# Reflection and Personal Health Informatics for People Living with HIV

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## Abbreviations

HIV: Human Immunodeficiency Virus

AIDS: Acquired Immunodeficiency Syndrome

PI: Personal Informatics

PHI: Personal Health Informatics

VL: Viral Load

ARV: Antiretroviral medication (also occasionally referred to as ART)

## Glossary

### Community-Aided Reflection

Community-aided reflection occurs when an individual reflects upon his or her personal health information alongside the knowledge, experiences, or health information of others who are similar, as a means for generating new knowledge or understanding about his or herself.

### Personal Informatics

Personal Informatics is "an activity where people collect and reflect on personal data to gain a better understanding of their own behavior" (Li, Dey, & Forlizzi, 2011)

### Personal Health Informatics

Personal Health Informatics is a process in which a person collects data about their personal health and reflects on it with the intention of gaining a better understanding of themselves or of their health.

### Reflection

Reflection occurs when an individual examines or explores their own experiences, situations, or knowledge, processing that information and relating it to their previous knowledge with the intention of generating new knowledge or understanding about themselves.

### Self-Management

"Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychological consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to effect the cognitive, behavioral and emotional responses necessary to maintain a satisfactory quality of life." (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002, p. 178)

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**Publications related to this thesis:**

Bussone, A., Buchanan, G., & Stumpf, S. (2015). A proposed process model for personal health monitoring. *Patient Safety with Interactive Medical Devices: A multi-disciplinary symposium.* Reading, UK. (Poster)

Bussone, A., Stumpf, S., & Bird, J. (2016). Disclose-It-Yourself: Security and Privacy for People living with HIV. Extended Abstracts of CHI, ACM Press.

Bussone, A., Stumpf, S., & Buchanan, G. (2016). It Feels Like I'm Managing Myself: HIV+ People Tracking Their Personal Health Information. In *Proceedings of the 9th Nordic Conference on Human-Computer Interaction (NordiCHI '16)*. ACM, New York, NY, USA, Article 55, 10 pages.

Bussone, A., Waugh, S., Stumpf, S. (2016). Self-Managing HIV Using Mobiles. Extended Abstracts of NordiCHI, ACM Press.

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# Abstract

Recent advances in medicine mean that millions of people who are living with the Human Immunodeficiency Virus (HIV) can expect to live normal life spans. However, HIV, the medication prescribed to control the virus, and living with a stigmatized disease, are each associated with a wide array of negative impacts on the body and mind, and these present a challenge in an individual's ability to self-manage their health information. A key aspect of self-management is self-understanding, and Personal Health Informatics (PHI) has the potential to help those living with HIV in understanding their health through reflection. However, there is little indication of the needs of people living with HIV and how PHI systems can best support them in reflecting on their health information.

In order to fill this gap, this thesis aims to answer the overall research question:

> **How can Personal Health Informatics systems support people living with HIV in reflecting on their personal health information?**

Answering this research question was approached in four parts:

- The development of a synthesized model of the process of PHI, as means of understanding the context of PHI.
- Interviews with HIV+ individuals were conducted to understand where there were opportunities for supporting reflection.
- An analysis of an online forum was conducted to determine what people living with HIV were trying to reflect upon, what health information was being asked about, and how the community attempts to support them in reflecting on their health.
- Two visual prototypes were designed to simulate community-aided reflection and support people living with HIV in reflecting on their personal health information. These were used during a user study to understand how reflection occurred.

My research is the first to explore how to support HIV+ people in reflecting on their personal health information. The main contribution of this research is a detailed understanding of how PHI systems can support people living with HIV in reflecting on their health information. This main contribution is comprised of four smaller ones:
- A six-stage process model of Personal Health Informatics
- A detailed understanding of how people living with HIV currently track and reflect on their personal health information, and design implications for PHI systems to support them in reflection
- An empirical understanding of community-aided reflection as it occurs in an online forum, alongside the identification of five common questions that people living with HIV seek help in online forums for reflecting upon, the information asked about, and how the community attempts to address the questions
- A detailed depiction of how reflection occurs when using a prototype designed to simulate community-aided reflection

# Chapter 1  Introduction

## 1.1 HIV

There are over 36.7 million people living with the Human Immunodeficiency Virus (HIV) around the world (WHO, 2016). Over 150,000 diagnoses have been made in England since the late 1980s (Public Health England, 2017), where this thesis was written. While HIV was once a terminal disease leading to death by the Acquired Immunodeficiency Syndrome, or AIDS, the introduction of antiretroviral medication has provided the ability to suppress the disease and enable them to live a long life (WHO, 2016). Because of this, HIV is no longer considered an acute disease, but rather a chronic one (Gifford & Groessl, 2002). Antiretroviral drugs (ARVs) reduce the amount of virus in the body, allowing the immune system to strengthen again. Once the viral load has been reduced to a point no longer detectable by blood testing machines, the HIV+ individual can no longer pass on the virus to others (see 2.1.1).

Thus, it is the role of the individual to routinely take the ARV drugs in order for their viral load to become undetectable. This aligns with the first aim of chronic disease self-management: to be able to comply with the required treatment (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). However, medication compliance for someone living with HIV is not a simple matter of taking pills each morning. The ARV medication regime can be strict and tedious: some ARV regimes involve taking numerous pills each day, or require that the pills are taken in very specific time windows, or that specific foods are ingested within particular time frames before or after taking the medication. Additionally, a variety of other seemingly harmless foods, drinks, or natural substances (e.g. grapefruit juice, St. John's Wort, etc.) can affect the efficacy of ARVs and must be avoided – the list of these interactions keeps growing, meaning that not all contraindications are listed on the prescription insert (International Association of Providers of AIDS Care, 2014). Given this, the ability to self-manage and understand personal health is an important aspect of living with HIV.

In the current medical domain, self-management of HIV is considered successful when an individual consistently complies with their medication regime and their lab results show that their viral load is undetectable (Gifford & Groessl, 2002). However, that perspective overlooks what is needed to actually live life each day with HIV and, arguably, continues to treat HIV+ people as acute patients rather than as experts in their own disease who deserve respect and authority (Gifford & Groessl, 2002). Moreover, if we look at what self-management is, we see that this focus is on just *one* aspect of what self-management involves - the management of treatment:

**"Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychological consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to effect the cognitive, behavioral and emotional responses necessary to maintain a satisfactory quality of life."** (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002, p. 178)

Even if comfortable with adhering to the medication regime, self-managing HIV involves dealing with changes in mental or physical health *for the rest of the person's life*. The virus's presence, the lowered immune system, and the antiretroviral medication used to fight the virus can all cause numerous short- and long-term effects on the body and mind of a person living with HIV. These changes may be seen in lab results, depression, fat redistribution, or even osteoporosis. For example, a seropositive (HIV+) female may suddenly find herself sweating profusely, constantly thirsty, sleepless, and not menstruating, and she is left to determine if these changes are a side effect of the medication, an opportunistic infection, or – worse – a sign that the virus is returning, only to learn that she is experiencing early-onset menopause caused by the virus (see Tariq, Delpech, and Anderson, 2016). In order to truly self-manage HIV, a person must be able to monitor their health, understand it, and determine how – if possible – to respond to such changes.

While people living with other chronic diseases often have access to systems that supports their self-management, the options available to those living with HIV are relatively few. For example: a review in 2011 of mobile applications for diabetics found 260 designed specifically for self-management alone (Chomutare, Fernandez-Luque, Arsand, & Hartvigsen, 2011), while a 2013 review of mobile phone applications related to HIV or other STDs revealed just 55, of which only 8 were actually designed to help users care for or prevent HIV/STDs (Muessig, Pike, LeGrand, & Hightow-Weidman, 2013). These 8 applications primarily focused on providing information, but also included features for tracking medication adherence, appointments, the names of clinicians, and viral loads (Muessig, Pike, LeGrand, & Hightow-Weidman, 2013). From the perspective of patient-empowerment, these applications can be considered to be medically patronizing and outdated, as they were designed around the 'medical model of measurement and management' rather than the needs of the individuals living with the disease (Churchill & schraefel, 2015) (see Section 2.1.3).

In addition, people living with HIV often take measures to prevent others from finding out that they are seropositive. Stigma and discrimination against those living with HIV are still prevalent around the world, even in the UK, and this can cause delays in accessing medical care, poor adherence to treatment, and poor mental health (Avert, 2018). Fearing discrimination based on this stigma, people living with HIV often avoid disclosing their status to family members, friends, partners, and even medical professionals (Avert, 2018). Research has shown that discomfort and fear of stigmatization affects the adoption and use of self-management tools by those living with diabetes

(O'Kane, Rogers, & Blandford, 2015), suggesting that this is likely to be a factor to consider for people living with HIV as well.

There is very little work in HCI that focuses on those living with HIV, and that which does is targeted towards interventions for medication compliance (e.g. (Salib, Maestre, Nimley, Dowshen, & Marcu, 2018)) or communication methods with healthcare professionals (e.g. (Gentry, Escobar, Vander Broek, Choi, & Ganchev, 2011). In the medical domain, research on the self-management of HIV again focuses overwhelmingly on medication compliance (Pellowski & Kalichman, 2012) which, as Gifford and Groessl (2002) wrote, fails to treat those living with HIV with the authority and respect they deserve. A shocking example of this medically patronizing perspective can be found in review of recent interventions targeted at people living with HIV highlighted that researchers often performed unannounced pill counts to determine if participants were untruthful in their self-reported adherence figures (Pellowski & Kalichman, 2012). In short, little research has been conducted to understand self-management for people living with HIV, how systems can support them in tracking and reflecting on their health, or what people living with HIV seek to understand through reflection.

## 1.2 Personal Health Informatics and Reflection

A common approach to understanding personal health information is through Personal Health Informatics. In this thesis, I define Personal Health Informatics as:

> **A process in which a person collects data about their personal health and reflects on it with the intention of gaining a better understanding of themselves or their health**

Personal Health Informatics, or PHI, occurs when an individual keeps track of their health information so that they can later reflect on it and gain a better understanding of themselves (Choe E. K., Lee, Lee, Pratt, & Kientz, 2014) (see Section 2.2). PHI is common amongst those living with long-term health conditions because it can not only provide support for tracking symptoms or health indicators, but also aid in finding causal relationships, viewing progress, and in generally understanding personal health (Fox & Duggan, 2013). Tracking and reflecting on personal health information can also have a positive impact on a person's approach to healthcare: by knowing more about themselves and their health, people may become empowered with the ability to personally manage and monitor their health (Fox & Duggan, 2013), thus placing them in a more central role in making decisions about the medical care they receive (Alzougool, Chang, & Gray, 2008).

While no process has been defined for Personal Health Informatics, there is a general understanding of how people engage in it: an individual becomes motivated to keep track of

details related to their health (e.g. mood, glucose levels, blood pressure levels, exercise activity, etc.), begins to capture those details, and then later engages with the captured information to reflect on their experiences and gain a new understanding about themselves (Choe E. K., Lee, Lee, Pratt, & Kientz, 2014). This may involve the use of technology (referred to in this thesis as PHI tools, technologies, or systems) – such as smartphone applications, wearable devices, or websites – to help in capturing the data, storing it, or representing it in a way that will make reflection easier. For example, people suffering from bi-polar disorder are able to understand what affects their mood by tracking their emotions, activity, sleep, etc. using MONARCA (a smartphone application) and reflecting on what has been captured (Frost, Doryab, Faurholt-Jepsen, Kessing, & Bardram, 2013).

Reflection is at the heart of Personal Health Informatics. Without it, there can be no knowledge gained or better understanding of the personal information tracked. Reflection is a cognitive mode that occurs when an individual seeks to understand or explain something (Baumer, 2015). Because PHI is focused on reflecting on *personal* health information, reflection is often thought to be a solo act (Baumer, 2015) but research in other academic fields show that it can be a socially-mediated one (Herrington & Oliver, 2002) that includes others who have had a similar experience (Kemmis, 2005) or specialized knowledge (Slovak, Frauenberger, & Fitzpatrick, 2017) (as discussed in Section 2.3).

The aim of this thesis is to understand how PHI systems can support people living with HIV in reflecting on their health information, but much work is needed to be done in order to meet this aim. Little is known about how to support or promote reflection for the self-management of chronic conditions, as researchers pay more attention to the technology and novelty of capturing information than supporting users in understanding it (Mamykina, Mynatt, Davidson, & Greenblatt, 2008). Furthermore, Baumer et al. (2014) argue that researchers of self-tracking have not demonstrated that they have a firm grasp on what reflection is, and rarely evaluate if it has even occurred. In order to support people living with HIV, we must understand what they need in a PHI system; systems which are not aligned with the needs of the intended users will fail to be supportive (Epstein, Cordeiro, Bales, Fogarty, & Munson, 2014). With this, there are several key points that we must address in order to understand how PHI systems can support reflection for people living with HIV.

Before we can understand how people living with HIV currently engage in the PHI process, we must first understand what the process might involve. Numerous process models relating to Personal Informatics, or describing how individuals gain understanding from data, have been described (see 2.2.1), yet none are pertaining directly to reflecting on personal health information. For this reason, I aimed to first understand what the process of PHI was (refer to RQ-1).

