Are HIV Smartphone Apps and Online Interventions Fit for Purpose?

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ABSTRACT

Sexual health is an under-explored area of Human-Computer Interaction (HCI), particularly sexually transmitted infections such as HIV. Due to the stigma associated with these infections, people are often motivated to seek information online. With the rise of smartphone and web apps, there is enormous potential for technology to provide easily accessible information and resources. However, using online information raises important concerns about the trustworthiness of these resources and whether they are fit for purpose. We conducted a review of smartphone and web apps to investigate the landscape of currently available online apps and whether they meet the diverse needs of people seeking information on HIV online. Our functionality review revealed that existing technology interventions have a one-size-fits-all approach and do not support the breadth and complexity of HIV-related support needs. We argue that technology-based interventions need to signpost their offering and provide tailored support for different stages of HIV, including prevention, testing, diagnosis and management.

CCS CONCEPTS

• CCS → Human-centered computing → Human computer interaction (HCI) → **HCI design and evaluation methods**

KEYWORDS: m-health; HIV; human immunodeficiency virus; user needs; qualitative research; mobile applications; sexual health; sexually transmitted diseases

1 INTRODUCTION

There are approximately 101,200 people living with Human Immunodeficiency Virus (HIV) in the UK, of whom 13% are unaware of their infection and at risk of unknowingly transmitting the virus through unprotected sex [1,2]. In the UK, 95% of new HIV cases are due to sexual transmission [2]. HIV prevalence is disproportionately higher in men who have sex with men and Black African men and women than in other groups [11].

HIV weakens the ability of a person to fight infections/diseases by targeting the immune system. However, early diagnosis of HIV coupled with effective antiretroviral therapy (ART) can mean that people have an almost normal life expectancy and a very low risk of transmitting the virus to others. Therefore, early HIV diagnosis is critical for better outcomes and to prevent onward transmission. Diagnosis of HIV at a late stage of infection (39% of new diagnoses in 2015 [1,2]), is associated with a much poorer prognosis, and increases the potential of inadvertent transmission. A significant proportion of people at risk of HIV have not tested for HIV in the preceding 12 months [2] and a concerning proportion of people living with HIV remain undiagnosed. The WHO cites stigma and fear of discrimination as the main reasons for people's reluctance to get tested, disclose their HIV status and take antiretroviral therapy (ART) [3]. Online HIV interventions offer anonymity and could break down the barriers to HIV prevention, testing and management. Existing HIV mobile health (m-health) initiatives include prevention messages, results notification, and improved ART adherence/ management [7,11] to overcome barriers and enable retention in healthcare. We want to understand how online technology can deliver advances in diagnosis and prevention, and support users based on needs at different stages of the pathway.

The number of people accessing health related information online is increasing, as indicated by the increasing number of health related app downloads [4]. However, there is currently little evidence on the quality of information on HIV and other sexually transmitted infections (STIs) available via online resources [5]. In addition, novel HIV diagnostic tests combined with advances in digital health provide new opportunities for people to self-sample, self-test, and receive a diagnosis remote from traditional health care services [6]. These advances need to be integrated with services (online or otherwise) to support people and link them to care.

In this paper, we focus on the potential for HCI to improve the experiences of, and options available to, people accessing HIV resources online. To this end, we started by conducting an autoethnography to identify issues in approaching online sources for HIV related information and support (Study 1). Following this, we investigated how existing online HIV apps and interventions address the needs of people and leverage the opportunities provided by technology (Study 2). This was achieved through a review of web and smartphone apps available to support HIV. An evaluation was conducted of features and functionality offered by the apps. Finally, we investigated user impressions of the apps using online reviews of the smartphone apps to identify the gaps and needs from technology (Study 3).

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Our paper makes three contributions: first, we disentangle the different aspects of the HIV pathway and identify the various aspects of HIV care, and hence target audiences for the different technologies. Second, through three qualitative studies, we identify the currently available technology and the strengths as well as gaps in designing for the HIV pathway, based on features available and desirable functionalities. Finally, we make recommendations for developing this area of research in HCI.

1.1 About HIV

HIV weakens a person's ability to fight infections and diseases as it targets the immune system. The commonest mode of transmitting HIV is having sex without a condom [7]. It can also be transmitted via sharing needles, through transfusion of infected blood products, and from mother-to-child during pregnancy. There is no cure for HIV; however, since highly active antiretroviral therapy was introduced in 1996, the life expectancy of people diagnosed with HIV has dramatically improved. To achieve better treatment outcomes and to prevent onward transmission, early diagnosis of HIV is critical. If a person with HIV is untreated then they are at risk of serious infections and cancers, which someone with a healthy immune system would fight off. Acquired Immunodeficiency Syndrome (AIDS) is defined as when a person with HIV has such an impaired immune system that they develop any of more than 20 opportunistic infections or HIV-related cancers [7].

It is common for people to feel distressed and experience feelings of anxiety and depression when diagnosed with HIV [8]. It is important that people have timely access to information and support they need. There continues to be stigma attached to HIV, which can act as a barrier to effective prevention and treatment of HIV/AIDS.

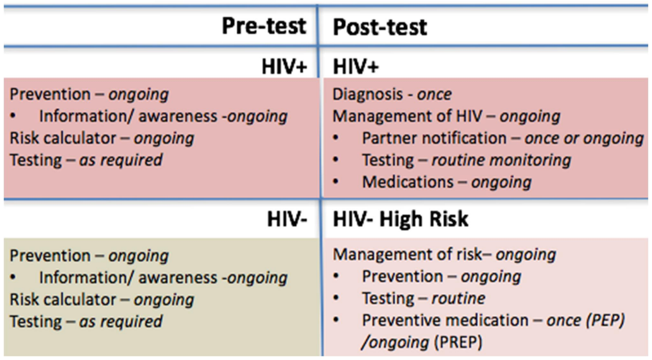
1.2 HIV Pathway of Care

There are a variety of reasons why people access online HIV resources. We divided the search for online resources into two broad categories: pre-test and post-test (see Table 1). At the pre-test stage, people may be looking for, or be directed by healthcare professionals towards, information on HIV prevention and safe sex, and to check their risk of being infected by HIV. People may also use online resources to access information about testing following a recent unprotected sexual encounter. They may be seeking a local sexual health clinic or for kits to test themselves.

