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# "It Feels Like I'm Managing Myself": HIV+ People Tracking Their Personal Health Information

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## ABSTRACT

Nearly 37 million people live with HIV globally and recent advances in medicine have transformed HIV to a chronic disease, if managed. Previous research in Personal Health Informatics has investigated how people self-manage other chronic conditions, such as diabetes, by tracking and reflecting on their health information but there is little knowledge of how people do so for complex and socially stigmatized diseases like HIV. A better understanding of their specialized needs could lead to the development of more appropriate tools to self-manage their condition. Our paper introduces an iterative process model of Personal Health Informatics. We then describe the results of an empirical study involving HIV+ adults aimed at understanding their issues, concerns and actions in each of the stages of this process model. We provide implications for the design of personal informatics tools and open research directions that can lead to better self-management for people living with HIV.

## Author Keywords

Personal Health Informatics; HIV; Personal Informatics; Self-Management; Model.

## ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

## INTRODUCTION

In 2014, an estimated 36.9 million people were living with HIV or AIDS globally, and 1.2 million lost their lives to the disease that same year [23]. While HIV cannot be cured, people who live with HIV can control the virus and live healthy lives by taking antiretroviral (ARV) drugs. However, this is only possible if these individuals comply with the strict and complicated regime required with taking ARV medication, as well as monitor their health closely. Doing so is not easy, and recent research has shown that in

the United States only one-third of HIV+ adults are able to successfully manage their health [3].

Many people living with a chronic disease are able to self-manage through a process called Personal Health Informatics (PHI), in which individuals collect data about themselves and reflect on those data to gain a deeper understanding of their behavior, drawing valuable insights related to their health [4,5,8]. PHI is untied to hospital electronic health records; this is in contrast to telehealth, which focuses on the exchange of data between clinician and patient for use in diagnosis and treatment. PHI may also involve use of a range of ad hoc tools other than mobile devices typically used in mHealth.

Research in HCI has focused on the technology and information needs in PHI. In particular, researchers have explored the challenges and benefits of PHI for people living with various health-related conditions, such as diabetes [16,18] and bipolar disorder [8]. Many of their findings provide implications that can be generalized across numerous health conditions. However, previous research has not yet looked at a health condition as complex and stigmatized as HIV, and whether or not the previous results can apply remains yet unknown.

In order to address this shortcoming, we conducted semi-structured interviews with people living with HIV who had tracked or were currently tracking their personal health information. Our main research question focused on investigating the actions, concerns and challenges of people living with HIV during the PHI process.

The main contributions of our research are a better understanding of the PHI process, particularly for people living a chronic disease, input to better design and development of tracking tools that are tailored to the needs of end-users living with a complex and highly stigmatized disease like HIV. Our aim is better support for people living with HIV to better manage their condition.

The structure of our paper is as follows. We first describe the context of our research and related work. We then introduce a new process model for PHI, consolidated from previous models. We briefly describe our method for data collection and analysis. We conclude with a description of the results related to each stage of the process and the implications for design and future work.

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## RELATED WORK

### Living with HIV

While there is considerable variation between countries in the background characteristics of people living with HIV, in England 64% of people diagnosed with HIV are between the ages of 35-54, with 67% males and 33% females [19]. Currently, sexual orientation is not included as part of the breakdown. However, the exposure through sex between two men comprises 45% of the infections while sex between a man and a woman comprises 48% [19]. Of heterosexual people living with HIV, 60% are of Black African ethnicity, of which 63% are women [19]. Black British Africans as an ethnic group make up 33% of HIV+ adults in England [19] even though they only represent 1.8% of the UK population [14].

HIV has a high level of stigma [14], and is associated with depression and suicidal thoughts [6]. The stigma related to HIV means that many affected do not disclose to others, feel isolated, and delay reaching out to support organizations [14]. In addition, there are reports of almost one-third of HIV+ people in England having been discriminated against, and almost half of these individuals have experienced discrimination from healthcare workers [6]. The discrimination in a healthcare setting incurs a distrust of health services and, in particular, the ability of these services and workers to maintain confidentiality [14].

Until ARV drugs were developed, HIV was a terminal disease; in the past, being diagnosed as HIV+ quickly progressed to dying of AIDS. Now, through careful compliance with ARVs, living with HIV means living with a chronic disease [23]. However, because these ARVs are a relatively new development that allow people with HIV to live longer, the demographic profile of HIV is shifting [21]. As such, there is little understanding about what it means to live a long life while being HIV+, in addition to the long-term effects of ARV treatments. For example, it has been suggested that early-menopause is linked to HIV [21]. HIV+ women may be taken by surprise by menopausal symptoms such as hot flashes, poor sleep, and mood changes and are left to determine if these new changes are side effects of the medication, symptoms of AIDS, or actually an age-related condition. Therefore, people with HIV must constantly monitor themselves for changes in their physical and mental well-being and determine if they are seeing a side effect, symptom, or new condition. The challenges faced by people living with HIV are likely to impact the way that they track their personal health information, and this is a focus of our research.