Second, we must identify the current approach to reflection for people living with HIV in order to determine how best to support it (RQ-2). Chronic diseases come with triggers, symptoms, and treatments that are individualized, and the subtle differences for each person make self-management difficult (O'Kane, Park, Mentis, Blandford, & Chen, 2016). As a result of this individualistic nature of disease, the information that people track must be catered to their personal needs (O'Kane, Park, Mentis, Blandford, & Chen, 2016). People living with HIV are no exception – they, too, require systems tailored to their particular needs (Schnall, Bakken, Rojas, Travers, & Carballo-Dieguez, 2015), yet, little work has explored what those living with HIV actually require (Gifford & Groessl, 2002).

Next, we must understand what people living with HIV seek to know or understand through reflection: systems for reflection can only be effective when it is understood what the user wants to know (Li, Dey, & Forlizzi, 2011). Researchers have shown evidence that people living with HIV do attempt to reflect on their health (Huber & Cruz, 2000), but there is no further detail on what they are seeking to understand through reflection. This means that we need to determine what questions people living with HIV have about their health information. Reflection on personal information is frequently thought of as a solo activity, despite research which has provided evidence of people living with HIV (e.g. Mo and Coulson, 2008), migraines, and diabetes (e.g. O'Kane, Park, Mentis, Blandford, & Chen, 2016) turning to online forums for support or information about their health. This approach to reflection has scarcely been researched in detail, so we must also understand how community-members aim to support individuals in reflecting on their health (refer to RQ-3).

With the above gaps in knowledge filled, we are then able to understand how to design a Personal Health Informatics system that could support people living with HIV in reflecting on their health information. However, such a system has never been observed in use – leaving a final question: how might reflection take place when provided with a system designed to support community-aided reflection (RQ-4)?

## 1.3 Research Questions

The work described in this thesis aims to fill the aforementioned gaps to determine how Personal Health Informatics systems could support reflection for people living with HIV.

To meet this aim, four research questions were developed:

**RQ-1: What is the process of Personal Health Informatics?** (Chapter 3)

**RQ-2: Where are the opportunities in the process of PHI for supporting people living with HIV in reflecting on their personal health information?** (Study One; Chapter 4)

**RQ-3: What kinds of questions about personal health information do people living with HIV seek support in reflecting on, and how does the online community aim to address them?** (Study Two; Chapter 5)

**RQ-4: When interacting with a prototype designed to support community-aided reflection, how does reflection occur?** (Study Three; Chapter 6)

## 1.4 Contribution

The overall contribution of this thesis is a detailed understanding of how PHI systems can support people living with HIV in reflecting on their personal health information. This contribution is comprised of smaller ones, each achieved through activities aiming to answer the four research questions.

**Contribution 1:** A six-stage model of the process of Personal Health Informatics

This contribution is associated with RQ-1, which was achieved by developing a process model specific to Personal Health Informatics by building upon previously existing representations related to Personal Informatics. The aim of this was to understand the activities involved, and how those activities related to reflection on personal health information. This process model was also used as a lens for analysis in Study One.

The PHI process model can contribute to academic research, as it provides a detailed account of the activities involved in, and flow of, personal health informatics. The model can be used as a framework for analysis for research conducted on Personal Health Informatics, as it was in Study One.

**Contribution 2:** An empirical understanding of how those living with HIV currently track and reflect on their health information, with design implications linked to the opportunities for supporting reflection

This contribution is associated with RQ-2, which was achieved through 16 semi-structured interviews with people living with HIV in England (Chapter 4, Study One).

The findings and design implications will be of benefit to developers of PHI applications – both for those living with HIV and others living with chronic or complex health conditions. Understanding the intentions that end-users have, and the information that they deem important to track, will help develop better designs that suit the needs of the end-users. Acknowledging that reflection on personal health information is not always an individual activity, and that individuals sometimes seek

the aid of others in reflection, should push designers to explore new ways of supporting communication of health information. The design implications discussed in Chapter 4 can be directly applied to PHI systems.

**Contribution 3:** An empirical understanding of community-aided reflection occurring in an online forum: the identification of the types of questions people living with HIV seek support in reflecting on, the health information they share and ask about, and how their community aims to address the questions

This contribution was achieved by answering RQ-3, through an analysis of 200 threads posted in an online forum for people living with HIV.

Healthcare professionals, particularly those focused on HIV, can benefit from this contribution, using it to tailor their care or the informational materials they provide to address the five question types identified. Researchers in PHI can use the above contribution to explore how their target group approaches reflection in an online forum, and how we can scaffold this process. Additionally, developers of PHI systems should consider the importance of community-input for those living with a chronic disease and begin designing features that support end-users in achieving this easily.

**Contribution 4:** A detailed depiction of how reflection occurs when interacting with a prototype that is designed to support community-aided reflection

This contribution is aligned with RQ-4, which was the focus of the Study Three (Chapter 6).

The above contribution will benefit developers of PHI systems, as it highlights the usefulness of viewing representations of personal health information during reflection, and the importance of having access to community input and information for support in reflection. Based on the designs developed for this research study, and the findings of how they were used, developers should be driven to make better and faster progress on the systems they offer, researchers should find new areas to focus upon, and healthcare professionals should be able to identify new aspects of care to target.

## 1.5 Methodology

At first, I [naively] believed my approach to this thesis to be one of 'bricolage' – a selection and application of the methods and systems most appropriate for each question at hand (see Braun & Clarke, 2013, p. 38). I feared that aligning myself with a methodology would mean ignoring my own thoughts and positions and instead committing to someone else's – meaning that this would be a label which dictated the direction I would take. I wanted to allow my interests and

perspectives to form based on what *I* felt, and that committing to a methodology would prevent me from ensuring my analyses were based around listening to what was being said and questioning my perspectives and concepts as a means of finding truth.

My personal position (which I will return to in Chapter 7) was that determining how PHI systems can support people living with HIV in understanding their health was only truly achievable through an involvement of those end-users and giving them a voice in the matter. The problems I sought to understand and learn about were not ones that could be answered through experimentation or quantification. Instead, I needed to understand the world of those living with HIV – what they needed in PHI technologies, what they sought to reflect upon – by indirectly observing their experiences and listening to their thoughts. As such, I chose to take a qualitative and empirical approach to the research. Empirical research is that which aims to understand the world by directly or indirectly observing it (Goodwin & Goodwin, 2016), and qualitative methods are those which seek to understand the thoughts and lives of individuals without placing emphasis on measuring it or quantifying it (Adams, Lunt, & Cairns, 2011). I felt that this approach was not just appropriate, but *required*, as it would entail listening and learning from those living with HIV, rather than making assumptions about what they felt and wanted.

I used thematic analysis for analyzing the data. Thematic analysis, a widely-used analytical approach for qualitative research, is a method for identifying, analysing, and reporting patterns in data in rich detail (Braun & Clarke, 2006). Unlike grounded theory, thematic analysis is not tied to a particular theory, and does not require the researcher to direct their analysis towards developing one (Braun & Clarke, 2006). I felt thematic analysis to be the most appropriate for the research, as its flexibility would allow me to explore the experiences, realities, and thoughts of the participants, and understand what those might mean in the context of PHI. Furthermore, it allows for both an inductive and deductive approach (Braun & Clarke, 2006), allowing me to apply my own pre-conceived concepts as codes, while also allowing the voice of the participants help me question myself and re-work my concepts and develop new ones.

While I did not follow a methodology for the research conducted, I have since reflected on my work and sense of self as a researcher, particularly while re-exploring the world of methodologies and all of the interwoven concepts. This has shown me that my notion of a methodology was incorrect at the start – a methodology does not have to be a 'thing' that you choose that dictates your approach. Instead, a methodology is formed out of smaller positions that describe your interest, perspective on the world, and thoughts towards creating knowledge (Braun & Clarke, 2013; Clough & Nutbrown, 2012). With this new understanding, I recognize that I as a researcher, and the work that I have done, align with the critical realist perspective to viewing the world.

Critical realism was founded by Roy Bhaskar in the 1970s, and has since become widely adopted in qualitative research (Braun & Clarke, 2013). Critical realism describes an ontological position, or a perspective of reality and the degree to which an individual believes it exists separate from human understanding, and the degree to which we can understand reality through research (Braun & Clarke, 2013). On one side is relativism, which takes the perspective that reality cannot be separated from our human intentions or knowledge – our view of reality will always be shaped through our thoughts (Braun & Clarke, 2013). On the other side is realism, which is the view that there is only one true reality which exists and it is not shaped by human intentions or knowledge and can be understood through research – what we observe in research is an active depiction of what is truly happening (Braun & Clarke, 2013).

Critical realism sits between these two positions. Its position is that there is a layer between true reality and what is experienced by people, and this layer influences how we perceive reality, as our knowledge is socially influenced (Roberts, 2014; Braun & Clarke, 2013). For example, the stigma that some people living with HIV feel is real and shapes their experiences with tracking their health information. Or, in other words, that 'our observations and knowledge can never be pure and unmediated, but are relative to our time period and culture' (Mingers, 2006, p. 19). In short – I believe that there is a true reality, but not one that we will ever fully be able to understand, as there are many facets to a human experience that can never fully be comprehended, but that does not mean that what we can observe is not true and real for those who experience it.

## 1.6 Outline of Thesis

The remainder of this thesis is as follows:

### Chapter 2: Background and Related Work

This chapter provides an overview of the literature that shaped this thesis and a detailed background of the multiple concepts focused on. It begins with a description of living with HIV and the need for self-management and self-understanding. Personal Health Informatics is then introduced as an approach to this, alongside the various ways in which it can provide support to those living with a chronic disease. Reflection – the heart of Personal Health Informatics – is then defined, described, and discussed. This is followed by a description of various features included in self-tracking systems that can support reflection. The chapter ends with a summary of the gaps in knowledge that must be answered in order to understand how PHI systems can support people living with HIV in reflecting on their health.

### Chapter 3: The Process of Personal Health Informatics

While several models describe how individuals learn by exploring data, there are none which describe tracking and reflecting on personal health information specifically. This chapter describes a process model specific to PHI, which is built upon other models. This stages included in this process model are later used as a basis for scoping and analyzing the three research studies that followed.

## Chapter 4: Opportunities for Supporting People Living with HIV in Reflecting with Personal Health Informatics

Chapter 4 presents the first research study conducted for this thesis: 16 semi-structured interviews with HIV+ adults in England. This study aimed to understand how people living with HIV go through the process of PHI, and where they faced challenges to reflecting.

## Chapter 5: Community-Aided Reflection in Online Forums

One of the findings from the first study was that people living with HIV often turn to the HIV+ community for aid in reflecting upon, and understanding, their personal health. In order to find out what they sought to reflect upon, and how the community responded in an attempt to address them, 200 online forum threads were scraped from an HIV online community and analyzed.

## Chapter 6: Observing Reflection on Personal Health Information with Simulated Community Responses

The first and second studies indicated that people living with HIV track a wide variety of health-related information, seek the input of their community to reflect and understand their health, yet have no representations of their health information to reflect upon, and rely upon written descriptions in a forum to make sense of. Chapter 6 describes the final study, which focuses on exploring how two different representations of health information that simulated community-aided reflection were used during reflection.

## Chapter 7: Discussion and Conclusion

In this final chapter, the work conducted in the thesis is revisited to discuss the contributions made, transferability of the work, limitations, and possibilities for future research.

# Chapter 2 Background and Related Work

This thesis is focused on Personal Health Informatics, HIV, and reflection. As such, literature on those topics were reviewed. However, what was read extends beyond those key terms, as the literature reviewed was drawn from a variety of academic backgrounds and foci.

PHI is a relatively new, and therefore small, field (as of 10 May, 2018, there were only 14 publications that turn up in the ACM digital library's results when searching "personal health informatics") which meant that a variety of publications related to information-tracking were needed to inform this thesis. The ACM digital library and Google Scholar were used to search for papers containing key terms or titles that contained the phrases "personal informatics," "personal health informatics," "quantified self," "self-tracking," "observations of daily living," and "lived informatics." The papers that turned up in the search results were then reviewed for relevance. As this thesis is *not* focused on changing behaviors or habits, publications focused on persuasive systems or gamification were excluded, unless they provided detail on different methods of tracking or visualizing data. The remaining publications were then examined. The references included in those publications were also explored to find additional research that may be relevant.

However, the publications that informed this thesis did not solely reside in one domain or discipline. Papers describing self-management, self-care, connected health, mHealth, eHealth, and digital health interventions were also reviewed (both in the HCI and medical communities). Understanding HIV was a rather large undertaking, as it was difficult to make sense of medical literature and jargon. Beyond just medical publications, several websites and forums were used to develop both a medical understanding and a perspective of what it means to live with the disease. Both medical and HCI domains were explored to determine what was needed and available for self-management and self-tracking. Research on reflection is relatively light in PHI and PI and had to be supplemented by philosophical and educational literature. As reflection in PHI often occurs with a representation of personal information, publications focused on representations of information and data visualization were reviewed, both in HCI and in the visualization communities.