Two types of remote testing options are available: (1) self-sampling (blood or saliva), where the person obtains their own sample and posts it to a laboratory for testing, or (ii) self-testing (blood), where a person takes their own sample and tests it themselves with a test kit which takes around 15 minutes to give results. The laboratory test used with a blood self-sampling kit gives accurate results at a month post exposure; self-testing kits and self-sampling kits with a sample of saliva, may not detect infection acquired within the past 3 months. For both types of tests, people must have another test in a clinical setting to confirm a positive result.

In cases of possible exposure to HIV, people can be prescribed post-exposure prophylaxis (PEP), which must be started within 72 hours of the exposure. People who are HIV negative but who are identified as being at high risk of being infected may benefit from behavioural interventions and should have regular testing for HIV and other STIs. They can also be prescribed daily ART (pre-exposure prophylaxis (PrEP)) to prevent them being infected with HIV.

People diagnosed as HIV positive, and therefore living with a chronic infection, may need support with managing their condition through monitoring appointments, medication reminders, information on test results, medication side effects, notification of their status to partners, testing for other STIs and psychological support. In assessing HIV apps, it is necessary to evaluate fitness for purpose for any or all these situations.



Pre-test	Post-test
HIV+	**HIV+**
Prevention – *ongoing* • Information/ awareness -*ongoing* Risk calculator – *ongoing* Testing – *as required*	Diagnosis - *once* Management of HIV – *ongoing* • Partner notification – *once or ongoing* • Testing – *routine monitoring* • Medications – *ongoing*
HIV-	**HIV- High Risk**
Prevention – *ongoing* • Information/ awareness -*ongoing* Risk calculator – *ongoing* Testing – *as required*	Management of risk– *ongoing* • Prevention – *ongoing* • Testing – *routine* • Preventive medication – *once (PEP) /ongoing* (PREP)

Table 1: Functionality accessed by people online based on their HIV status and if they have been diagnosed. People living with HIV are referred to as HIV+. People not diagnosed with HIV are referred to as HIV-.

1.3 Using Online Resources

Internet access and advances in web and smartphone capabilities have brought new opportunities and challenges. Social and sexual networking sites have seen increased access: more than 70% of online adults use one of the social networking sites, and over half of them use multiple sites [9]. Recently many apps for dating and sexual hook-ups have become available and some studies indicate that the incidence of HIV and STIs has increased as a consequence [10, 11]. However, the uptake of sexual health apps is still low as they are negatively received by users and have failed to attract user attention [12]. While reviews of apps and other technologies designed for STIs have been conducted (e.g. [5,13]), these either do not specifically target HIV or do not discuss whether the available technologies meet the needs of the target users. Furthermore, the landscape of both smartphone ownership and number and type of apps available has changed dramatically since these reviews were conducted [4]. For example, the number of dating apps for people with HIV has gone up from one reported in 2013 [13], to at least 12 found in the search for this review.

Widespread access to the Internet and the many web and smartphone apps available mean there is the potential to reduce the gaps in HIV prevention, testing and management. Existing m-Health prevention and management initiatives for HIV include promotional prevention messages, test result notification, and improvement to adherence for anti-retroviral therapy (ART) and management [13, 14]. While phone-based interventions for HIV have mainly utilised voice or text messaging (SMS) functions, smartphones are capable of delivering more complex, interactive, and tailored interventions via mobile web and native apps [13, 14].

For people who encounter barriers to care, such apps could enable entry to and retention in the healthcare system.

Advances are also being made in technologies for testing and diagnosing HIV. Researchers are creating the first smartphone accessories that will enable people to self-test for HIV just using their phones [15]. Licensed HIV self-testing kits, available in the UK since 2014, give a diagnosis in 15 minutes but are not available via the National Health Service and do not link people with specialist care and healthcare resources for counselling and support. Studies report anxiety, depression and social isolation following a diagnosis [8]. There is therefore a need to understand how technology can deliver not only advances in diagnosis and prevention but also emotional support and management. These needs can differ at different stages of the pathway.

In addition to designing technologies that target different parts of the pathway, consideration is needed towards other needs and behaviours related with privacy, security, and trust in designing for sensitive issues such as HIV and other aspects of sexual health and STIs. However, we found that there is a general dearth of research addressing these areas [16, 17]. Recent work in HCI has explored many traditionally sensitive areas including intimate care of women's bodies [18] and made contributions on the topic of sex in divere contexts such as virtual worlds, online pornography, or human-robot interaction [19] but has largely ignored sexual health.

HIV remains a stigmatised chronic condition. HCI research investigating the design of technologies for chronic conditions suggests that user needs for technologies supporting chronic disease differ based on the level of stigma [20]. HIV is under-researched in HCI [21]; while recent research has emerged on managing HIV [12, 22], medication adherence, and support for tracking personal health information [23], barriers affecting adoption of such technologies such as privacy, security, and trust have been ignored [20, 24]. As an interdisciplinary field, HCI is in a good position to develop for, evaluate and create real impact on sexual health and HIV.