### Tracking Personal Health Information

There is a long tradition of supporting the tracking of patient information through the use of personal health records (PHR) and electronic medical records (EMR). Both are tightly linked to healthcare services and are used to record decisions made regarding a patient's treatment and to document their progress. While EMRs are controlled by

healthcare professionals, PHRs provide patients with the opportunity to access or add to their medical record [15]. However, patients find it difficult to access or make sense of the information contained within some records [15].

There are also tools designed for people to use to measure and track personal health information, not specifically tied to PHRs or EMRs i.e. *unanchored* from healthcare systems. Previous research has investigated technologies for PHI [20], mainly focusing on chronic diseases, e.g. diabetes [16,18] and hypertension [9]. A well-known web application for tracking health information is *Patients Like Me* ([www.patientslikeme.com/](http://www.patientslikeme.com/)), which can be used to log emotional changes, physical changes, and lab results. Apple's HealthKit (<https://developer.apple.com/healthkit/>) supports the collation and display of data collected from a variety of iOS and watchOS apps, to support tracking of activity data such as workouts, number of steps, calories burned/consumed, and physiological data such as heart rate. However, there are currently very few PHI tools dedicated to HIV. TIDES [11], an application developed in academia, is designed to provide targeted interventions to HIV+ people to support self-care and avoid depression. A solution from industry, *myHIV* ([www.tht.org.uk/myhiv](http://www.tht.org.uk/myhiv)), can be used to set up reminders to take pills and record lab results.

The informed and detailed understanding of the technology needs of people living with chronic diseases other than HIV can help frame our initial examination of PHI. However, there are differences between HIV and other conditions, which will shape how HIV+ users employ PHI tools and how they potentially adapt the PHI process to their needs [20]. This is the main aim of our investigations in this study.

### The Process Of Tracking Personal Information

One current model of how people track personal information is a model of behavior change, outside of the health domain, which comprises five stages: preparation, collection, integration, reflection, and ending with the individual taking action [12]. Lived Informatics describes a process model, again outside of health, which features the iterative paths of repeated collection and lapsing/resuming the process [7]. Another model focuses on patients tracking information for healthcare professionals, which focuses on the motivations and barriers which patients go through to collect observations of daily living [5].

A number of researchers have focused on the reciprocal process between tracking health information and the patient's state of health, often characterizing periods of stability against those of change [13,18]. Typically, patients monitor more systematically when their condition is unstable, and neglect their data-gathering when it appears to be managed. However, what we are concerned with are the detailed activities which people tracking their personal health information engage in, in order to support them by building better tools, tracking the right kind of information, and helping them make sense of their own data.

## A PROCESS MODEL FOR PHI

We based our conception of the Personal Health Informatics process on models previously proposed [1,5,7,12]. Our new model consolidates these models and comprises six stages (Figure 1). We will now explain each stage that will be investigated in detail through our participant interviews.

### Intention

This stage involves the individual recognizing a need for tracking their health data, and concerns their motivation or purpose for tracking personal information. Intention is a crucial first step in the process, as it influences what information is gathered by users [12] and what insights they hope to gain [22]. Additionally, it has been suggested that an individual's intentions change as a result of insight [12], therefore this model features a link from Reflection back to Intention.

The intentions that drive end-users to begin tracking their personal information are frequently acknowledged and discussed in research (e.g. [4,5]). For personal health information, it has been shown that intentions such as to cure a condition, achieve a goal, find triggers, identify relationships, and execute a treatment plan are important [4]. However, how intentions of people with HIV differ from other conditions is yet little studied.

### Identification

After forming an intention to collect data, users identify appropriate type(s) of information to collect [12], the frequency of collection, and what tools to use [5,16]. In the context of personal health information, we know that individuals consider the features available on the tool [17], the ease of use [5], and the visibility of the tracking tool – particularly when considering societal perceptions or personal confidence [16]. In this paper, we place special emphasis on how they find potential tools for tracking.