This chapter presents the context surrounding this thesis, the related work, and the gaps that led to the research. It begins with a section on HIV, in which the medical details of living with HIV are summarized, followed by an overview of the HIV+ population living in the UK, the presence of stigma that surrounds the disease, and how the complexity of the disease and the medication means there is a strong need for self-management and self-understanding for those living with HIV. In the following section, Personal Informatics – of which Personal Health Informatics is a part – is introduced as an approach for self-management and self-understanding, as well as the various process models describing how individuals engage with information to understand or develop new

knowledge. After describing the numerous motivations for engaging in Personal Informatics, how PHI helps those living with long-term conditions is presented. Next, reflection is introduced as the key to developing self-understanding through PHI. After describing the levels of reflection, and the use of information in doing so, different methods of supporting reflection are described. The chapter ends with a description of several features of PHI systems that resulted from a review of 16 existing self-tracking systems, as a means of highlighting how such systems can support reflection.

## 2.1 People Living with HIV

### 2.1.1 The Human Immunodeficiency Virus

The Human Immunodeficiency Virus is an incurable condition caused by a virus that damages the immune system (Terrence Higgins Trust, 2018). If left untreated, HIV weakens the body's natural defense system, leaving it vulnerable and prone to various negative conditions that go beyond the typical symptoms of HIV infection (flu-like symptoms, fatigue, aches, swollen glands). Infections that cause skin sores, bumps in the skin, and diarrhea are harder for the body to fight off. Pneumonia, shingles, and tuberculosis are easily acquired. Nerve damage and inflammation can occur, causing seizures, pain, weakness, eye problems, and balance issues (Figure 1). Cognitive functions may be impaired, leading to memory loss or dementia, and kidney function may be affected from a condition called HIV-associated nephropathy. People living with untreated HIV can typically live for up to a decade before developing AIDS, after which the survival rate is approximately 3 years. (Pietrangelo & Cherney, 2017)
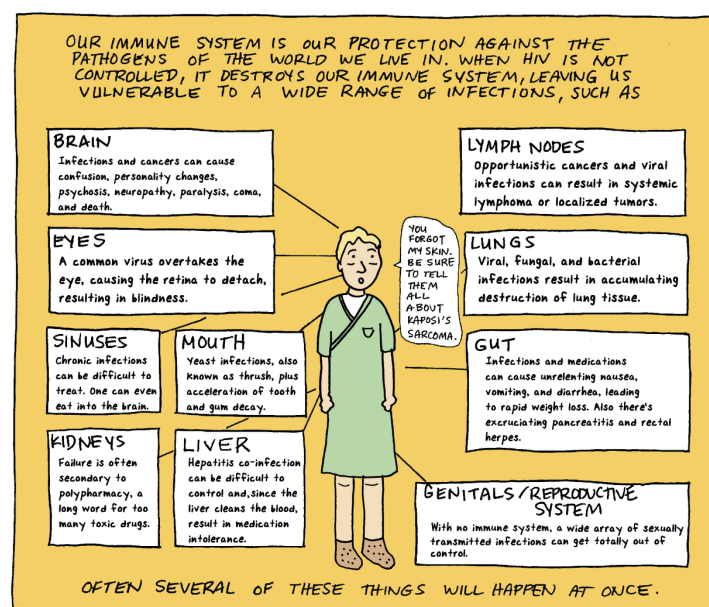


Figure 1: Graphical depiction of the various conditions that come when HIV is not controlled, from (Czerwiec, 2017)

When a person becomes infected with HIV the virus begins to multiply rapidly while also depleting the immune system cells that fight back (known as *CD4* cells). As the amount of virus in the blood (the *viral load*) continues to rise, and the number of CD4 cells continue to drop, the person will begin *seroconverting*, during which time they may experience a wide range of symptoms, from headaches to fatigue or fevers (i-base, 2015). Once seroconversion has occurred, the virus is *detectable*: a lab test will be able to detect the viral load and CD4 count in a small drop of blood (i-base, 2017b).

Each individual, whether HIV+ or not, has their own typical CD4 count; for those who are HIV-, this ranges between 430 and 1690 (i-base, 2017a). A person who has just been diagnosed with HIV will likely see that their viral load is in the thousands or millions, while their CD4 count is in the low hundreds. As time goes on, the viral load will increase and the CD4 count will decrease (Figure 2a). When the CD4 count falls below 200, the person's disease has progressed to AIDS (U.S. Department of Verterans Affairs, n.d.). As such, a person may be living with HIV but not have AIDS, but a person with AIDS is also a person living with HIV.

Until the introduction of antiretroviral medication (*ARVs*) in the 1990s, being diagnosed with HIV was considered a death sentence (Gifford & Groessl, 2002). However, ARVs have changed HIV from a terminal illness to a chronic disease. ARVs fight back against the virus and allow the CD4 cells to replenish, reversing the trajectory that began with seroconversion (Figure 2b). With each lab test, the individual will begin to see their viral load drop and their CD4 count rise. Once the viral load has dropped below the point which the testing systems can detect (for most testing facilities, this is below 50), the viral load is *undetectable* (i-base, 2012). Becoming undetectable is the goal, as it means that the amount of the virus in the body is so small that the disease is untransmittable – this is often referred to as 'U=U' (Figure 3) (i-base, 2017b).



a) After infection, the viral load increases while the CD4 count decreases

b) Following antiretroviral therapy, the viral load often drops to undetectable levels and the CD4 count returns
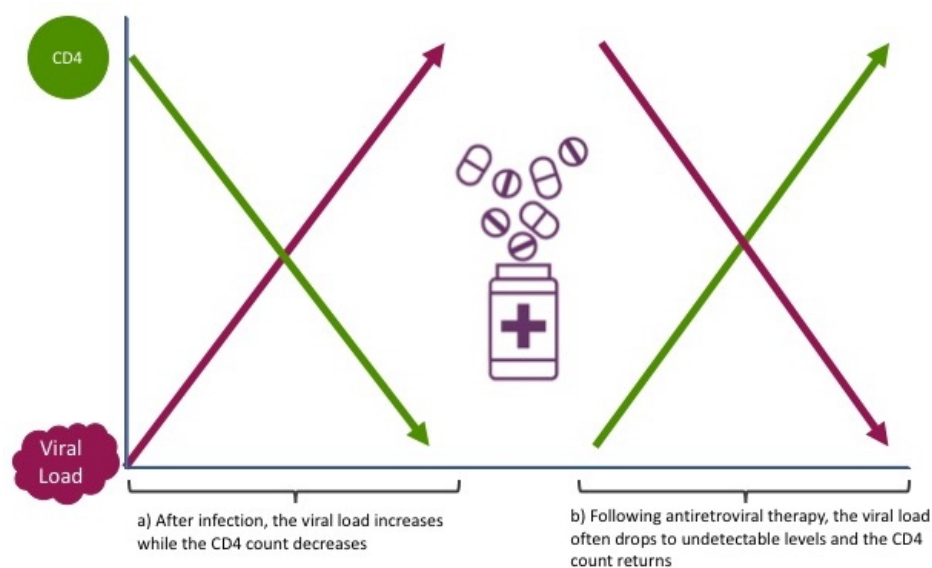
Figure 2: Simplistic depiction of viral load, CD4, and effect of ARV drugs

Figure 3: The U=U logo was shared widely in 2017 to bring awareness to the medical advances in HIV and reduce stigma. Taken from i-base, 2017b

## 2.1.2 People Living with HIV

An estimated 36.7 million people were living with HIV or AIDS in 2016 (World Health Organization, n.d.). While the disease is most predominant in African countries (where 25.6 million people live with the disease), it is spread around the world (World Health Organization, n.d.). There are an estimated 2.4 million living in Europe (Figure 4). In England, 150,726 HIV diagnoses have been documented since 2016 (Public Health England, 2017). In 2016, the overall prevalence of HIV was 2.1 people per 1,000 among people aged between 15 and 74 years of age (Public Health England, 2017).
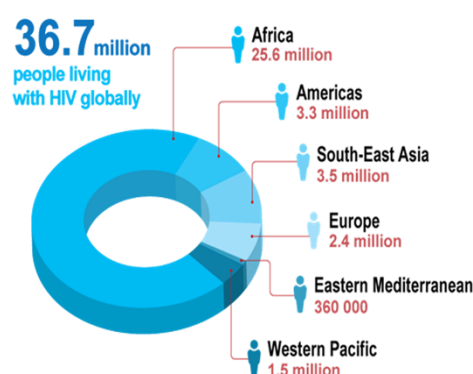


Figure 4: Regional breakdown of estimated numbers of people living with HIV, image taken from WHO data and statistics website on HIV/AIDS (http://www.who.int/hiv/data/en/)

*Demographic Details*

This thesis did not exclusively focus on people living with HIV in England. However, the majority of participants who took part in Study One and Study Three were residing in England, and every individual involved in Study One, Two, and Three spoke English. For this reason, the demographic details described here will be regarding those living with HIV in England, rather than world-wide.

Of those accessing HIV care in England in 2016, 67% identified as male and 33% identified as female. While the actual ages of people living with HIV living in England are not available, Public Health England (PHE) does release the age groups: 15-24 years make up 3%, 25-34 make up 16%, 35-44 make up 32%, 45-54 also make up 32%, 55- 64 make up 11%, and 65+ make up 4% of the adults accessing HIV care in England. (Public Health England, 2017)

Public Health England does not indicate the sexual orientation of those diagnosed, but does indicate the route of probable exposure, and these numbers show that acquiring HIV is not something limited to those who consider themselves to be gay. Of those diagnosed in 2016, more than half (54.4%) were males who were likely exposed through sex with other males. However, this was closely followed by exposure through heterosexual sex (40.9%); with 22.1% of the diagnoses being females and 18.8% being males. Drug use likely led to only 2.5% of the 2016 exposures, and the rest either unknown or falling into other exposure categories (e.g. mother to child or blood products). (Public Health England, 2017)

The ethnicity of those living with HIV in England is also diverse. In 2015, 52% of those living with HIV in England were born in the UK, while 48% were born abroad (Public Health England, 2016). In England, one in seven gay or bisexual men living with HIV are black, Asian, or from another minority group (Public Health England, 2015b). While men who have sex with men (MSM) are still the highest-risk group for HIV, the Black African community is close behind. This ethnic group makes up one-third (33%) of HIV+ adults in England (Public Health England, 2015b), despite constituting just 1.8% of the UK population (National AIDS Trust, 2014).

Capturing a representative sample of the population was not a focus of the research conducted in this PhD. However, collecting input from a diverse group of participants was felt to be important, particularly as research on HIV in countries like the UK tends to focus on men who have sex with men – thus overlooking a large portion of the population of those living with HIV.

*Stigma and Discrimination*

Living with HIV is not simple or straightforward – those living with the virus are still surrounded by a heavy level of stigma. Stigma can cause individuals to adjust their behavior to prevent others from discovering their secret, meaning that it is an important factor to be aware of. It is an

unfortunate truth that HIV has a high level of stigma, both internal (self-stigma) and external (social prejudice) (Elford, Ibrahim, Bukutu, & Anderson, 2008). When a person is stigmatized, they are suffering from socially constructed shaming – often felt more through attitudes than actual negative actions (National AIDS Trust, 2014, pp. 50-55). Still, almost one-third of people living with HIV living in London have been outwardly discriminated against because of their seropositive status, and almost half of these individuals said they experienced discrimination from healthcare workers. For HIV+ gay men and heterosexual black African women, discrimination related to their status is associated with depression and suicidal thoughts (Elford, Ibrahim, Bukutu, & Anderson, 2008).

While discrimination is felt equally by homosexual and heterosexual people living with HIV, stigma is very common amongst black Africans. The stigma related to HIV causes low self-esteem, fear of abuse, and fear of being the topic of gossip in the African community (National AIDS Trust, 2014, pp. 50-55). As a result of this, and previous experiences of family or friends breaching confidentiality by disclosing to others, black African HIV+ individuals feel isolated socially and delay reaching out to support organizations (National AIDS Trust, 2014, pp. 50-55). Additionally, the experience of being discriminated against within the healthcare setting imbues a distrust of health services and, in particular, the ability of those working in the healthcare setting to maintain proper confidentiality (National AIDS Trust, 2014, pp. 50-55).

Fear of being stigmatized or discriminated against will cause a person to change their behavior or make certain choices. While it will effect perceptions on technology, stigma and discrimination must also be kept in mind when reading this thesis - particularly with regards to recruitment and willingness to share experiences or personal health information.

### 2.1.3 Self-Management of HIV

People living with long-term illnesses or chronic diseases self-manage with each health-related decision they make (Bodenheimer, Lorig, Holman, & Grumbach, 2002). Self-management, occasionally referred to as 'self-care', is about the individual's ability to manage the various aspects of their life that are inherent in living with a chronic condition, from the symptoms and treatment, to the physical, psychosocial, and life style changes associated (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002, p. 178). 'Efficacious self-management' occurs when an individual is able to maintain a satisfactory quality of life while monitoring their condition (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002, p. 178). As such, self-management is not limited to the direct treatment or monitoring of a condition: it also includes building knowledge about a condition and its treatment, as well as problem solving to understand, reduce, or withstand the impact the disease holds over mental or physical health (Clark, et al., 1991), including symptoms, side effects caused by medication, and emotional wellbeing.

With ARV medication, people living with HIV are able to enjoy a normal life expectancy, much like others living with chronic illnesses such as diabetes and hypertension (Swendeman, Ingram, & Rotherham-Borus, 2009). Antiretroviral medication regimes are complicated (Nyberg, Patterson, & Williams, 2011): depending on the drug prescribed, a person living with HIV would need to take multiple pills each day, at a specific time, and make sure that they eat/drink certain things two hours beforehand (HealthTalk, 2017). Balancing such an important schedule with daily activities is not easy, which may be why recent research has found that only one-third of HIV+ adults living in the United States are able to successfully manage their health (CDC, 2016).