2 RESEARCH AIMS AND METHODS

To understand the landscape of existing technology for HIV, we conducted a review of current trends and available resources in online and mobile health technologies for primary, secondary and tertiary HIV prevention, testing and management. We conducted the three studies that we report next*:*

2.1 An auto-ethnography style self-observation

The first study was conducted using autoethnographic methods, using self-observation with the first author as participant [25, 26], to experience the process of accessing HIV related information. This method was adopted for three reasons: (i) to familiarise the researcher with HIV related resources, (ii) to empathise with experiences of users in different and difficult to access contexts when using online HIV resources, and (iii) to simulate how a search for online resources might be conducted by a naïve user who did not have experience of looking for this information.

The researcher does not have HIV and identifies as a heterosexual female in a long-term relationship. She had not used online resources to conduct a focused search for information related to HIV prior to this. The autoethnographic study was used as a formative method to inform the design of further studies and the development of online results and management pathway for HIV.

A scenario of looking for information on HIV testing and symptoms following an unprotected sexual encounter was used to look for information on the web and through apps in the UK Apple iTunes Store (www.apple.com/itunes/) and Google Play (play.google.com/store/apps). The study focused on the impressions that the online material made on the researcher.

Guided by discussions with a sexual health clinical academic (second author), the researcher carried out this study over a period of a week. The study was designed based on first encounters with materials related to HIV on the web and was more exploratory in nature compared with the functionality reviews of apps that were conducted later. The researcher carried out a thematic analysis of diary entries and screenshots. This engagement allowed the researcher to gain an understanding of online resources for HIV.

2.1.1 Findings.

The researcher started by searching on Google using phrases such as "could I have HIV?", and "testing options for HIV". Most search results were known healthcare sites such as NHS choices or clinic-based testing sites. One striking aspect of the search was the number of promotional links that appeared when searching for HIV testing, most of which linked to the sites selling HIV self-testing or self-sampling kits. When searching for HIV testing on the app stores, the most relevant apps that appeared were risk calculators and symptom checkers for HIV. None of the apps linked to provision of self-sampling or self-testing sites or kits. However, some GPS-based apps allowed the user to locate a local testing facility.

Public use.

HIV app icons and names were not discreet. Some HIV-related apps and websites had explicit images or content that came up without warning, causing embarrassment at times. The presence of the obvious HIV app icon on the researcher's screen became a point of conversation. The researcher also felt uncomfortable using HIV apps when on public transport where she often uses her phone otherwise for finding information or to access social media because they were not discreet.

Lack of tailoring and transparency

Often the content and risk assessment questions were not filtered depending on gender and sexual preference. While the need for direct language and questions is necessary in asking people what kind of sexual activity they have performed to inform a future course of action, the questions could have been more tailored to the sexual orientation and preferences of the individual. For example, it is unnecessary to ask explicit questions about sexual activity between men and women to a man who only has sex with men to determine HIV risk. Instances where apps and websites did not make this distinction could be off-putting and erode trust in the results that the site provided. In some cases of risk analysis apps, it was not obvious how they calculated the risk of infection and many of the apps were scaremongering (e.g., Figure 1 - Right, Middle).

When downloading HIV apps on the app store, many permissions were required for downloads, particularly with the Google Play store. Apps asked for permission to access identity, contacts, and sending SMS messages automatically and did not state what the permission and access would be used for. Further, apps did not have obvious links to healthcare providers. The researcher used a department phone available to do the study rather than a private one, as she did not want to expose her data or contacts. This is, however, a choice that is not available to all users.

You need to get a medical examination. You have a lot of HIV/AIDS symptoms!

Our results says there is a high chance of Infection ,you can consult with your doctor for more info,we are calculating the results with our algorithm

Figure 1: (Left) Screenshot of app icons on the author's home screen. (Middle and Right) App screens showing results from risk calculator apps. The user interfaces for the apps show bad colour contrast (e.g., "83%" is barely visible in the app on the left), and have distracting or provocative background images.

Stigma, language and general ignorance

The researcher also examined the app descriptions before downloading the apps and some of these showed ignorance about HIV and stigma. One of the apps for HIV included in the description, "*If you think you have recently been close to someone with HIV/ AIDS it is best to quarantine yourself faraway from other people and call a nearby medical center/ doctor*"

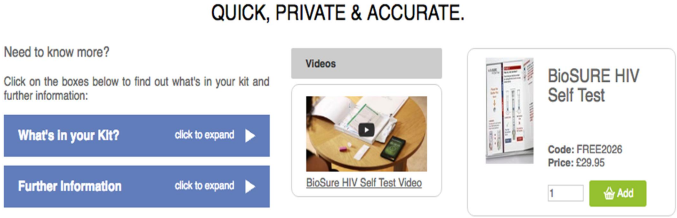
Many prank HIV diagnosis apps (n=18) came up in the initial search claiming to assess people by taking their fingerprints on the screen as a method to test if they have HIV as a prank or joke. The large number of downloads and positive reviews of these apps working on people suggest that people found the apps credible.

The researcher looked for HIV test kits on sites such as Amazon while being logged into Google and Facebook. She had also looked for a pair of shoes previously and added the two to a basket on Amazon. While advertisements of shoes started appearing on her profile on these sites, no HIV related information was targeted at her. It appears that targeting based on sexual health is against policy. For example, Google's personalised privacy policy says, "*Because we understand that sexual experiences and interests are inherently private, we don't allow categories related to sexual interests*", which extends to sexual health.

Jargon and issues of trust

One of the challenges faced by the researcher was navigating through a new set of acronyms, slang, and terminology. For example, one of the apps was named *Online Elisa test* with the description of the biomedical *Elisa test* from Wikipedia. However, it was a risk calculator and made a diagnosis based on sexual behaviour questions, completely unrelated to the biomedical test. Further, the test used incorrect terminology such as "*risk of AIDS*" instead of "*risk of HIV*". Such apps can be misleading for users, particularly those who are vulnerable.