### Capture

A large part of personal informatics is collecting and capturing data by the user [20], and this stage may be repeated numerous times if the individual is content with their process and maintains the same intention [22]. Previous research has demonstrated the wide array of tools that support data capture for Personal Health Informatics, such as wearable devices and smartphone applications [5], the types of data that are important for users tracking their health, for example, many people with diabetes track glucose scores and insulin units, and potentially their

exercise or food intake [18], and how to capture it either automatically or through self-reported data by the user [22]. We were interested in the current capture practices of people living with HIV and how they might differ from other, less stigmatized conditions.

### Management

Once data is captured, it might be further manipulated, ready for use in representation and reflection. Actions that users might do include transferring from one medium or tool to another, integrating data from various sources, and/or editing the captured data. There are some tools that are capable of supporting the user in managing their data in addition to capturing it [22] and we wondered about the management needs of our user group.

### Representation

Transforming and depicting the data in a representation will support the user's reflection. Data representations and data visualizations can either be created by the tool or by the user [22], but tools that create representations often offer the user little or no control over selecting the style [10]. We will focus on the needs of people with HIV that provide guidance for creating representations useful for them.

### Reflection

The user finally looks at the representations and relates them back to the original intention, hopefully gaining some insight from this stage, either to change their behavior or having a better understanding of themselves [20]. Reflection has been studied relatively little in personal health informatics, even though it is one of the fundamental aspects of making sense of the user's own data.

Other models conclude with a stage of reacting to the reflection, such as *insight* or *action* [1,12], giving emphasis to promoting changes in thought or behaviour. In contrast, we focus on supporting individuals in tracking and managing their personal information, and thus treat insight as an optional aspect of reflection.

## METHOD

We conducted a qualitative study, gathering in-depth data about the PHI process, associated actions, needs and concerns of people living with HIV through semi-structured interviews.

We recruited 16 adults (Figure 2) living with HIV in England through sexual health organizations, social media, and online forums: 8 male and 8 female. The ages of these participants ranged from 18 to 57 years old, with an average

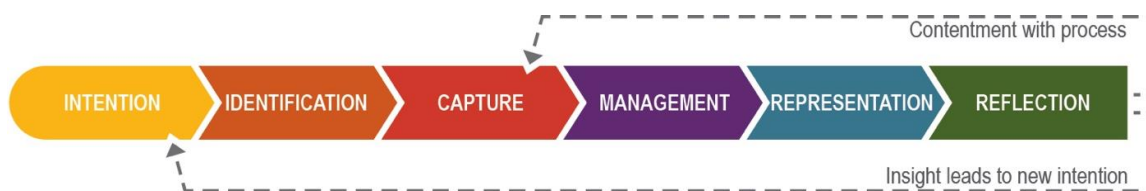
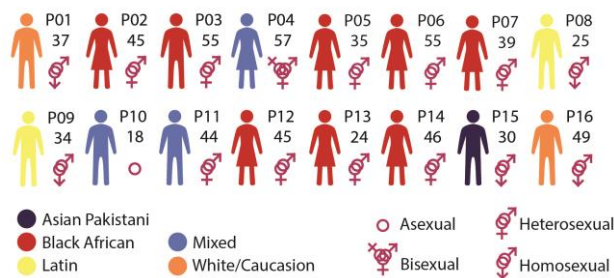


Figure 1: The process of Personal Health Informatics comprises six stages and two iterative paths



**Figure 2: The gender, age, ethnicity, and sexual orientation ranged across the sixteen participants**

age of 39.87. Fourteen of our participants identified as Black, Asian, or minority ethnic; nine identified as heterosexual. Participants varied in their time since diagnosis, from two participants living with HIV for less than a year to 25 years. Comparing this breakdown with that of the larger population described in Related Work, our sample is skewed against the national average by including proportionally more heterosexual Black African women, however, despite increasing diagnosis rates in this segment, this group is rarely involved in studies of this nature [19].

Our procedure considered ethical implications early, especially important with a study involving this type of users, and consent forms and study details were provided to each participant prior to the study start. Thirteen participants were interviewed one-on-one in private locations within London and three were interviewed online over Skype. At the start of the interview session, participants were asked to complete a short questionnaire to gather demographic details. The main part of the interview was audio-recorded and later transcribed and anonymized for detailed analysis. We used a discussion guide to structure the interview, focusing on each of the stages in the PHI process in turn, how they tracked and used their personal health data, and if their needs were currently met. Participants also brought along samples of their tracked data to show the researcher, and, if agreed, a digital photograph was taken of the sample data. All photographs were later inspected for identifiable information, which was then removed from the image. Each participant was interviewed for approximately 30 minutes. At the end of each interview, participants were reimbursed for their travel costs, when applicable.