Medication compliance is an important factor for managing the virus, and frequently the point of focus for clinicians and medical literature, but it is only one aspect of the self-management of living with HIV (Gifford & Groessl, 2002). People living with HIV must be knowledgeable and capable with regards to their symptoms, side effects, and other fluctuations in health as they live and age with the disease (Gifford & Groessl, 2002). Since the transformation from terminal to chronic (Gifford & Groessl, 2002), people living with HIV are growing older, meaning that the demographic profile of the disease is shifting (Tariq, Delpech, & Anderson, 2016). Additionally, ARVs are a relatively new development, which means that there is little understanding about how the disease or the drugs will affect a person's body in the long-term – meaning that literature available to those living or working with HIV are frequently outdated (Huber & Cruz, 2000). Furthermore, ARVs are known to cause a variety of side effects, from nausea to fat redistribution or high cholesterol, and these side effects do not always occur when the individual first begins taking the medication – they may also appear many years later, causing individuals to question the source of a change in their health (HealthTalk, 2017).

For example, an HIV+ woman in her early 40s may suddenly find herself sweating profusely, suffering from poor sleep, and experiencing mood swings. This woman is then left to determine where these changes came from: is this a new condition she has acquired due to her weakened immune system, new side effects of her ARV medication, or – worse – signs that her medication is no longer working and that the virus is re-growing in number? This woman may be confused and concerned about these changes in her health, and may struggle to understand it, only to finally be told that she is experiencing early-onset menopause, which we now know is linked to HIV (Tariq, Delpech, & Anderson, 2016). Thus, self-management of HIV is not simply a matter of taking medication; people living with HIV must understand the various facets of their health and make sense of any changes.

Despite this, there is still little research detailing the self-management needs of people living with HIV beyond that which focuses on medication compliance, clinical attendance, and safe sex (McGowan, et al., 2017). One publication, referencing the mental and physical challenges of living with HIV, urged a call to action for medical researchers and practitioners to look beyond the target

of viral suppression and extend their focus to ensuring those who are virally stable have a good health-related quality of life (Lazarus, et al., 2016). Still, systematic reviews of the few systems designed to support people living with HIV in self-management show that such applications focus almost exclusively on compliance, attendance, and prevention (Daher, et al., 2017; Singh, Gibbs, Estcourt, Sonnenberg, & Blandford, 2017), leaving those living with HIV are on their own to understand their health and manage their disease.

## 2.2 Personal Informatics and Personal Health Informatics

Self-management involves monitoring personal health, managing changes and adhering to treatment, while also living well with a disease and having the skills to adapt and respond to changes as they come (Nunes & Fitzpatrick, 2015). Self-management requires an individual to know themselves, their condition, and their health, and this is often achieved by tracking and reflecting on health information (Fox & Duggan, 2013), which I refer to as Personal Health Informatics. Engaging with Personal Health Informatics has been shown to empower people living with a chronic condition with the ability to better manage, monitor, and understand their condition (Fox & Duggan, 2013). For this to be true, however, PHI systems need to not just support users in tracking their health information, but moreover in *reflecting* on that information.

Personal Health Informatics is a subset of Personal Informatics. Personal Informatics, or PI has been defined as:

> **'an activity where people collect and reflect on personal data to gain a better understanding of their own behavior' (Li, Dey, & Forlizzi, 2011)**

PI is based on the idea that a person who collects data about themselves and reflects on that data will be able to draw insights that develop a deeper understanding of themselves (Choe E. K., Lee, Lee, Pratt, & Kientz, 2014). Personal Informatics has gone by many names, such as: 'quantified self' (Choe E. K., Lee, Lee, Pratt, & Kientz, 2014), 'personal tracking' (Rooksby, Rost, Morrison, & Chalmers, 2014), 'observations of daily living' (Cohen, et al., 2015), 'lifelogging' (Epstein, Cordeiro, Bales, Fogarty, & Munson, 2014), 'self-surveillance,' and 'personal analytics' (Li, Dey, & Forlizzi, 2010).

Personal Informatics involves the collection of, and reflection on, any kind of personal data, while Personal Health Informatics is focused only on personal health data. My definition of Personal Health Informatics was adapted from Li et al. (2010)'s of PI (above) and is as follows:

> **Personal Health Informatics is a process in which a person collects data about their personal health and reflects on it with the intention of gaining a better understanding of themselves or their health.**

PI and PHI are about learning and understanding one's self, meaning that there are two key requirements (illustrated in Table 1) that differentiate them from other tracking purposes (e.g. telehealth, monitoring, etc.). First, it requires that the individual is the one leading the data gathering; that they are the one interested in learning or understanding themselves better. Second, it requires that the individual is the one leading the reflection; they are not relying on a family member, social group, or caretaker to reflect on their information for them – although those others might include their own information, experiences, or expertise in some way to support the individual in reflection. As Boud, Keogh, and Walker wrote of reflection: only the individual can experience, and only the individual can truly reflect on their own experiences (2005). Reflection is a focus on the self (Boyd & Fales, 1983), but can be 'mediated' or 'supported' by others (Herrington & Oliver, 2002).

| | | Gathers Data about Individual: | |
| --- | --- | --- | --- |
| | | Individual | Second Party |
| Reflects on Data about Individual: | Individual | ✓ | ✗ |
| | Second Party | ✗ | ✗ |

Table 1: Personal Informatics only occurs when an individual gathers and reflects upon data about themselves

In this section, details about Personal Informatics will first be reported, beginning with the process models describing how people gain understanding or new knowledge from data. This will be followed by the different motivations that spur people to begin tracking personal information. From there, Personal Health Informatics will be described, alongside the prevalence and importance of tracking and reflecting on health information.

## 2.2.1 Models of Personal Informatics

Several models describing the stages involved in Personal Informatics have been proposed (e.g. Epstein et al., 2016; Rooksby et al., 2014), the most frequently cited is by Li et al (2010). This sub-section provides an overview of various process models describing the how individuals can gain new knowledge or understanding through explorations of tracked data.

Li et al.'s model of Personal Informatics was derived from an analysis of 68 surveys and 11 interviews with individuals who partake in personal informatics. The resulting stage-based model (Figure 5) contains five stages: preparation, collection, integration, reflection, and action.
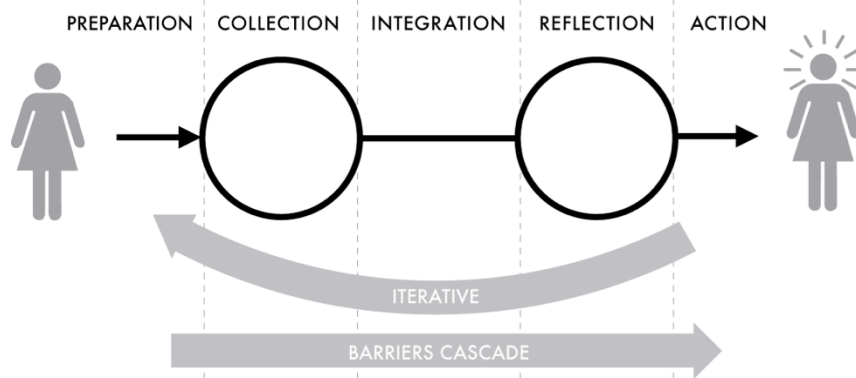
Figure 5: The Stage-Based Model of Personal Informatics Systems. Image from Li et al. (2010)

- The first stage is *Preparation.* During this stage, an individual has formed a motivation for collecting personal information, determines what information they need to collect, and determines how they will collect it.

- The *Collection* stage occurs when the actual information is being collected. The frequency with which collection takes place is dependent on the information being collected, or the system being used to do the collection. While one person might track information several times a day (e.g. food consumption), others might track just a few times each month (e.g. books read).

- Before the information can be reflected upon, *Integration* occurs. In this stage, the collected information is prepared, combined, and transformed into a suitable form for reflection (e.g. visualization). The *Integration* stage might be invisible to the individual, if the system they have selected conducts it for them, or it might involve considerable effort on their behalf if they have to personally prepare their information.

- The next stage, *Reflection*, occurs as the individual looks at, explores, or interacts with their collected personal information. This may occur immediately after capturing the information, or could take place after much more time has passed (days, weeks, or even months).

- The final stage is *Action*, in which the individual determines what action they should take as a result of their reflection and new understanding; taking on new or different actions to see a change in their personal information, or altering their actions to reach a goal. From this stage, the individual returns to *Preparation.*

A similar model of collection and reflection was presented by Cohen et al. (2015). Unlike Li et al.'s, this one was developed as a means of explaining the motivations and barriers that patients go through when collecting information about themselves, which Cohen et al. refer to as 'observations of daily living' (ODL). The authors conducted an analysis of the design documents and focus group transcripts created during five health-related projects with an immersion-

crystallization and cross-case comparison approach. Each of these projects asked participants to collect ODL (via a device, such as smartphone, sensors, or biometric devices) for their own condition or for the individual they were caring for. From their analysis, the authors created a depiction of a four-stage (*Influence, Collection, Increasing Information and Awareness, Changing Outcomes and Behaviors*) process of ODL collection (Figure 6).
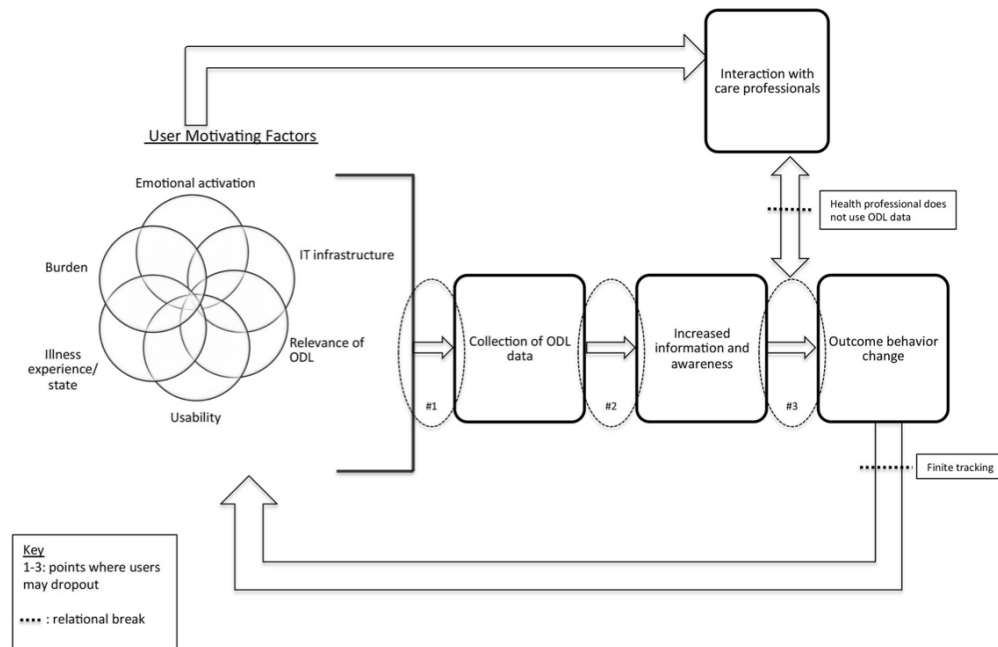


Figure 6: Model of Patient Motivation and Collection of Observations of Daily Living. Image from Cohen et al. (2015)

- On the left side of the model are six influencing factors that motivate a person to collect observations of daily living. Whilst not explicitly stated by the authors, this can be considered the first stage in the process, which I will refer to as *Influence*. As described by Cohen et al., an individual will have an experience (either positive or negative) which then influences them to embark on Personal Informatics. From their research, the authors identified six influences: Emotional activation, Burden, IT infrastructure, Illness experience/state, Usability, and Relevance of data. Depending on the number of negative influences, this stage may result in a failure to progress and successfully transition to *Collection*.

- *Collection* is the time in which a patient develops the desire to collect, determines how he or she can collect the necessary data, and begins to use the system to do so. This stage can map to the *Preparation* and *Collection* stages described by Li et al. (2010).

- Following this is *Increasing Information and Awareness*, in which the individual views their data or visual depictions of their data and potentially gains new information about themselves. This stage maps to the *Reflection* stage Li et al.'s model (2010).

- Finally, the individual enters the stage of *Changing Outcomes and Behaviors*. In this stage, the user is intended to change their behavior based upon what was learnt, mapping to Li et al.'s stage of *Action*.

Both Li et al.'s model, and Cohen et al.'s, end in stages that involve the individual acting on their new understanding of themselves, which suggests that those individuals are actively changing their behavior or habits as a result of tracking and reflecting on their information. However, behavior change is not always the desired outcome; individuals may also decide to track their information out of curiosity or for record-keeping (Rooksby, Rost, Morrison, & Chalmers, 2014). *Lived informatics*, a term coined by Rooksby et al. (2014), refers to the use of personal informatics for purposes that may include, but are not limited to, behavior change. Building on the work of Rooksby et al., Epstein et al. (2015) conducted three surveys of people who tracked their physical activity (n=105), finances (n=99), and location (n=83), as well as 22 interviews to develop a process model of *lived informatics* (Figure 7). It should be noted that the authors did not focus on tracking for health-purposes, and stated that their model might not be representative of the process of tracking for health or chronic conditions.