In many cases, the window period for HIV testing (the time between someone becoming infected with HIV and being able to detect it in the saliva or blood) was not explained or in small print as shown in the example in Figure 3. Consequently, a naïve user may not get the help they need in making an informed choice about kits and testing.



Need to know more?

Click on the boxes below to find out what's in your kit and further information:

Code: FREE2026
Price: £29.95
1

Figure 2: A screenshot from a site offering an HIV self-test kit. The information that the kit will not detect infection before 3 months since exposure is under the *Further Information* link in blue on the left.

2.1.2 Conclusions.

This study was helpful in gaining a first-hand understanding of the types of online resources available and provided insight into the issues in using them beyond functionality. Personalisation, privacy, trust, jargon, stigma, lack of transparency and relevant information to make informed choices were the main aspects that emerged. The study gave insight into the challenges some users could face in using these apps and online resources in different contexts and for different reasons. In some cases, these resources could be reinforcing stigma and ignorance of the condition. We are very aware that the researcher in this study did not have HIV and perceives herself at low risk of contracting it. However, we were reflexive and ran the study from the point of view that anyone, regardless of sex, sexuality, or general risk levels could have the need to access HIV testing or information. We believe that this method gave us valuable insights that will be useful in designing further studies with the general and at-risk populations for accessing these resources. As suggested by O'Kane et al. [26], who used autoethnography to study medical device use, we are using this study method as a first step to understand the online landscape of HIV related resources from a user standpoint. From this scoping review, we established inclusion and exclusion criteria for the systematic review of web and smartphone applications to identify the features that are offered and what is missing. The main category of apps excluded at this stage was prank apps as they did not provide health related information.

2.2 Functionality Review of Existing Apps

Many apps provide HIV prevention and care services via web and smartphone applications and there is a wide range of features on offer. We conducted a review of currently available apps with a focus on their offered functionalities and features.

2.2.1 Method.

We searched for HIV-related web-apps using Google search. For smartphone apps, UK Apple iTunes (/www.apple.com/itunes/) and Google Play (play.google.com/store/apps) stores were searched using the keywords: HIV, human immunodeficiency virus, acquired immunodeficiency syndrome, and AIDS.

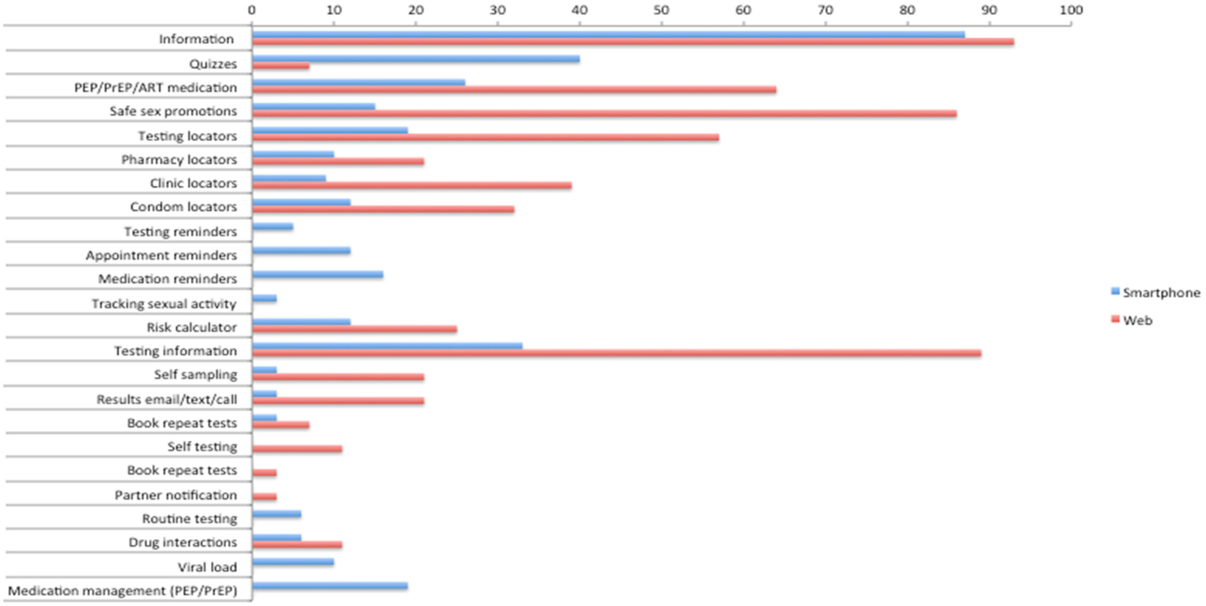


Figure 3: Features in apps and websites. Blue lines show the percentage of smartphone apps with the feature listed on the y-axis. Red lines show the websites with the corresponding feature in the y-axis.

The search was conducted in August 2016. 683 smartphone apps (296 for iPhones and 387 for Android phones) were returned. We excluded apps if they did not have HIV content, targeted only healthcare, medical, industry or research professionals, did not work when downloaded, provided only information on conference schedules and events, were fundraisers, if they were not available in English or had not been updated in the last three years. "Casual", "Games" or "Entertainment" apps were included if they provided information or resources for HIV per the app description. We reviewed websites up to the first three pages of search results, as most users do not go past the first three pages [27]. We conducted more specific searches by adding the terms "prevention", "testing", "management", and "diagnosis". 69 native apps (46 Android apps and 23 iPhone apps) and 28 web-apps were selected as relevant.

Before doing the main analysis, we prepared a list of features based on the first 10 web apps and smartphone apps found in each store and grouped the features into categories for easier data collection. We recorded feature categories for all apps (web and smartphone) during initial data gathering. In addition, for smartphone apps we recorded details including name of app, its user rating, number of reviews by users, and age rating. Additional categories were created when we encountered features that were missing in the original list.

