 28, 2017 from http://www.who.int/features/qa/71/en/%0D

[66] WHO, UNICEF, and UNAIDS. 2011. Towards universal access. Vasa: 1–233. https://doi.org/ISBN 978 92 4 150298 6

[67] Matthew Wood, Andrew Garbett, Kellie Morrissey, Peter Hopkins, and Madeline Balaam. 2018. " Protection on that Erection?": Discourses of Accountability & Compromising Participation in Digital Sexual Health. In Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems, 1–12. https://doi.org/10.1145/3173574.3174238

[68] Wendy Wood and David T Neal. 2007. A new look at habits and the habit-goal interface. Psychological review 114, 4: 843–863. http://doi.apa.org/getdoi.cfm?doi=10.1037/0033-295X.114.4.843