Figure 7: Process of Lived Informatics. Image from Epstein et al. (2015)

- The process begins with *Deciding*, in which the individual makes the decision to track their personal data whether for behavior change, instrumentation (tracking with the goal to record behavior but not change it), or curiosity. The authors write that each of these three reasons have a different effect on selection, use, and lapsing. The authors found that people focused on behavior change often tracked physical or financial information, instrumentation often tracked location, and curiosity spread across all three.

38

- *Selecting* occurs when the individual selects a tool to use for tracking. The authors note that selecting a tool can range from a very minimal activity (e.g. if someone gives you a tool) to a relatively difficult one (e.g. comparing systems to use). The authors found that recommendations from family/friends are the most common method of tool selection. If the focus was behavior change, individuals tended to select systems that had features supporting their goal. If focused on tracking for instrumentation, individuals sought systems that were popular amongst others or offer the most rewards. For those focused on curiosity, however, selecting a tool was determined by whichever they found interesting (potentially mentioned in the media or from friends).
- *Tracking and Acting* is the ongoing process of *collecting, integrating,* and *reflecting.* Again, the authors write that this stage may be repeated more or less frequently, depending upon the reason for tracking. People focused on behavior change tracked frequently, whilst people focused on instrumental tracking tracked when capture was easy to do (e.g. through wearables, etc.). Meanwhile, curiosity-driven individuals tracked data inconsistently.
- *Lapsing* occurs when an individual ceases to use a tool. Epstein et al. describe four categories of lapses: forgetting, upkeep, skipping, suspending. Some individuals departed from the tracking process at this point, whilst others eventually resumed.
- *Resuming* is what occurs following a short-term lapse

Another way of looking at the process of Personal Informatics is by thinking of it as a scaled-down version of Knowledge Discovery in Databases (KDD). KDD is often referred to as data mining, although that is only one step in the process of knowledge discovery. It is defined as 'the non-trivial process of identifying valid, novel, potentially useful, and ultimately understandable patterns in data' (Fayyad, Piatetsky-Shapiro, & Smyth, 1996). The study of Knowledge Discovery in Databases developed in the late 1980s in response to the growing desire for extracting knowledge from large sets of data and the need for new computational approaches for doing so. Thus, whilst KDD focuses on larger amounts of data and less personal information, it ultimately shares the same intent as personal informatics.

The process of Knowledge Discovery in Databases is similar to the process of Personal Informatics in that both involve the integration, transformation, and interpretation of collected data in the attempt to gain knowledge. Both are iterative, interactive, user-centered processes. The differences between the two are largely regarding the data itself: PI is about an individual tracking their own data, while KDD is about any kind of data. PI can be done with small amounts of data, while KDD typically involves significantly large amounts of data. In PI, people develop new understandings about themselves by reflecting upon the visual representations of their data, in KDD people develop new knowledge about domains by evaluating and interpreting the data

patterns expressed by the computer. Personal Informatics involves more introspective consideration while KDD requires rigorous analysis. (Fayyad, Piatetsky-Shapiro, & Smyth, 1996)

The process of KDD is an interactive one between the user and the data (Fayyad, Piatetsky-Shapiro, & Smyth, 1996). Whilst the authors did not label the steps of the process directly, I will use those terms that appear in the rounded boxes (Figure 8) to identify the steps.
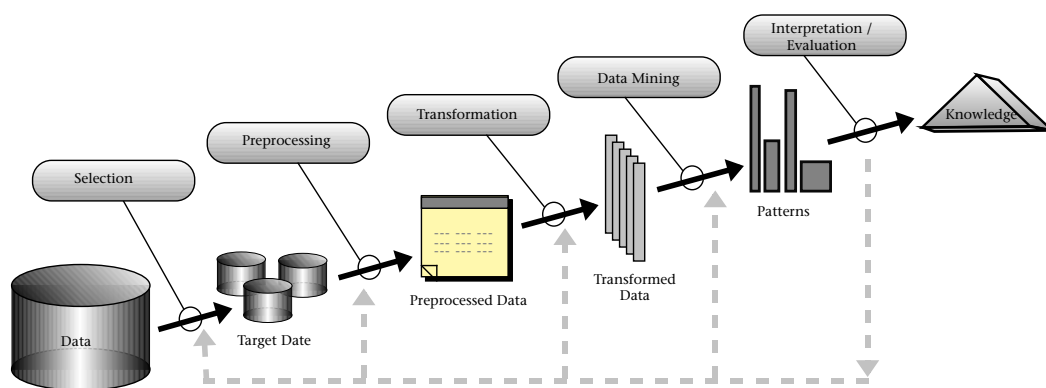


Figure 8: The steps comprising the KDD process. Image from Fayyad et al. (1996).

- The first step is *Selection*, in which the goal or purpose of the KDD process is identified and an understanding of the domain is established. The authors describe two types of goals: *Verification* (in which a user has a hypothesis that is to be verified or proven incorrect) and *Discovery* (in which the goal is to identify new patterns). *Discovery* is broken into two subdivisions: *Prediction* (where the goal is to identify patterns that enable the prediction of future behavior) and *Description* (where new patterns are identified and presented to the user in an understandable form). A desirable set of data or data samples are then selected based upon this goal.

- Following this is *Preprocessing,* in which the data set is cleaned and preprocessed (removal of noise, adjustments for missing data fields, etc.).

- *Transformation* comes next; the data is reduced or transformed to lower the number of variables or identify normal representations of the data.

- The *Data Mining* step begins by selecting which data mining methods best match the goal identified at the beginning of the process. The data is then represented accordingly (with clustering, classification rules, etc.) and interesting patterns are identified.

- At this point, the mined patterns are presented to the user for *Interpretation/Evaluation.* This may include the visualization of the identified patterns or models.

- Finally, the *Knowledge* stage has been reached in which the knowledge that has been discovered is documented or acted upon.

Each of the models discussed above are useful representations approaches to using data to gain a greater understanding, yet none are adequate descriptions of Personal Health Informatics because they emphasize action or change as an outcome, do not describe the iterative cycle, are not focused on health, or – in the case of KDD – are not tailored to personal information in particular. Thus, there is a gap in knowledge regarding what the process of Personal Health Informatics is (see Chapter 3), and how people engage in it (Chapter 4).

## 2.2.2 Purposes for Personal Informatics

There are various purposes for engaging in PI, and these can be understood through the motivations which prompt individuals to begin tracking information, such as those defined in previous research conducted by Choe et al. (2014). An analysis of fifty-two Quantified Self videos conducted by Choe et al. (2014) identified three main motivations (and thirteen sub-categories) for tracking personal information (Table 2).

- The most common motivation, *improving health*, was found to be the motivation in 67% of the videos. Health improvement was found to be a motivation for healthy individuals as well as those with a health condition. For example, one video presentation was focused on a diabetic using personal informatics to track blood glucose levels, while another tracked sleep and exercise activities to find a balanced lifestyle. An example of the sub-categories related to this motivation include *finding triggers*, *achieving a goal*, and *executing a treatment plan*.
- The second motivation identified was *improving other aspects of life*, which included two sub-categories: *finding balance* and *maximizing work performance*. Examples of this motivation include tracking time spent on activities with the aim of maximizing performance, or logging the mood of each day over the course of a year.
- Finally, the third motivation was *finding new life experiences* through personal informatics, which was broken down into four sub-categories (*being mindful, satisfying curiosity, exploring new things,* and *learning something interesting*). The authors write that the individuals with this motivation do not appear to have specific goals but rather tracked data with the idea of discovering new things about themselves or their lives. An interesting example of engaging in PI for this motivation came from a description of a man who tracked his heart rate continuously for one year which allowed him to understand how his body responds to emotions or events. (Choe, Lee, Lee, Pratt, & Kientz, 2014)

There are also variations in the style of interaction between the end-user and their personal data, and these are based on how the end-user collects or reflects on their information (Rooksby, Rost, Morrison, & Chalmers, 2014). In an effort to understand how consumers use existing personal tracking systems, Rooksby et al. (2014) conducted unstructured interviews with 22 participants.

These interviews were transcribed and analyzed thematically, with some pre-determined themes derived from prior research findings. Five different 'styles', which may overlap, were identified: *directive tracking, documentary tracking, diagnostic tracking, collecting rewards,* and *fetishized tracking*. I have drawn connections between the styles identified by Rooksby et al. (2014) and the motivations described by Choe et al. (2014) and mapped the two together, as shown in Table 2, described in the bullet points below. Connecting the motivations for PI, and the style of engaging with PI, can help us understand the perspective of end-users, why they begin tracking, and how they approach it.

| Motivations | Sub-Categories | Directive | Documentary | Diagnostic | Collecting rewards | Fetishized |
|---|---|---|---|---|---|---|
| Improving health | Cure / Manage a condition | | | | X | |
| | Achieve a goal | X | | | X | |
| | Find triggers | | | X | | |
| | Answer a specific question | | | X | | |
| | Identify relationships | | | X | | |
| | Execute a treatment plan | | X | | X | |
| | Make better health decisions | | | X | X | |
| | Find balance | X | | | | |
| Improving other aspects of life | Maximize work performance | X | | X | X | |
| | Be mindful | | X | | | |
| Finding new life experiences | Satisfy curiosity / Have fun | | X | | | X |
| | Explore new things | | X | | X | X |
| | Learn something interesting | | X | | | X |

Table 2: Motivations and Styles of Personal Informatics

- *Directive tracking* - one of the most common styles - is that which is done in reference to a goal (Rooksby et al., 2014). This style of tracking applies best to the motivation of improving health, particularly the sub-category of achieving a goal. With directive tracking for improving health, for example, the end-user might set themselves a goal of losing weight and begin tracking their activity levels and calorie intake, then reflect on their captured data daily to determine if their desired goal has been met.

- The second most common style, *documentary tracking*, is done with the purpose of recording experiences but *not* with the intention of changing behavior (Rooksby et al., 2014). This style maps to the motivation of finding new life experiences, as it is not done with the purpose of change. Here, Rooksby et al. (2014) provide an example of workers tracking their steps to underscore their activity. Documentary tracking and finding a new life experience are about explorations of personal self.

- *Diagnostic tracking*, which is the use of trackers to determine cause and effect, was surprisingly uncommon amongst the individuals in the study conducted by Rooksby et al. This style of tracking is intended for identifying relationships and causal factors, and it maps to several sub-categories; four within improving health, and one within improving other aspects of life. These are: *finding triggers, answering a specific question, identifying relationships, making better health decisions,* and *maximizing work performance*. For example, a person experiencing an upset stomach might start a food diary to determine what was having a negative effect on their digestion.

- *Collecting rewards,* only slightly more popular than *diagnostic tracking*, refers to individuals trying to race others, win badges, or claim prizes by using their trackers (Rooksby et al, 2014). This style is one which often overlaps others, most commonly *documentary tracking* (Rooksby et al., 2014). However, *collecting rewards* does have an emphasis on meeting goals or challenges in order to receive rewards. As such, it maps across all three motivations. An example of this style could be an individual tracking their steps each day, striving to do more than 10,000 to be awarded a badge in their tracking app.

- Finally, the fifth style is *fetishized tracking*, which refers to those individuals who either collect data without a clear purpose, or wear trackers for the aesthetic (Rooksby et al., 2014). This style most clearly relates to the motivation of finding new life experiences, particularly the sub-categories of being mindful, satisfying curiosity/having fun, and exploring new things. One example of fetishized tracking may be an individual who records every cup of coffee drank over a year, just out of curiosity.

The uses of Personal Informatics can be explained through motivation, as shown by Choe et al. (2014), and understood through the style of collection and reflection, as shown by Rooksby et al. (2014). Choe et al.'s work was focused on experts ('quantified self-ers'), while Rooksby et al.'s was a self-selecting group of participants. Thus, the motivations and styles described in these two publications may not provide a complete picture of how typical users approach personal informatics – there may be additional motivations or styles that are not yet accounted for. However, by drawing connections between the two, as above, a foundation is formed which allows us to better understand the perspective of the end-user.

### 2.2.3 Personal Health Informatics

**Personal Health Informatics is a process in which a person collects data about their personal health and reflects on it with the intention of gaining a better understanding of themselves or of their health.**

My definition of PHI (above) is intended to frame Personal Health Informatics as a process that involves tracking and reflecting on health information. While there are process models describing PI, there are none describing PHI (see Chapter 3 for more detail).

The most common motivation for tracking and reflecting on personal information is for health purposes (Choe, Lee, Lee, Pratt, & Kientz, 2014). In the USA, the majority of the adult population (69%) tracks at least one aspect related to their health (Fox & Duggan, 2013). Whilst some of these individuals track using medical devices, many others are using consumer-available systems such as wearables or smartphone applications. Personal health information is tracked by both those who are healthy and those who are ill; given this, there are likely to be different intentions that drive people to embark on PHI.