2.2.2 Findings.

Our reviews showed that most of the apps available on the main app stores were underused, with a median of 100-500 downloads on Google play for all apps. The iTunes store does not reveal the number of downloads. The apps were not highly rated or reviewed. The total number of reviews for 47 android apps was 2319, of which 873 were of a single general sexual solutions app, "Sex Solutions", with information about safe sex and HIV. Only 11 apps had more than 5000 installs. Many people uninstall apps after installing them, especially free apps, but this information was unavailable.

Target audience

82.6% of the apps on the Google Play Store had a PEGI rating of 3, considered a rating level where content is suitable for all age groups. 13% of apps were unrated and only two apps were rated 16. This is surprising as some of the apps dealt with content more suited for mature audiences. The iTunes Store was more discerning, with 30% of apps rated 4+, 48% rated 12+ and the rest rated 17+. 37% of the smartphone apps were classified as *Medical* apps, 32% as *Health and Fitness* apps and 17% as *Education*.

Functionality

To evaluate the functionality provided by the apps we divided it into broad areas: (i) HIV prevention including information/ awareness and sexual behaviour change applications (risk reduction/ safe sex promotions/ condom use), (ii) HIV risk calculators and symptom checkers, (iii) HIV testing and links to care (including window periods for testing), (iv) HIV management (including pathways for people living with HIV as well as those who are at high risk of HIV). Additional functionality that emerged included HIV news, which was included with the first category of information. We looked at emerging HIV relationship and hook-up apps, which allow people with HIV to meet people based on their HIV status. However, only one of these apps was included, as even though they were meant for people with HIV, they did not include any other HIV related material. Three apps were identified that specifically targeted HIV related stigma.

While 87% of the smartphone apps provided some HIV related information, this was not clearly signposted. The naming of apps did not always reflect the focus of the app. For example, "*Health is vital*" does not indicate that the app is focused on HIV information. Although the discreetness of the app may encourage people to download it, the lack of signposting in the store indicating that this is an HIV app means that people are unlikely to access it for this purpose. One app overcame this issue by signposting the app as an HIV app in the app store and then removing HIV from the name and having a discreet icon when downloaded. 93% of web-apps provided information and this was clearly signposted and linked to resources. The majority of the reviewed web-apps were either linked to the NHS or non-government organisations. Home-testing options were available in only one smartphone app but were present in 21% of web-apps. Interactive content such as reminders, quizzes and risk calculators were predominantly found in smartphone apps. This shows that there are clear differences in the functionality offered by smartphone and web-apps. We present the functionality and features provided by smartphone apps and web-apps in Table 2 and Figure 3. Risk calculators and symptom checkers were interchangeably named – while some apps checked for risk based on type of sexual activity, others classified risk based on symptoms experienced by the person. We treated both these categories of apps as risk calculators. The outputs and next steps from risk calculators were often alarmist (e.g., Figure 1 - Middle). During the review, we identified app features needed for each stage of the HIV pathway. Table 2 shows the percentage of apps with the identified features.

Functionality Category	Features	%apps	
		S*	W*
Prevention	Information	87	93
	• Quizzes	40	7
	• PEP/ PrEP/ ART medication	26	64
	Safe sex promotions (e.g., condoms)	15	86
	Locators		
	• Testing locators[ab]	19	57
	• Pharmacy locators[ab]	10	21
	• Condom locators	12	32
	Reminders		
	• Testing reminders[ab]	5	0
	• Medication reminders[ab]	16	0
	Tracking sexual activity/ partners	3	0
Calculating risk	Checking risk (including risk calculators and symptom checkers)	12	25
Testing	Testing information	33	89
	Home testing		
	• Self-sampling	3	21
	○ Results email/text/call	3	21
	○ Book repeat test	3	7
	• Self-testing	0	11
	○ Book repeat test	0	3
	Partner notification	0	3
Management (HIV +)	Reminders		
	• Appointment reminders	12	0
	Locators		
	• Clinic locators	9	39
	Routine Testing	11	0
	Treatment (ART)	16	0
	Drug interactions	6	11
	Monitoring		
	• Viral load	10	0
Management (HIV- high risk)	Medication management (PEP/PrEP)	19	0

Table 2: Division of app functionality by stage in HIV pathway. S* = Smartphone apps; W*= Web apps. a= In Management (HIV+) as well; b= In Management (HIV-)

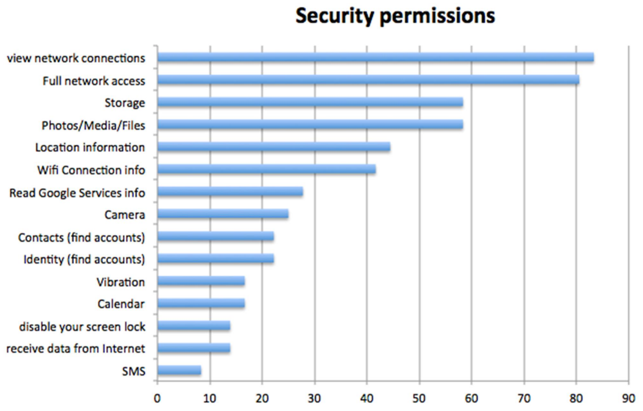


Figure 4: Percentage of apps using various permissions

App creators
In 63% of smartphone apps, the source of information or links to healthcare professionals (HCPs) or medical evidence was unclear. There was therefore no way of assessing whether the information provided was reliable. Only 9% of the apps facilitated interaction with healthcare professionals (HCP). Most of them did not say which type of HCP they would be communicating with. In contrast, 97% of web-apps were from trusted sources such as known healthcare providers, charities and high street pharmacies.

User interaction
Many apps were poorly designed in terms of basic user interactions: e.g., the back-button functionality did not work for 22% of smartphone apps. 12% apps did not allow the user to exit the app.