The researcher interviewing also carried out the transcription and data analysis, and so was highly familiarized with the data. A combination of *a priori* and inductive analysis was used. First, the transcripts were reviewed to identify when different stages of the process were being discussed. These comments were then separated and inductive coding was applied to identify themes within each stage of the process. This approach was taken to ensure our analysis focused on the process model while also allowing unexpected themes to emerge from the data. Applying codes used in research on other conditions, we felt, would have limited our findings and prevented the

voices of the participants from being heard. These themes were continuously discussed and refined amongst the authors, in order to gain agreement and reliability.

## RESULTS

We now describe the main issues, concerns and actions for each of the stages in the proposed process model, from Intention to Reflection. It is worth noting that at the time of the interviews, all participants were currently tracking some personal information about their health, or had done so in the past. We pay particular attention to aspects that are distinct for people with HIV, in order to provide more appropriate tools for their specialized needs.

### Intention

Intention is the stage in which an individual recognizes a need to track data, and two intentions arose from statements made by sixteen participants: *monitoring* and *acting*. Acting aligns with the idea of making change; it is the intention to inform what actions should be taken or to observe the effects of prior actions. It is commonly suggested that the intentions to track information are based on a desire to make changes (e.g. [12]), but our data suggests that monitoring is actually more common amongst people living with HIV. Monitoring does not concern making change, but instead relates to tracking information with the purpose of having a record or reference point.

Seven participants tracked with the intention of acting upon their health information, using their collection to inform what actions should be taken or observe the effects of them. For example, P06 made the decision to take up exercise in order to control her cholesterol levels which were affected by the ARVs she took. To see if her actions were having an effect, she tracked her exercise: *"Last time I went to the dietician I said I'd start cycling ... So, I took a note of that, the last time I went it was better than [the time before]."* (P06)

While behavior change is a common focus of PHI research, less than half of our participants had this intention. However, this also demonstrates that participants, in order to inform how to change their behaviors to improve their health, needed to track a number of different data types, and then to relate them together. This is likely to influence later stages in PHI, particularly in Capture, Representation and Reflection.

Fifteen participants had the intention of monitoring their data. From these statements, it emerged that an important aspect of this intention for the vast majority of our participants was to personally *own* their data. In doing so, they felt that they were taking control of their own health: *"I would write it in my small diary for my own use. But the hospital, of course, they would have their own records for everything"* (P12)

In contrast to what has been found for other conditions, our participants often needed to monitor some health data at the same time as actively managing their health. Seven of the

participants had both monitoring and acting as their intentions. Previous work has described how health can influence tracking behavior [18]. It has been suggested that when health is stable, it is enough to just collect data whereas when health is unstable then users will need to reflect more on their data to make changes to their behavior [18]. This might explain why both *monitoring* and *acting* co-occurred for many of our participants. However, it also points to the complex nature of tracking HIV information for self-care.

### Identification

Once their intention has been formed, an individual needs to identify an appropriate tool to use, and eight participants described their approach to finding a potential tool to support their tracking needs. These statements indicated two strategies: either using a *health-related source*, or a *general-purpose source*.

When it comes to chronic diseases, healthcare systems or settings often direct their patients to existing personal health informatics tools. However, only three participants said they would turn to a *health-related source*, e.g. a medical website or HIV brochure, to find a possible tool. With so few considering approaching a health-related source, this seems to put intended users at a disadvantage of finding out about tools appropriate for them. None of the participants mentioned asking their local sexual health clinic, support group, or healthcare provider for a recommendation on a tracking tool.

The most popular strategy, mentioned by six participants, was to use a *general-purpose source* to find a tool. Three of the participants mentioned that they would use a search engine, and four would look in the app store on their smartphone: "*You type 'HIV' into Apple.*" (P01)

However, as we will discuss in the next section, many of our participants also raised trust and security concerns, which seem to run counter to their identification strategies for appropriate tools.

### Capture

All sixteen of the participants made statements about Capture, the stage in which personal information is collected. In comparison to Intention and Identification, the results related to Capture include more complexity. First, we found that the perception of security influences the chosen tool for storing captured data. Second, because of the far-reaching effects of HIV, a broad range of data is captured.

#### Security

Security refers to the safety of a user's personal information, and the measures taken to protect it against unwanted access [2]. The statements by participants in our study showed that security is particularly important to HIV+

individuals because of the need to protect their status and, as such, protect themselves from discrimination and stigmatization. Our participants show that the selection of a tool to track information is largely based upon the perceived security of the tool, although additional security measures are also put in place to protect their data from unwanted access.