Many people living with a long-term health condition seek to understand or make sense of their health through Personal Health Informatics as a means of effective self-management (Mamykina, Smaldone, & Bakken, 2015). However, health conditions fluctuate over time, meaning that an individual may be experiencing stable, under-control health one day, and then find themselves confused and uncertain about how to deal with a new symptom another day (Owen, Pearson, Thimbleby, & Buchanan, 2015; Mamykina, Smaldone, & Bakken, 2015). What people living with such conditions seek to understand from tracking is linked to their current state of living with the disease (Mamykina, Mynatt, Davidson, & Greenblatt, 2008; Owen, Pearson, Thimbleby, & Buchanan, 2015; O'Kane & Mentis, 2012), meaning that reflecting on tracked information can be done at different times to develop different understandings.

Recent reviews of digital systems aimed at people living with HIV have shown an overwhelming focus on tracking clinical attendance, ARV adherence, and preventative behaviors (Daher, et al., 2017; Pellowski & Kalichman, 2012). The vast majority of these systems are not truly Personal Health Informatics ones, but mHealth systems designed to be connected to clinical systems (Daher, et al., 2017) or used for delivering interventions (Pellowski & Kalichman, 2012). In addition, research on the use of mHealth systems to support people living with HIV has largely focused on low and middle-income countries, leaving those living in high-income countries like the UK under-researched and under-served (Schnall, Bakken, Rojas, Travers, & Carballo-Dieguez, 2015).

Tracking symptoms or health indicators is very common amongst those living with one or more long-term health conditions (Fox & Duggan, 2013). Of those living with a chronic disease in the United States, one in five uses some sort of Personal Health Informatics tool, such as a smartphone application or medical device (Fox & Duggan, 2013). The healthcare industry has endorsed the use of self-tracking systems for those who are chronically ill, even providing links to various PHI applications on patient-facing websites (e.g. https://apps.beta.nhs.uk). By encouraging patients to track their health information at home, the healthcare industry hopes that

the role of the patient will be transformed from a receiver of care to an engaged participant in the decision-making process (Alzougool, Chang, & Gray, 2008). Indeed, tracking personal health information can affect a person's overall approach to health, empowering them with the ability to better manage and monitor their disorder or disease (Fox & Duggan, 2013).

To date, there are few examples of PHI systems designed specifically for people living with HIV in a high-income country like England. One, a website called myHIV, was developed by the Terrence Higgins Trust (THT) charity (Terrence Higgins Trust, 2018), while the other, a mobile phone application called BeYou+, was developed by a team of clinicians (CW+, 2018).

THT, a charity organization providing HIV and sexual health services across the UK, developed an online tool for people living with HIV. This tool, myHIV, provides people living with HIV in the UK with free access to online counselling, online advice, and community forums. In addition, it offers users access to free tools intended to help them manage their HIV and improve their health and wellbeing. Users can set up medication and appointment reminders that are sent to them by email, and log their lab results (see example in Figure 9). myHIV also includes a digital notebook in which users can jot down notes to self, questions for their consultant, or write about a side effect they experienced (see example in Figure 10). (Terrence Higgins Trust, 2018) While this allows users to note down their side effects with the tool, it does not provide them with visualizations of these side effects or how they have changed over time.
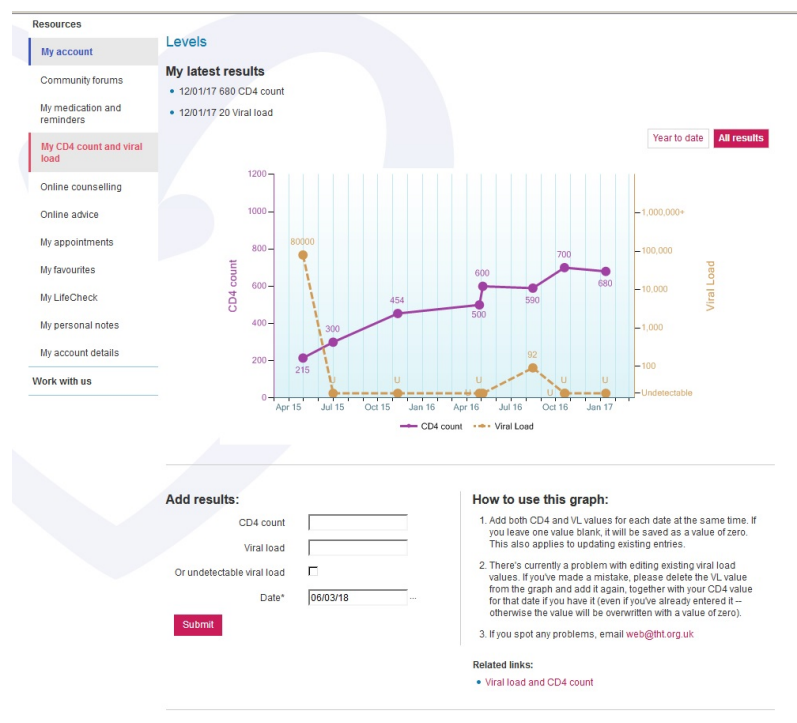


Figure 9: Example of CD4 and Viral Load graph on myHIV website
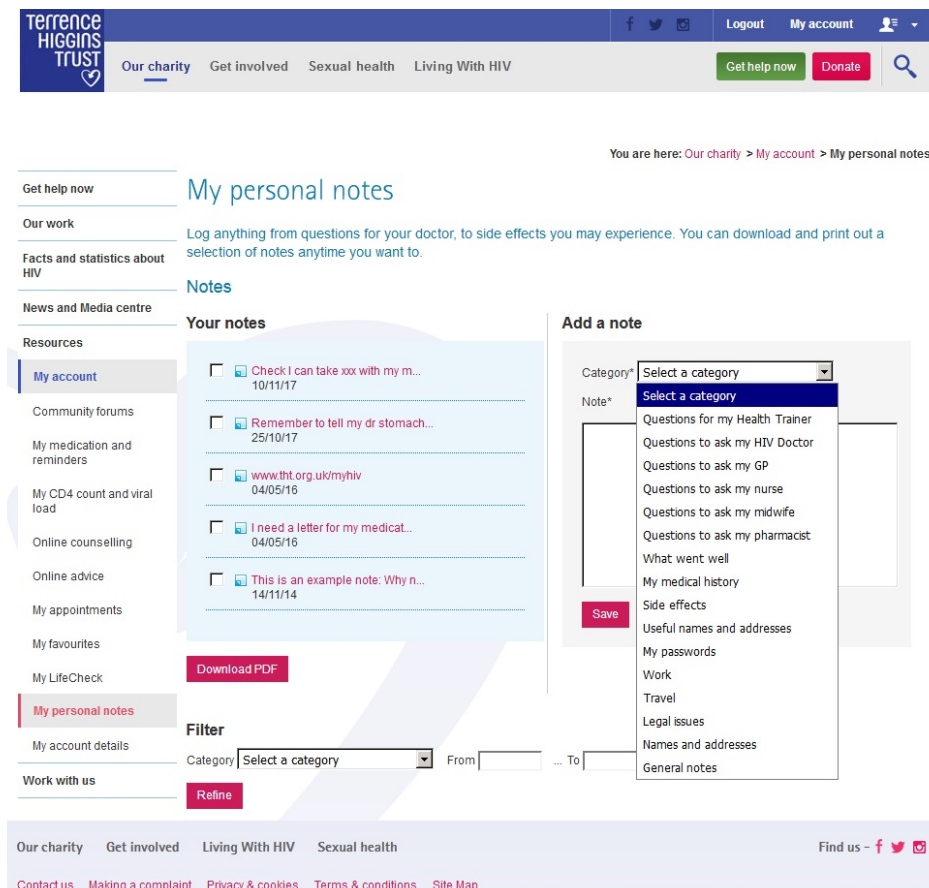
Figure 10: Example of digital notebook used to track questions and concerns on myHIV website

BeYou+, a mobile phone application, was developed by HIV experts at the Chelsea and Westminster Hospital in London. BeYou+ provides users with a wealth of information about living with HIV, but also provides users with the ability to track their lab results, prescriptions, clinicians, and appointments. Users are also able to set goals and track progress (Figure 11, left). Additionally, the app provides users with a visualization of their lab results over time (Figure 11, right). (CW+, 2018) However, this application does not facilitate its users in tracking any other personal health information.
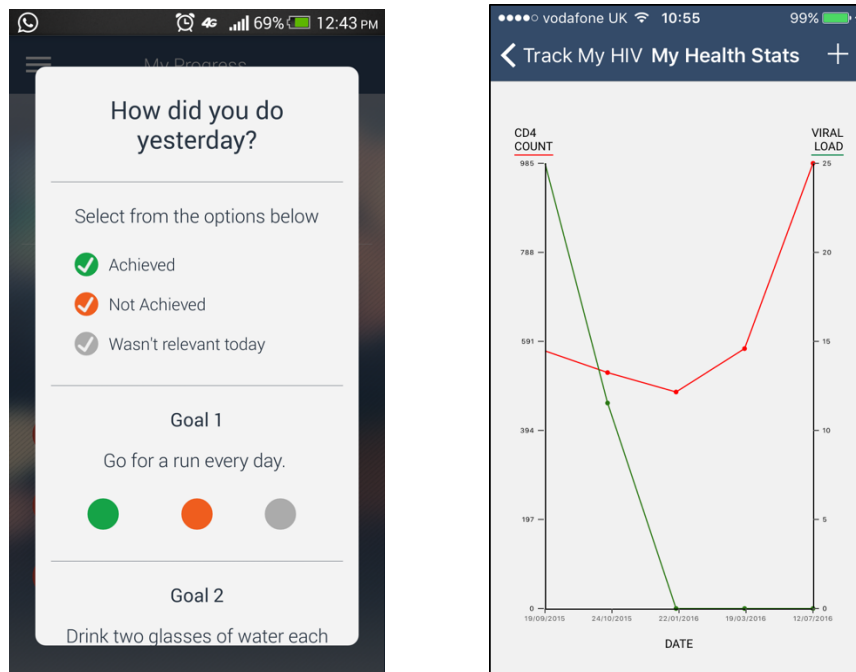
Figure 11: Example of goal-tracking (left) and lab results (right) with BeYou+

People living with HIV need systems tailored to their disease in order to support them in reflecting on their information as way of self-understanding and self-managing (Schnall, Bakken, Rojas, Travers, & Carballo-Dieguez, 2015). Designs of PHI applications, regardless of the target demographic, must first and foremost take into account the needs and desires of the end users, *not* the medical perspective of what indicates good health or a compliant patient. Research in the medical industry has recently shown that people living with HIV wish to track more than just their lab results and appointments (Schnall, Bakken, Rojas, Travers, & Carballo-Dieguez, 2015). In order to support people living with HIV in understanding their health for self-management, we must support them in reflection.

In order to support people living with HIV in reflection through PHI, we must understand what is needed from a PHI system - it must be suited for the purposes of those who will use it. PHI systems may suffer from lack of adoption if they are not suitable for collecting the desired data (Cohen, et al., 2015), or collect data considered irrelevant (Owen, Pearson, Thimbleby, & Buchanan, 2015). Additionally, potential users may avoid selecting systems which they feel stigmatize them or make them look ill (O'Kane, Rogers, & Blandford, 2015). A tool may be abandoned if it requires too much effort in capturing data (Cohen, et al., 2015), or if a user no longer feels it is interesting or necessary (e.g. Cohen et al., 2015; Owen et al., 2015). Even if a tool is adopted and used, there are still barriers to reflection and, thus, developing an understanding. Poor representations of captured data, the inability to combine multiple types of data, or graph literacy all create obstacles for reflection (Faisal, Blandford, & Potts, 2012; Whooley, Ploderer, & Gray, 2014; Mamykina, Mynatt, & Kaufman, 2006).

There has been no work that focuses on self-tracking a complex and stigmatized chronic disease, such as HIV, or what considerations need to be taken to support them in reflecting on their health information. Unfortunately, the answer to this is not simply a matter of transferring findings from PHI research on other conditions: research on self-tracking has focused largely on conducting evaluations – testing out different methods of capturing data or representation styles (Rooksby, Rost, Morrison, & Chalmers, 2014) rather than investigating how to support reflection on the information that has been captured (Mamykina, Smaldone, & Bakken, 2015). In order to support people living with HIV in reflection through PHI, a closer inspection is required – one that begins with the intended user (Mamykina, Mynatt, & Kaufman, 2006).

## 2.3 Reflection

From the start, reflection was placed at the heart of Personal Informatics (see Li et al.'s (2010) definition of Personal Informatics): simply tracking information or having it available is not enough to gain understanding or new knowledge (Baumer, 2015).  Thus, reflection is at the heart of Personal Health Informatics as well.

Recently, however, much more emphasis has been placed on the role of reflection in self-management (e.g. Kendall, Morris, & Tan, 2015; Mamykina, Smaldone, & Bakken, 2015; Owen, Pearson, Thimbleby, & Buchanan, 2015). Arguing that the self-management of health involves not one-off decision making, but rather repeated attempts at problem-solving, understanding, and making sense of situations, Mamykina et al. wrote that reflection is an integral part to self-managing chronic disease (2015). Because of this, it is imperative that PHI systems adequately support reflection.