Revenue model
Most apps on the iTunes and Google Play store were free. The only paid Android app had never been downloaded. On the iTunes store two apps were paid apps. The revenue model adopted most commonly was of ads within the app (17%) and in-app purchases.

Security permissions
On Google Play, apps require users to give permission upfront for using certain phone capabilities. However, it was not always clear how these permissions would be used. For example, over 20% of apps required access to the user's identity and contacts but why the permissions were needed was unclear as the apps mainly offered information. Similarly, only 31% of apps had location-aware functionality but nearly 45% used location services. The Apple app store is stricter about permissions and users give permission at the time of use, so the user knows the context. For other permissions required by apps, see Figure 4.

2.2.3 *Conclusions.*

The functionality provided by the apps differed widely. However, the trustworthiness of information was difficult to establish. Many parts of the HIV pathway were inadequately or not addressed by the available functionality. In our next study, we investigate if the apps meet user needs and how useful the users find them.

2.3 User Reviews Analysis

2.3.1 *Method.*

We recorded all available reviews for each app. We only included reviews from Google Play apps, as the iTunes App Store does not allow copying comments. Besides, most apps on the iTunes store did not have any reviews, instead displaying the message, "*Not enough ratings*". We classified each review by the general sentiment expressed (neutral, negative or positive) and type of review (general request for new feature, new or lost functionality, complaints). The first author assigned codes that described the review and validated them with the second author. Thematic analysis was used for data analysis [28].

2.3.2 Analysing Reviews.

In total, we collected 345 reviews. Since user reviews on the app store can be quite skewed, we focused on reviews with specific comments about app functionalities and feature requests. Based on the overall sentiment expressed in the review and its content, we divided user comments into two main groups: (i) general review comments about the users' attitude towards the apps, and (ii) complaints or comments related to specific functionality. General praise about the apps (e.g., "Good app") were ignored unless they mentioned specific aspects of the app. 48% of the reviews fell into the category of functionality comments/ requests. Of these, 51% comments were complaints of functionality lost due to updates, non-working features, application crashes and other general comments (e.g., "awful app"). The remaining were positive comments about specific aspects of the app or how it had been helpful to users.

2.3.3 What do users want?

We categorised the reviews as they raised separate issues linked with different functionalities and features.

Information on HIV

For apps that people relied on for the latest HIV information and news, the frequency of app content updates was an issue. *"I love this app and reference it often, but the content listed has not updated for the last two weeks. Please fix.*" Review #73. Incorrect content was also an issue in many comments and raises the important issue of reliability of apps. "*Incorrect info. Links to where info came from goes to page not found. Nothing in this app talks about person with hiv on meds how risky? If someone is on meds the risk is almost zero."* Review #321

Risk calculators

The risk calculator apps gave no indication of how they were calculating risk. They queried sexual behaviour and symptoms to give a verdict about what percentage risk of HIV a person had. A few reviewers commented: "*Interesting, but is not scientific. Each AIDS' sign is a 6% more. I answered with 3 answers positives, and I got 18%, it's interesting the concept but is not realistic."* Review #45. Another user commented on unlikely results given by such an app. "*Um I got a 54% chance and I'm a virgin. I'm pretty sure that is not how HIV/Aids works."* Review #61

Diagnosis and linkage to care

The emotional impact of HIV diagnosis was further highlighted by comments people left on being diagnosed after being prompted to test by a risk assessment app based on answers they gave. *"Saved my life. If it were not for this I would have died. I had no idea I was HIV positive and when I got 81% chance I went straight to doctors and I am now in treatment for a few months."* Review #31. Some people turned to the apps for information and guidance due to lack of information, emotional support and guidance from healthcare avenues. "*I bought a home AIDS test kit, sent it out in the mail and waited the 4 days for my results. Called and the lady on the other end yelled out 'You're Positive' Worst news and most uncaring way to tell it. I haven't been the same since. This site has definitely helped with the healing process."* Review #222.

Some apps offered interactions with healthcare professionals but according to the reviews, this was misleading. E.g., "*Not a good app I thought it was good and all but then they disappointed me. They're not online when they are supposed to be online." Review #273.*

"You saved my life. Early diagnosis ftw" Sic. Review #322

HIV management

People used the management apps to store much of their HIV data and reliability of the app and security of the data was of concern. People asked for features such as backup options in these cases. *"Good app, but lost 4 years of data when lost my phone, data backup would be a nice feature" Review #12*

Many apps did not support an offline mode of working and needed to be connected to the Internet. "*It can only work with data connection. It suppose to be accessible fully even in offline, then people can upgrade the data base periodically as new things are added to it continuously. Try and organise it so that person can use it even in environment where data connection is poor." Review #143*

Usability and security

Usability of functions was another issue that caused people to be frustrated with apps. *"The user interface leaves a little to be desired, though, at least on Android. For example, you can theoretically set reminders to take your drugs throughout the day, but it isn't clear how to create these reminders." Review #17*

Analogous to the autoethnography, there were many comments concerning security, privacy, offline access to information, data backups and the combination of different types of functionality in one place. These issues can be very important for an application for dealing with HIV or any medical or health condition where privacy and security of data are important. Hence, trust emerged as an issue in many reviews as people questioned why apps needed so many permissions, "*This app is very handy, a great idea, but should an app that's just 'storing' medical info need so many additional permissions"* Review #341. Users also wanted or appreciated password protection functionality when it was present because of the personal nature of the information that they needed to store. "*I have told both my doctor and social worker about it and they have said they are recommending it to some of their other clients. Oh, *IT HAS PASSWORD PROTECTION*, just go to the little gear symbol and enable it*". Review #218

In some of the apps, excessive use of ads hindered the actual usage of the app. "*It's the most annoying app I've ever come across due to the annoyingly nonstop ads pop-ups that has characterised it". Review #54*