This need for heightened security emerges when examining the choices our participants made to store tracked information in a *generic* storage tool over a *specific* one. *Specific* storage was used by four, and these were storage tools that were intentionally designed for HIV+ people. The remaining twelve participants used *generic* storage, such as notebooks or general health applications. This is in contrast to their strategy for finding out about such tools during identification activities, which included specific HIV-related terms.

Using generic storage is a way to hide that the information being tracked is related to HIV, as six participants indicated. For example, an HIV-specific application might feature a red-ribbon icon or terms that can be easily recognized by a casual observer, but a generic application is less likely to give their status away: "*Well, I'm always making sure there's no one around me anyways, when I do anything on my phone. ... For my memo notes, I don't title it 'My HIV medications,' I just don't label it.*" (P08)

Furthermore, their security concerns also seemed to influence the choice of medium for tracking information. Seven participants used only *paper* e.g. notebooks, diaries, while five only used a *digital* medium e.g. smartphone applications, computer documents. Statements made by participants indicated that these choices were based upon their perceptions of the security of the medium. For example, those who used paper felt that their choice offered them more security than a digital medium would, particularly because they were in control of keeping it secure: "*A diary you can hide it, nobody can come in your room and take it. The best place to keep stuff is a diary.*" (P05)

Those that used digital mediums also felt that their information was secure. As with paper, this was because they had personally taken extra steps to ensure this security: "*One thing I don't do with my HIV, I don't put it on the cloud. I don't do that. I don't put it on the cloud.*" (P02)

Masking mechanisms like encryption are important to people living with HIV [2], and they were applied regardless of the medium used. For example, data written in a paper diary might be encrypted with symbols, while data recorded in an application might use vague or incomplete language: "*I put a star, you know, an asterisk. I just put it in red like that ... then I know it's uh, HIV.*" (P14)



Additionally, when encryption is not an option, an individual may choose to remove links to their identity, which is another example of masking: "Oh, yes, I mean, the day I was diagnosed I just created a completely anonymous email account so I could sign up to these things so that nothing traced back to my usual email." (P01)

#### Tracked Information

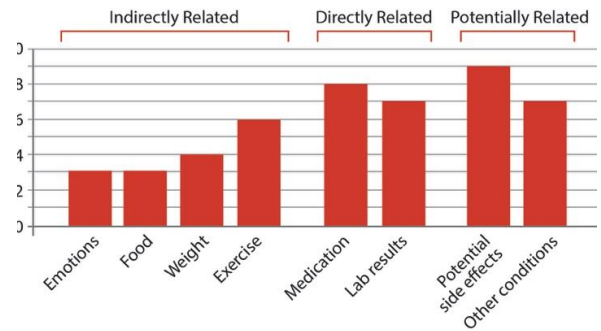
Fifteen participants made statements about the types of information they capture (Figure 3). With the exception of *exercise*, all of the information captured by the participants was *self-reported* rather than sensed or measured by a digital tool. This is in contrast to many other chronic conditions that have specific devices which are able to measure and record health-related data for the user. When considering the numerous kinds of information that is being tracked, this places an added burden on HIV+ people.

Additionally, we found seven participants who track their lab results, which comprises their CD4 count (a type of white blood cell that helps protect the body) and viral load. Regular checks on health are common for many other chronic conditions, for example, people living with diabetes have kits that they can use frequently to measure their blood sugar levels. However, people living with HIV must wait until their semi-annual consultation to find out their levels: "Well I wish I could have some technology to measure my CD4. Because now they have HIV tests you can take at home. I wish they could have something like that to take your CD4 or viral load, instead of going to the hospital. ... I go twice a year. It's just twice a year." (P09)

Examining the different kinds of information that is tracked by our participants shows that capturing a broad range of information is necessary to have a holistic view of health. This is because the effects of HIV reach far beyond the immune system. There were eight types of information captured, and these were broken down into three categories based on the type of relationship to HIV: *directly related*, *indirectly related*, and *potentially related*. Directly related information is that which is specific to HIV: the medication and the lab results. Indirectly related information is that which is not specific to HIV, but does relate to their health and wellbeing. Finally, individuals might not yet know the relationship between specific data they are concerned with and the disease; this is potentially related information. Twelve of the sixteen participants tracked more than one kind of information (Figure 4).