Reflection is an approach through which individuals seek to understand or explain something (Baumer, 2015). Reflection is an intentional act, a response to a feeling of discomfort and the need to generate new knowledge or understanding (Atkins & Murphy, 1993; Boud, Keogh, & Walker, 2005). Reflection has been defined in many ways, likely a result of the various communities within which it is researched (Baumer, 2015). For example, it has been described as the process of creating and clarifying what experiences mean personally, or in relation to the world (Boyd & Fales, 1983), and also as the act of reviewing previous experiences or events and putting them together in a way that forms a better understanding (Baumer et al., 2014). My definition of reflection, below, is based on descriptions by Atkins and Murphy (1993), and Boud, Keogh, and Walker (2005):

> **Reflection occurs when an individual examines or explores their own experiences, situations, or knowledge, processing that information and relating it to their previous knowledge with the intention of generating new knowledge or understanding about themselves.**

In academia, reflection is a term often used to describe the act of looking back upon personal data to understand something: to develop new knowledge (Boud, Keogh, &Walker, 2005), gather a status update (Li, Dey, & Forlizzi, 2011), or remember something (Baumer et al., 2014). Thus, reflection does not necessarily result in a change of perspective or new knowledge (Atkins & Murphy, 1993). Reflection is sometimes referred to as sensemaking, particularly when referring to instances that are central to forming and changing perspectives (Boyd & Fales, 1983) or involving a more cognitively effortful act (Weick, Sutcliffe, & Obstfeld, 2005). Sensemaking, in particular, is about knowledge management and how people make sense out of the world (Dervin, 1998). In this thesis, the term *reflection* is used primarily, with the exception of when referring to research or concepts that describe *sensemaking* explicitly.

The notion of reflection dates back to the time of Aristotle, with the term itself arising out of a need for describing how students process information received in relation to their prior knowledge to form a new understanding (Boud, Keogh, & Walker, 2005). Thus, the roots of reflection lie in philosophy, most notably in the interests of Dewey, Schön, Habermas, and Moon, who sought to understand how humans view reality, form understandings, and change perspectives (Boyd & Fales, 1983; Baumer et al., 2014; Atkins & Murphy, 1993). Now, reflection is a key focus not just in education, but also in design, healthcare, personal informatics (Baumer et al., 2014). Sensemaking, in particular, has been a focus of data analysis (e.g. Pirolli & Card, 2005) and software de-bugging (e.g. Grigoreanu, et al., 2012). Given that the work on reflection in PI and PHI is relatively new, and often includes limited discussions of reflection (as argued by Baumer et al., 2014), literature from these various areas were reviewed and used to inform concepts in this thesis.

### 2.3.1 How Reflection Occurs

In order to support reflection, we must understand how it works. As with the multiple definitions of reflection, there are many descriptions of *how* reflection occurs, and each of these come from a different approach. However, these descriptions are often quite similar, differing mainly through terminology, level of detail, and hierarchical order (Atkins & Murphy, 1993). This sub-section will first describe how pieces of information are used while reflecting, as depicted in Pirolli and Card's (2005) model of sensemaking. This will be followed by Fleck and Fitzpatrick's HCI-specific definition of reflective levels (2010) that describe the different levels of reflective thought. Through these, we can develop a holistic understanding of the structure of reflection from an informational and cognitive perspective.

A process model (Figure 12) was developed by Pirolli and Card to describe sensemaking (2005). This model was developed through a cognitive task analysis of expert intelligence analysts and describes the phases of making sense of information through both a bottom-up process (where an idea is formed from the data) and a top-down process (where the data is used to test or confirm a theory) (Pirolli & Card, 2005). The phases (which will be described here through the order in the bottom-up process) detail the actions of the individual through how they interact with the data. In the visual model, the collections of data are depicted in boxes, while the actions of the individual are depicted in circles overlaid on arrows:

- Search and filter: In this stage, an individual will search external sources of information (Box 1) for data, then filter the results of those searches based on perceived relevance to what they are trying to understand. The results deemed relevant are placed together in a 'shoebox' (Box 4).
- Read and extract: The evidence in the shoebox is read to extract pieces of evidence that could be useful for drawing inferences or developing a theory. The relevant snippets are then placed in an 'evidence file' (Box 7).
- Schematize: With the evidence collected, the individual can begin re-representing it, organizing it in various ways to create schemas (Box 10).
- Build case: The individual will build a theory or a case from the schemas, using them to provide evidence that supports or disconfirms it (Box 13)
- Tell a story: The hypothesis or theory is described in a manner that can be presented and understood by an audience (Box 16)
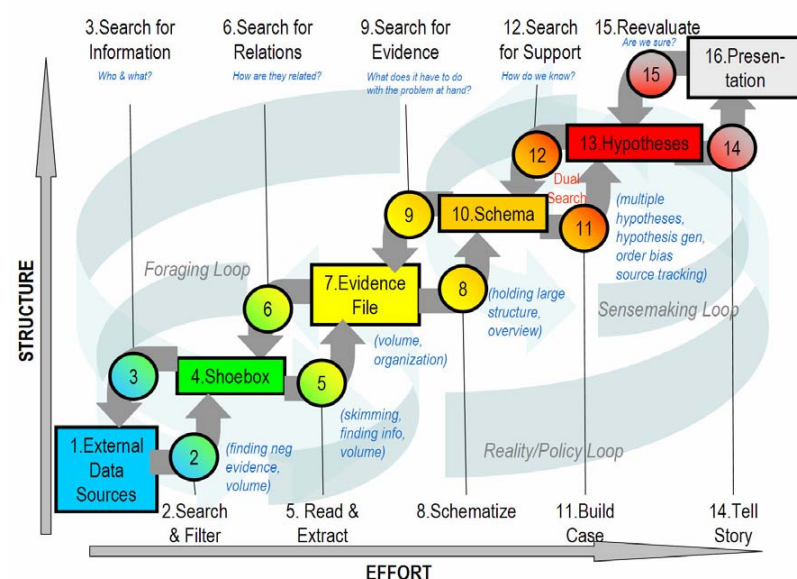


Figure 12: The model of sensemaking defined by Pirolli and Card (2005)

Pirolli and Card's model describes how pieces of information are used throughout the sensemaking process, and this can be used to view how end-users of PHI systems use their information to reflect and understand their health. However, this process only works when individuals have access to the right information. In order to support them in reflecting or making sense of their health information, we must first support them in capturing the correct data.

*Levels of Reflection*

There are levels of reflective thought that an individual may go through when reflecting, and they may not always achieve the highest level. Fleck and Fitzpatrick (2010) conducted their own review of reflection, with the intention of relating it to HCI. From their synthesis of the literature, five levels of reflection emerged:

- *R0 Description: Revisiting*
  R0 is non-reflective thought, it occurs when an individual describes or provides a statement about events that have occurred, but does not reflect on them.
- *R1 Reflective Description: Revisiting with Explanation*
  This level occurs when explanations, justifications, or reasons are included in descriptions of past events. However, this stage involves only limited analysis and does not involve the exploration of alternative reasons/explanations, or exploring different perspectives.
- *R2 Dialogic Reflection: Exploring Relationships*
  Level R2 involves more thought than the previous levels. During this level, relationships are sought between experiences or knowledge, and there is evidence of interpreting, questioning, and considering different possibilities or points of view.
- *R3 Transformative Reflection: Fundamental Change*
  In R3, an individual will re-visit an event or prior knowledge with the intention of re-organizing and/or doing something differently. Asking fundamental questions and challenging personal assumptions is evidence of this level. Unlike R0 and R1, this level can result in a change in knowledge or action.
- *R4 Critical Reflection: Wider Implications*
  Building on the previous levels, R4 involves a consideration of social and ethical issues, a consideration of the wider picture. Fleck and Fitzpatrick note that this level of reflection is rare.

Fleck and Fitzpatrick's framework of reflection has been used by researchers to describe and examine the quality of reflection individuals achieve (e.g. Choe E. K., Lee, Zhu, Riche, & Baur, 2017). However, simply providing access to data neither guarantees that reflection occurs, nor that a high level of reflection will be achieved (Slovak, Frauenberger, & Fitzpatrick, 2017). While some authors argue that reflection needs to be triggered (Isaacs, et al., 2013; Slovak,

Frauenberger, & Fitzpatrick, 2017), others focus on how it can be supported (Li, Dey, & Forlizzi, 2012; Rivera-Pelayo, Zacharias, Muller, & Braun, 2012; Owen, Pearson, Thimbleby, & Buchanan, 2015).

## 2.3.2 The social side of reflection

Reflection occurs when an individual examines their own information or experiences, processes that information and relates it to their previous knowledge with the intention of generating new knowledge or understanding about themselves (Atkins & Murphy, 1993; Boud, Keogh, & Walker, 2005) (depicted in Figure 13). An individual cannot reflect on information that they have not personally experienced (Boud, Keogh, & Walker, 2005), but this does not mean that reflection is not social (Kemmis, 2005; Puussaar, Clear, & Wright, 2017).
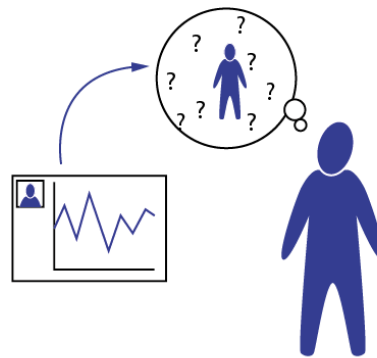


Figure 13: An individual reflecting alone with a visualization of their data

There are different ways in which reflection can be social, and each of these have a different reason for including others in their self-reflection: individuals might learn how to reflect on their own information by exploring another person's data ('shared reflection'), by actively involving others in their reflective process ('social reflection'), or – as recent research has begun to explore - an individual may use the experiences or information of others to reflect on their own information ('community-aided reflection'). Many current tools used for tracking information are designed for individual use, not supporting the sharing and viewing information of others that is required for social reflection (Nunes & Fitzpatrick, 2015).

*Shared reflection*

Some researchers argue that individuals need to learn how to reflect, and can do so through something called 'shared reflection' (Graham, Tang, & Neustaedter, 2016). The idea behind this is drawn from the educational perspective of learning through teaching: individual learns how to reflect on their own information by considering the information of others (Graham, Tang, & Neustaedter, 2016). Shared reflection is tool-agnostic, it requires only that (1) two individuals swap their tracked data, (2) reflect on the other person's data by writing feedback from their perspective,

and then (3) swap back to reflect on the feedback they received (depicted in Figure 14). While this process could be entirely supported by a tool, there are no existing ones that do so at this point.
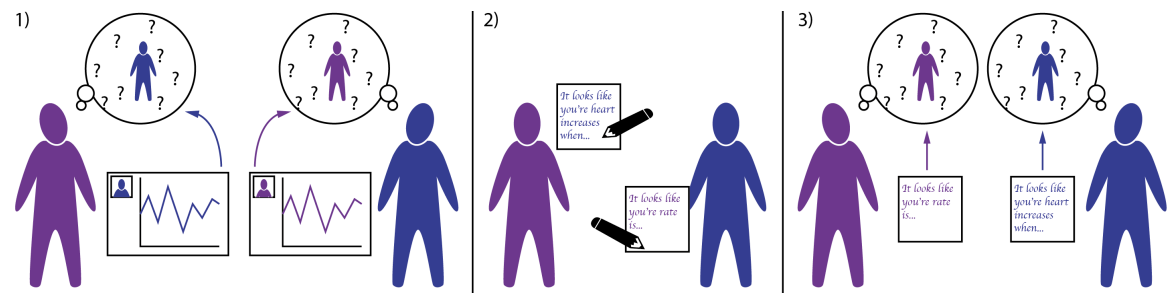


Figure 14: Process of shared reflection

*Social reflection*

'Social reflection,' is focused on scaffolding the process of reflection. Researchers have argued that allowing an individual to access and explore their data is insufficient to support reflection (Mamykina L. , Mynatt, Davidson, & Greenblatt, 2008) and that reflection needs to be scaffolded by in-the-moment support from mentors or more experienced individuals (Slovak, Frauenberger, & Fitzpatrick, 2017). Thus, social reflection occurs when an individual reflects on their experiences or knowledge, accompanied by another individual (typically a mentor or someone more experienced) who attempts to progress the reflection with questions and comments (Fleck, 2012). An example of this can be found in the MAHI system (Mamykina L. , Mynatt, Davidson, & Greenblatt, 2008), which monitors the health of newly-diagnosed diabetics and enables discussions between them and diabetes educators who help them understand the information that has been tracked (Figure 25).
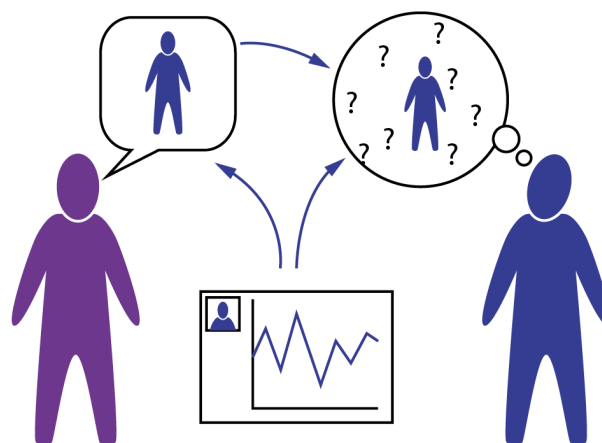


Figure 15: Depiction of social reflection

Tools that support this are often designed to connect patients with their carers or healthcare professionals (Puussaar, Clear, & Wright, 2017; Nunes & Fitzpatrick, 2015). These provide a

unidirectional flow of information sharing, where others (carers/providers) can view the data tracked by another individual, but not share their own information. MAHI is an example of connecting newly-diagnosed individuals with educators, but other examples include sharing 'patient' information with carers (e.g. Nightscout (Kaziunas, Ackerman, & Lindtner, 2017)) and medical professionals (e.g. Monarca (Frost, Doryab, Faurholt-Jepsen, Kessing, & Bardram, 2013)).