Due to stability issues, apps were often regarded unreliable. Users often complained that apps stopped working, and lost data or alerts after they had been updated. Many people reported that app updates froze their smartphone. Many apps frequently crashed and reduced users trust. "*Meh It worked ok for a couple of days, yesterday I tried to go in and log my doses but it kept crashing...*

same thing today. Just uninstalled it and will try to wait for a working copy....” Review #115. Users’ trust was also eroded by smaller issues/ incidents such as alerts that sometimes did not work, did not work as expected. There were at least four cases of self-promotion that were obvious in app reviews, which gave the apps a five-star rating. For example, “*If you need help and you don’t know who to turn to, this is the app for you. [App name] is online Sun - Thurs 19h00-21h30 for live individual counselling. It is free of charge. You may stay anonymous. The app has lots of information about issues young people struggle with. There are also about 30 self-test quizzes you can do. Please recommend this to a friend.”* These reviews also reduce users’ trust in the app and the review process.

Bias

There were cases of biased reviews based on the target audience. “*So how come the users also installed segment had all 3 gay oriented apps? Am straight so that does that make me think about this app. Explains why only 5k installed, though.”* Review #299

2.3.4 Conclusions.

Results show that users want more functions specific to support, diagnosis and care of HIV and their concerns were specific to the functionality they needed. There was also concern around incorrect information, the source of information, and privacy and security of provided information. Apps often did not declare what the source of their information was, or whether it was linked to healthcare providers. Many reported frustrations around non-updating apps and content, non-working apps, lack of backups or offline mode and freezing or crashing apps.

3 DISCUSSION

This functionality review of HIV apps was undertaken to inform the design of technology, specifically for an online pathway for taking people from seeking information on HIV, testing, results management and engagement in care and health promotion. We began with assessing whether HIV apps are fit for purpose. To evaluate this, we identified aspects of HIV care and hence different purposes and target audiences for these aspects (Table 1). We conducted an autoethnography study, an app review and a further analysis of user reviews. Our studies revealed that while many web and smartphone apps are available, very few provide the functionality and information required to support the needs of people seeking information on HIV. It was difficult to identify useful apps that supported people at specific stages of the HIV pathway. However, we also identified privacy, security and disclosure issues. Our review showed a low level of engagement with the apps based on the low number of downloads (median 100-500 downloads on Google Play), ratings and reviews.

Our findings have several implications for the design of apps in this space. There is a need for much more focus and commitment from both the technology perspective for designing higher quality, thoughtful technologies and from the health perspective to ensure reliable content. Here we discuss five main points that emerged.

3.1 Do apps provide required functionality?

As discussed, HIV is a diverse infection affecting different populations and people have different needs at different stages of pre- and post-infection. None of the reviewed smartphone apps provided the full functionality of general information, prevention, risk calculation, testing, diagnosis and post-test management. While such comprehensiveness is not imperative, it would be useful to signpost what stage of HIV and aspects of the HIV pathway the app is targeting to engage users. Lack of signposting makes it hard to assess the relevance of the apps. While web-apps provided comprehensive information about prevention and testing, they lacked support for managing HIV. Smartphone apps provided more interactive features and personal tools such as reminders and location finders in comparison to web-apps. Thus, there were clear differences between features offered by smartphone and web apps based on their capability and reasons for use. 60% of web-apps provide links to smartphone apps for more specific information and localised services. Both types can co-exist but we need to understand which one is better suited for different requirements at each stage of the pathway.

Many aspects of care were not present in the online resources for HIV. Online interventions for some other health conditions now provide emotional and psychological support. Considering that there is a move towards home testing for HIV and self-management of it as a chronic condition, this is a notable gap, with few resources providing such support. In contrast, many apps were alarmist in the way they tell people about their risk of HIV and few provided any next steps or safe sex advice. They did not motivate testing, risk reduction or provide targeted information based on user answers in risk analysis apps. This is a lost opportunity. Signposting biomedical prevention strategies such as pre-exposure and post-exposure prophylaxis were also lacking in smartphone apps. Web resources were better at providing such information.

The link between technology, the person diagnosed with HIV, and the healthcare provider could also be strengthened through tools such as virtual support, symptom checking, monitoring of side effects and provision of advice and information in real-time. Prevention messages for reducing HIV transmission, and notification of partners after a diagnosis were notably absent from smartphone apps. Of the available apps, only one provided behaviour modelling or coping information, such as disclosing HIV status to others and sexual decision making with partners.

Finding the right information/ intervention at the right time

The low level of engagement is likely to be compounded by the difficulty of identifying relevant apps. With smartphone apps, it is necessary to find and actively download the app. The app store provides no options to filter apps and apply advanced search criteria or exclusions. Thus, app designers need to find ways to make apps more accessible to their audiences. If they are not adequately signposted or do not meet people’s needs and expectations, they are either not downloaded or, if downloaded, are likely to be deleted as smartphone real estate is valuable [12].