Tracking directly related information to HIV (*medication and lab results*) was mentioned by ten participants. Ten people wanted to track their lab results and eight tracked their HIV medication, either changes in their prescriptions over the years, or their compliance: "For example, I just put the date and make a tick to say I took my medication." (P09)

For these individuals, tracking directly related information was done not as a way to make changes to their lifestyle,



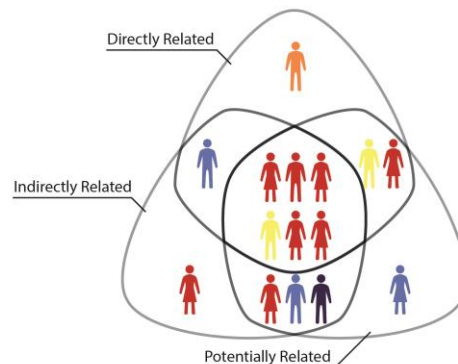
**Figure 3: The type of information gathered by participants, with varying directness in relation to their HIV status**

but as a way to ensure they were doing their best to manage their HIV.

Eleven participants mentioned tracking indirectly related information (*emotions, food, weight, and exercise*), meaning that more participants wanted to track indirectly related information than directly related information: "I track what I eat. Yeah. Because, um, eating is really important for me. I've had to adjust my diet in regards to my health." (P11)

At first these do not seem obviously connected to HIV, but two reasons make these particularly important for HIV+ people to keep track of. First, being diagnosed as HIV+, as well as taking ARV drugs, can have negative effects on a person's mental health. Because depression is a significant factor related to ARV non-compliance [11], it is important to maintain a positive mental wellbeing. Second, it is important for people living with HIV to maintain a stable and healthy body-mass index; being over-weight or under-weight means poorer increases in CD4 over time.

The interviews revealed that ARVs can have drastic effects on a person's body, and this led to twelve participants tracking potentially related information. This included potential side effects and other conditions – information that involved uncertainty related to their link to HIV. For example, ARV medication can cause various side effects, from fat re-distribution and spots on the skin, to sweating and insomnia. For this reason, ten participants tracked



**Figure 4: Tracking more than one kind of data was common among twelve of the sixteen participants**



*potential side effects* so that they could monitor changes in their body. As mentioned, determining the difference between side effects, symptoms, and other conditions is difficult for people living with HIV, so tracking this information is done as a way to do so: "Yeah, I write 'On this day I felt like this, I'm not sure if it is the medication or it's just a normal feeling.'" (P14)

HIV and its treatment can also lead to comorbidity, i.e. the co-occurrence of HIV with a secondary disease, such as high cholesterol or osteoporosis: "A lot of people, as soon as they started HIV medications they developed cholesterol problems." (P04)

As such, eight participants mentioned tracking information about *other conditions*: "The only thing I keep track of right now which is a serious concern is my cholesterol levels. They are on the high side." (P06)

In summary, as our participants have demonstrated, people living with HIV need to track a large amount of highly varied information in order to form a better view of how their health is changing and monitor existing conditions. Nearly all of this information is self-reported into generic tools; one reason for this is the need for tools that are secure and covert. This means that HIV+ people currently undertake a heavy burden in order to better understand their health.

### **Management**

Only five of the sixteen participants stated that they managed their collected data in some way, possibly because the prevalence of recording information on paper makes many management activities difficult. However, all participants who spoke of management activities edited, deleted, integrated, or transferred their data; suggesting that these are essential functions that need to be integrated into PHI tools designed for people living with HIV.

### **Representation**

Representations of personal data support people in developing insights about their health, and our participants made it clear that such insights would be valued. However, only four participants mentioned visual representations, all of whom used digital tools to track health information that made these representations available automatically. None of the participants reported personally creating representations of their tracked data.

Of the four participants, two discussed representations of data that was directly related to HIV, such as medication compliance and lab results, while three discussed representations of indirectly related data, such as weight and exercise: "It visualizes everything, and you can see it on the chart and data, so all the pinpoints. So for my medication, it pinpoints the data every day." (P10)

Although these were limited in terms of complexity and relatively commonplace, the participants still seemed to appreciate them. However, as previously discussed, many

of our participants had the intention to inform or observe the effects of actions, especially exploring a relationship between indirectly related information and potentially related data. None of the tools used by these four participants generated representations that allowed participants to relate these two types of information. This presents a potential barrier to these participants from having a holistic understanding of their health.

### **Reflection**

As stated, our participants had the intentions to track multiple kinds of information in order to monitor their health or act upon it. Despite the lack of representations available, fourteen participants mentioned reflecting on their data to gain insights. From the statements made by these fourteen, we discovered that they were applying three different strategies to reflect and gain insights: *solo reflection*, reflection through their *community*, and reflection through their *healthcare professional*.

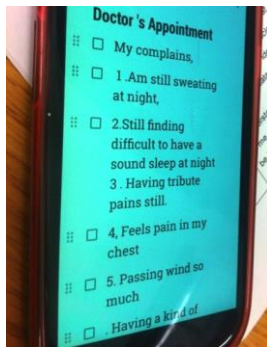
Ten of the participants reported reflecting by themselves, which we will refer to as solo reflection. Four of these ten had representations available, which they found to be useful: "Yeah, I do [look at the graph], because it's helpful information. Maybe I need to improve my workout here or maybe I need to slow down a little." (P10)

The remaining participants conducted solo reflection by looking back through their captured data in its existing form. For example, P11 developed osteoporosis of the spine from his ARVs and used his hand-written notes to gain insight on how he was healing after a spinal operation: "I'm just looking to see if I'm doing the right thing for myself." (P11)

In solo reflection, the data being reflected upon ranged across all the information types previously described. However, when the participants focused on potentially related information – data about which they were uncertain as to the link to HIV – they turned to their community or healthcare professionals to support reflection. We have discussed the complexity of HIV and the difficulty of determining whether something is a side effect or unrelated. As such, turning to healthcare professionals or HIV+ communities is done as a way of using external knowledge to support reflection and gain insights.

Five of the sixteen participants mentioned that they turned to their community – support groups, online forums, and even social media – to help reflect on potential side effects. These participants summarized their data and asked others to report if they have had a similar occurrence. This was done in order to determine whether their experience was related to the disease: "Again, through Twitter you go 'Right, I've seen this, is this true? Does this ring true to anybody else?' and yeah." (P01)

Only five of our participants reported reflecting through the community, but other statements indicated it to be a common activity across the wider population of people



**Figure 5: List of information written by a participant to be reflected on during a consultation**

living with HIV: *"What I saw online, and speaking to other HIV positive people, the information I can tell you is that a large part of our community – patients – they rely on these websites."* (P15)

Possibly, the need to turn to the HIV+ community to support reflection arises due to the nature of data collected and its representation (or lack thereof). Because the personal health information of HIV+ individuals is currently not tied in to other individuals' data sets, people living with HIV need to turn to their community to identify if their experience fits a pattern in a larger sample.

Eleven participants made statements about using their healthcare professional to help them reflect upon their previously captured data, usually during their infrequent consultations, to discuss potential side effects and other conditions. For example, P02 makes a list of potential side effects (Figure 5) such as night-sweats, poor sleep, and chest pains. She did this to determine if she was indeed experiencing side effects or if she was entering early menopause: *"So I keep a diary so when I see my consultant – I see him in [six months] – so when I see him we go through these, all the things that have been happening to me, so that I can find out [what it means]."* (P02)

While our interviews indicate that reflecting with the HIV+ community or a healthcare professional is common, they do not provide detail on the interaction as a whole. Further work is needed to explore what occurs during these interactions but the statements made by our participants suggest that turning to the community or healthcare professional is done as a way of confirming a hypothesis.

### IMPLICATIONS AND DISCUSSION

Our research was based on HIV+ people living in England, but HIV is a global issue. Black African women were heavily represented in our study, and this indeed gives voice to the concerns of a large segment of people living with HIV globally. We believe that privacy and security are universal needs for our population, given the stigma of the disease. However, future research is warranted that considers the relationships between participants' backgrounds and the local culture, context of use, and technology available. For example, socio-economic circumstances might affect technology adoption, and this

might have an impact on HIV-related information tracking.

Our findings have shown that there is a need and desire for people living with HIV to track their personal health information, but that current technology does not yet meet their tracking needs. We argue that work is needed to expand into more complex diseases like HIV, to spread the benefits of PHI to others who need it. We have demonstrated that people living with HIV face numerous challenges in tracking their information and gaining insights about their health. Research has shown that individuals living with other chronic diseases have needs that are not adequately supported by tracking tools (e.g. [9,15]). Our findings support this, and indicate several unique needs that arise from the complexity and stigma associated with HIV. While our participants have shown that they have the desire to track information and gain insights in order to better self-manage their disease, the tools that they currently use fail to provide adequate support. We discuss four specific aspects that have design implications and opportunities for further research.

### Information

Tracking a number of different kinds of information was highly important to our participants. Because their disease causes changes over the course of their lives, the type of information which is tracked will fluctuate with their health concerns. Our findings are the first concrete evidence of chronically-ill individuals needing to monitor a large range of physiological and psychological information in order to self-manage. This is in contrast to other conditions, such as diabetes, which typically have a more limited range of informational needs. Given the complexity of HIV and changing informational needs, it is not surprising that current tools do not adequately support HIV+ people in tracking a holistic and fluctuating amount of data.