3.2 Is the information reliable?

Most smartphone apps did not specify their source of information or links to healthcare providers and making it difficult to assess their credibility and trustworthiness. Many were excluded from our review because they have not been updated in the last three years. Although we did not set out to specifically assess content, some smartphone apps clearly had inaccurate description and content. The inaccuracies are concerning as users have no way of identifying trustworthy apps. This raises the need for a review process agreed by healthcare authorities, app providers and app stores to assess apps based on agreed guidelines before making them available to the public, particularly for apps for medical conditions. However, several authors question the feasibility and usefulness of accrediting medical health apps as it is a time intensive process [29]. For example, the US, Happtique Health App Certification Standards that certified apps based on criteria including content quality, usability, connectivity, security and privacy were suspended in 2013 as several previously certified apps were found to have security issues [29]. Happtique's was a voluntary process and time consuming (18 months to certify 16 apps [29]). The US Food and Drug Administration (FDA) and Medical and Health Regulation Authority (MHRA) attempt to regulate some medical mobile apps that they define as medical devices. MHRA classifies apps as 'low risk', 'moderate risk' or 'high risk'. Their guidance only applies to 'moderate' or 'high risk' apps, which leaves out the vast majority [30]. There are fears that regulation could limit innovation through introducing unnecessary bureaucracy, increasing cost and delaying time to market [31]. Some argue that users should be educated on criteria about how to assess if an app is a trustworthy source of information [32]. Further, accurate and accessible apps could be recommended (or prescribed) through trustworthy offline and online sources [32] such as healthcare professionals. However, app education may differ based on target users and potential for harm. Even for apps that do not collect personal or medical information, app providers have a responsibility to ensure correct and current information as users may base their decisions and actions on the information provided. Our review highlighted that some apps do not provide information based on current evidence and recommendations but since the content of the apps was not the focus in this paper, we will address this aspect in our future work.

3.3 Is it discreet and does it allow control over disclosure?

We are entering an era where major m-Health interventions are being proposed to increase the proportion of people with HIV who are diagnosed and engage with care [15, 33, 34]. HIV remains stigmatized and people living with HIV may be reluctant to disclose their diagnosis [12, 23], which can result in other issues such as not accessing health services, or not taking medication regularly.

One of the reasons for accessing home testing and online interventions is privacy and poor design interferes with that goal. Some studies have highlighted how young people do not want to use HIV related apps for fear of others identifying the app's purpose from its icon or finding the app on their phones [14]. Apps and online interventions can potentially be convenient and discreet. However, our studies found that app designs were typically not discreet and attracted unwanted attention. Most app icons made it apparent that the app was HIV-related (see Figure 1 - Left). Recent studies (e.g., [23]) have recommended that appearance, language and icons should be non-medical and discreet to avoid unintentional disclosure of HIV status if someone glances at or uses their phone. Thus, technology designers need to design appropriately for HIV information seeking and post-diagnosis support apps to not cause unintended disclosure and embarrassment due to notifications or visual design. This could be done through more neutral language and iconography [23], by providing security features such as password protection [14] and through discreet user interface design. Dating and hookup apps are increasingly focusing on these issues [35] and this learning can be extended to HIV-related apps.

3.4 Is it trustworthy, private and secure?

Apps require access to user information to tailor/ personalise information and services. However, they can inadvertently or explicitly provide a wealth of information about users and their medical condition to third parties [36]. Since apps differ in the functionality they offer, and the information that they collect, the potential for damage differs from one app to the next. Some apps collect personal and medical user information where the potential for damage is high if there were a leak. For example, as recently as 2015, a well-known HIV dating app leaked data related to over 5000 users including personal messages, HIV status, and personal information [37]. Such leaks could lead to identity theft, extortion demands and psychological harm. It is important for technology designers to understand the risks to users and use adequate data encryption and provide security and protection to users if they collect such data [38]. Since HIV-related apps collect different types of user information, there is no one-size-fits-all approach that could be advocated for all the apps and therefore measures for security need to be tailored. Smartphone apps are not transparent in how they deal with users' data, where it is stored and how it is used [38]. It is of concern if even the simple task of looking for information, checking symptoms or calculating the risk of infection can give an unknown app access to people's contacts, social media or location. On the other hand, reviewed web apps were obviously related to trusted healthcare providers and charities. This may be because we only reviewed the top three pages of search results which are highly assessed.

Many Android apps required upfront permissions for accessing data and identity related information and control aspects of the smartphone hardware, such as the camera. It is difficult for the end user to assess and make an informed choice about how features would be used. The iTunes app store was better as it asked for permission in context of using a feature that required it.

In the end, users must decide what apps to use or information to share. However, it is important to support users in this decision and sensitize them to the risks involved in the sharing of sensitive private or medical information and provide easy ways of assessing and controlling privacy in m-Health apps [36]. App providers and stores need processes that ensure some protection before apps are publicly accessible. Experienced users, researchers, clinicians and others can contribute to this process by signposting good quality apps, identifying harmful apps, and disseminating findings.

3.5 Does/ can the user use it?

Well-designed apps should allow users to tailor their experience by selecting useful app features, personalising app messages and providing options for notifications through the app/ email, or text messages. The constant availability of app interactive functions can allow users to engage with the app whenever convenient. However, we found that even where offline features were available they often did not work. Most apps underused the potential of smartphones by not providing tailoring or interactivity options. Again, this represents an opportunity for future developments. A large proportion of apps were poorly implemented, many lacked basic functionalities such as back buttons, had distracting user design, had too many ads, which discourage users and often crashed.

Our findings highlight many opportunities for improved design of digital resources for prevention, testing and management of HIV. There is an urgent need for trustworthy resources to support people accessing information online and to reduce barriers to care. From the person seeking information following a sexual encounter, to someone using a self-testing kit at home with no immediate access to care, to the person living with HIV, apps can provide support. This is a significant opportunity to bring together the strengths of HCI, with relevant clinical expertise, to address issues common to apps for other health conditions [14,21] and those specific to sexual health/ HIV.

4 CONCLUSIONS

There is a need to build more acceptable, well-informed and well-designed online resources for HIV. Appropriately tailored, interactive applications that address user needs can increase the acceptance and adoption of new or existing apps and resources. On the biomedical side, new and improved technologies and medications are being created to diagnose and prevent HIV. These fuel the need for innovative technology to improve the uptake of online/ mobile technologies, and for exploring behavioural interventions to reduce gaps in HIV prevention, testing and care.

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COMPETING INTERESTS

The authors have declared that no competing interests exist.

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