Thus, tools to support people living with HIV must be flexible in allowing a user to begin and end tracking certain data as they deem necessary. This flexibility could perhaps be achieved through a highly customizable tracking tool; one which allows the user to determine what information is tracked and create their own terminology, possibly similar to *DAYTUM* (<http://daytum.com/>). However, for nearly one-third of our participants, it was important to determine if their experience was shared amongst others, yet individually-generated terminology or measures would be difficult to integrate with other users' data. This would pose a significant challenge for HIV+ individuals during the Management step of the PHI process.

### Representations

Our participants showed a clear desire to gain insights about their health, whether to monitor its stability or to inform the actions that they should take. However, the tools that are currently available to them do not provide representations which allow the individual to form a holistic understanding of their health. *Patients Like Me*, for example, provides separate graphs for each data type,

leaving the burden on the user to draw connections. One approach would be to visualize the links between multiple types of data; researchers could build upon the work of others, such as [18], to address this challenge.

Developers of PHI tools should also consider creating representations and visualizations that map the individual's data to the collected data of a larger sample. Doing so would allow people living with HIV to determine if their experiences are shared by others and possibly related to HIV, and help users draw better and more accurate insights.

### **Ownership, Security and Privacy**

Personal ownership of their data was highly important to our participants, both because it promoted the sense of self-management and the sense of data security. This suggests that users should be given the option of where their data is stored, as well as provided with clear information regarding the security measures in place. Additionally, trust in a tool can be promoted by providing transparency. By taking these measures, it may be possible to increase adoption of digital tools amongst people living with HIV.

Having a covert tracking device, one with very low visibility, was important to our participants. Previous research has discussed the need for covert tracking devices for people who are uncomfortable with publicizing their disease; for example people living with diabetes may wait for a private moment to perform self-care activities [16]. For our participants, however, simply being discreet about tracking information is not enough to make them feel comfortable and secure. Through the common use of generic storage devices and encryption, our participants have made it clear that an appropriate tool is one that will never indicate its true purpose. As such, extra care must be taken to avoid symbols, terms, and names associated with HIV – not enough consideration of the covert needs could risk the exposure of an individual's status, sparking stigmatization and discrimination.

It is clear, through both our study and previous findings, that there are privacy and security considerations to be made when an HIV+ individual shares their information [2]. There is currently much interest within healthcare to use personal information to research health phenomena, as well as for individuals to share data with their community to support reflection and identify trends and patterns. However, it is an open research question how to motivate HIV+ users to open up the access to their data for this purpose, and under what circumstances they would be willing to do so.

### **Connecting with Clinicians**

Our participants showed a desire to draw insights on their collected information with the help of their clinician's knowledge, but we do not yet know enough about the details that surround this activity. This personal information is invaluable for managing HIV but does not form part of official health records. Further research is warranted to

explore how this fits into the flow of a consultation visit, how tracking tools could improve the communication between patients and doctors, and how to balance self-ownership and data-sharing within a clinical setting. Addressing these knowledge gaps would help HIV+ people self-manage, while improving the exchange of information between patients and doctors.

### **CONCLUSION**

HIV is a complicated disease, and our participants have demonstrated the importance and challenges of tracking health information to support self-management. Our paper introduced an iterative process model of Personal Health Informatics and presented the results of a qualitative empirical study of how HIV+ individuals go through this process. Our analysis highlighted several challenges that these individuals currently face:

- *Stability and Change:* HIV has a wide-spread effect on a person's mental and physical health, which means that a person living with HIV may need to manage a number of different needs and intentions at the same time.
- *Self-Ownership and Security:* Our participants showed a strong desire to personally own their data. This seemed to function to maintain security and give a sense of empowerment. To protect themselves from accidental disclosure, HIV+ people are more likely to select a generic storage tool. Appropriate devices must be extremely covert in order to be adopted.
- *Information and Representation:* People living with HIV track a broad range of information in an attempt to self-manage, and require representations that visualize these data holistically in order to gain useful insights.
- *Reflection and Insight:* There is a strong desire to gain insights, but current tools do not support reflection. Our participants have shown that they gain insights through reflection on their data by themselves, as well as through the knowledge of their community and healthcare professional.

The findings of this research take a first step toward understanding how people living with chronic and socially stigmatized diseases, like HIV, proceed through the process of Personal Health Informatics, in order to better support these individuals by building tools that empower them to self-manage: *"I'm the focal point. If people have to get a better result, what I believe is I have to be involved. I'm at the center of the service."* (P06)

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