Some tracking technologies intended to help users manage chronic conditions facilitate a unidirectional sharing of information, where others can view the data of an individual, but cannot share their own. Often, these connect 'patients' with their carers (e.g. Kaziunas, Ackerman, & Lindtner's Nightscout tool, described in a 2017 publication), healthcare professionals (e.g. Frost et al.'s Monarca in a 2013 paper), or health educators (e.g. Mamykina et al.'s MAHI, published in 2008). While carers and professionals may have knowledge and experiences with the chronic disease being tracked, they do not have the experience of actually living with the condition that community-members do.

*Community-aided reflection*

The third type is community-aided reflection. Community-aided reflection has been researched in the education community, but has also been highlighted recently with regards to health and chronic conditions. My definition of community-aided reflection is based on the writings of Atkins & Murphy (1993), Boud et al. (2005), Harrington & Oliver (2002), and Kemmis (2005):

> **Community-aided reflection occurs when an individual reflects upon his or her personal health information alongside the knowledge, experiences, or health information of others who are similar, as a means for generating new knowledge or understanding about his or herself.**

Community-aided reflection occurs when individuals connect with their peers to discuss their experiences and reflect on them (Nicholson & Bond, 2003). Research in the education field showed that teachers in training would turn to an online forum populated by their peers to reflect on their day and seek input or advice for how they might improve. Their peers, in turn, would respond with their own experiences, comments, or suggestions, as a means of supporting them and helping them understand where they could make changes (Nicholson & Bond, 2003).

Recently, the use of online forums for understanding health information has been revealed, though not in any great detail. Research has shown that individuals turn to online communities and forums for social support regarding their health or health behavior (e.g. Paay, Kjeldskov, Skov, Lichon, & Rasmussen, 2015; Mo & Coulson, 2008). For example, a recent investigation of the online information-seeking behavior of people with diabetes or chronic migraines showed that individuals often wanted to determine whether their personal health information was typical, or 'normal,' for

someone with that condition, and sought input from others to try to understand their health information (O'Kane, Park, Mentis, Blandford, & Chen, 2016).

Such research has provided little further details on community-aided reflection, how to support it, nor how it might be involved with PHI. However, we can deduce how it might currently take place (Figure 16). First, an individual may reflect on his or her tracked data and realize that they would like the aid of their community in reflecting upon it. Then, they turn to an online forum and re-enter their tracked data, as well as their question, seeking input from other forum users. Those users, in turn, respond on the forum by entering their own tracked data and comments (seen in the second panel of Figure 16). Finally, the individual reflects on their question and information, considering both their tracked data and the community's input in conjunction.
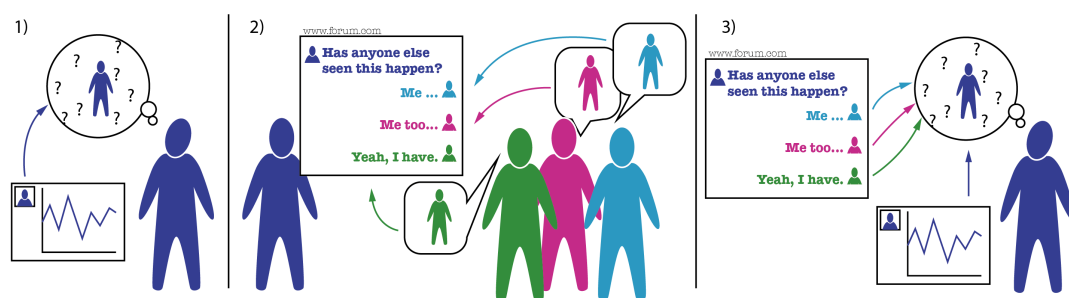


Figure 16: Current state of community-aided reflection

Many current PHI systems are designed with the intention of supporting individual use and individual reflection, these systems rarely support users in sharing and viewing the information of others (Nunes & Fitzpatrick, 2015) – two of the key aspects of community-aided reflection. Even more rare are PHI systems which allow users to both share data *and* converse with the community in the same visual space; this functionality is largely left to be conducted in online health forums (Nunes & Fitzpatrick, 2015; Puussaar, Clear, & Wright, 2017).

Those technologies which do enable two-directional sharing of information amongst community-members are rarely focused on chronic diseases, but do support tracking of more general information related to health. However, these are nearly always designed to promote competition or motivation  (Kersten - van Dijk & Ijsselsteijn, 2016) by allowing users to compare summaries of their tracked data with others as a means of spurring competition, goal setting, and behavior change. One example of this is VERA, an application that allows individuals to share their health decisions and thoughts with others through photographs and notes (Figure 17, right), which other users of the app can comment on (Baumer et al., 2013). Another example is Citizense Makers (Figure 17, left), which allows users to view and compare their heart rate and step-count with others in their workplace environment (Puussaar, Clear, & Wright, 2017).
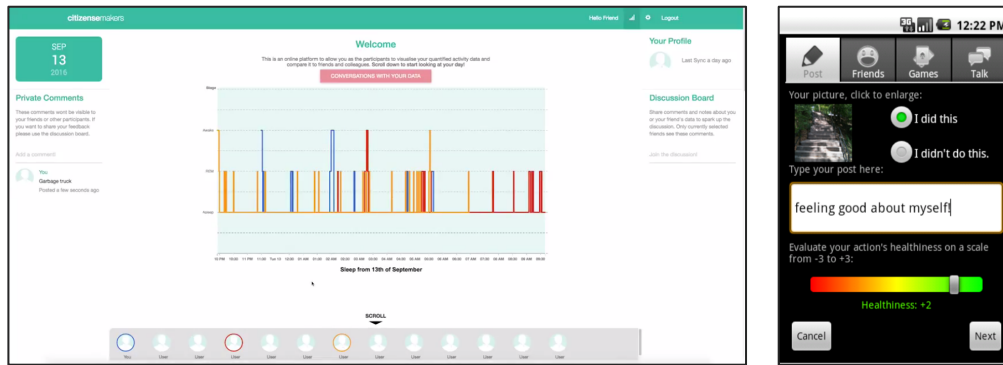
Figure 17: Citizense Makers (left) screenshot taken from https://citizensemakers.co.uk/ and VERA (right) screenshot taken from Baumer et al. (2013)

At this current point in time, there appears to be only one tool which supports individuals with tracking their health information and viewing the health information of others for the purposes of self-management and self-understanding: PatientsLikeMe. PatientsLikeMe is a website where individuals, often living with one or more health conditions, can keep track of various health-related information (e.g. medication, side effects, mood, symptoms). Users of this website (referred to as 'patients') are provided with graphs of their tracked health data (Figure 18), which they can use to reflect upon their past experiences. Users can also write journal entries and rate how they are feeling (Figure 19). Both the tracked information and journal entries are readily available to be viewed by other users of the website, and the journal entries may be commented on.
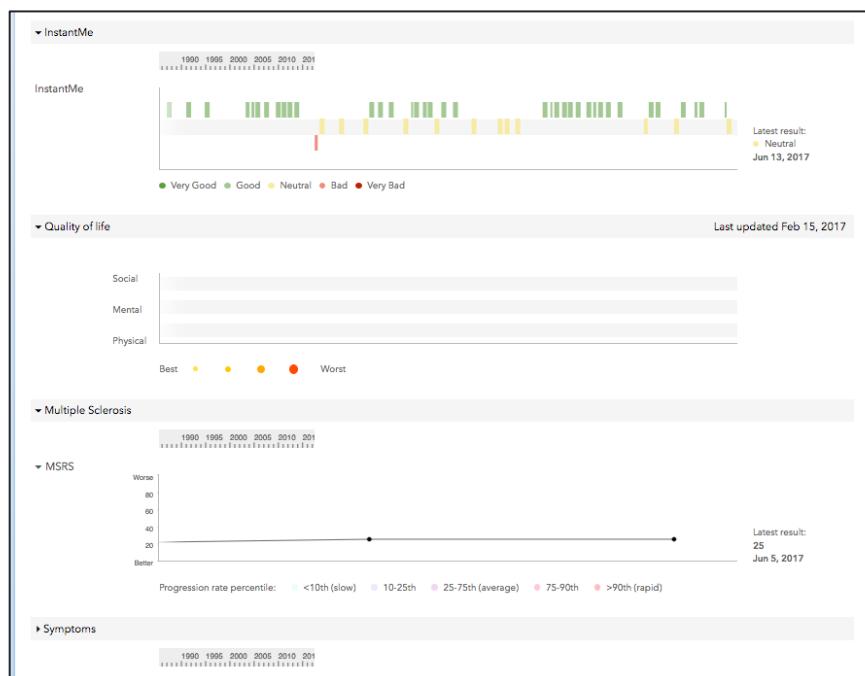


Figure 18: Example of representations of tracked data on a PatientsLikeMe user page
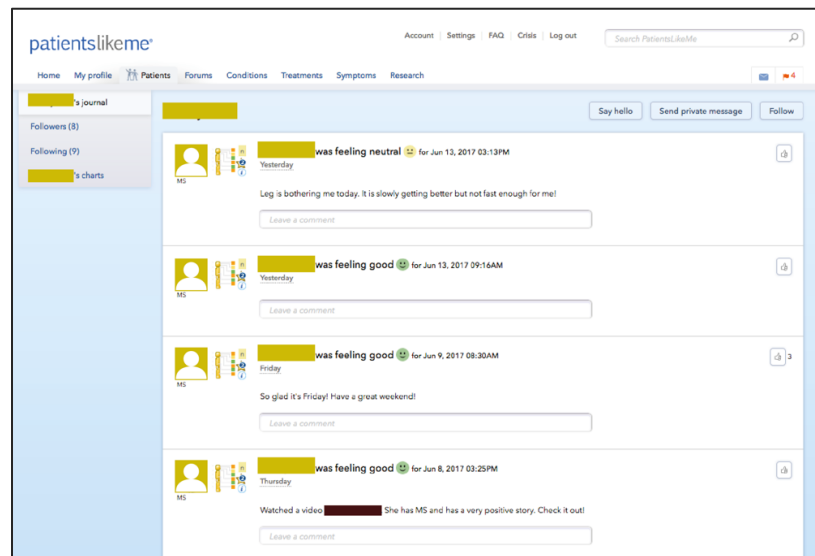
Figure 19: Users of PatientsLikeMe can write journal entries, as well as view and comment on the entries of others

Research has shown that users of the website do refer to the information of others, and ask them questions, as a means of informing their own personal care (Frost & Massagli, 2008). However, users of PatientsLikeMe cannot view their health information and the health information of another user simultaneously in a shared representation. Additionally, if a user has a question about their personal health information, they must ask it in the PatientsLikeMe forums (Figure 20).
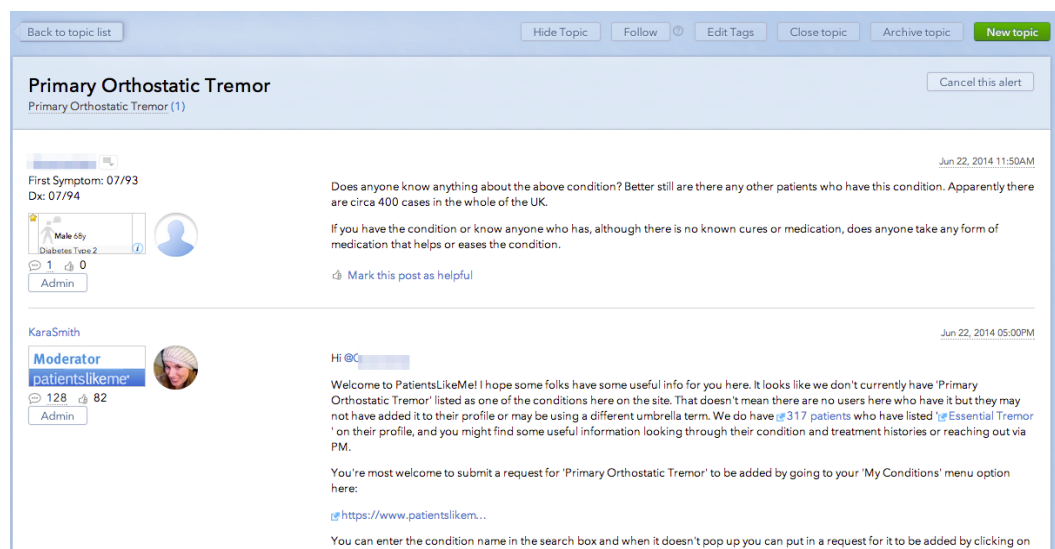


Figure 20: Example of a PatientsLikeMe forum page

While online forums may be a common place for community-aided reflection to occur, they are not designed specifically to support such use. Online forums provide the ability for users to write freely, asking questions or providing responses in any way they choose. These forums also allow

users to choose what, if any, personal health information to share. However, it would be easier and more efficient if users were not required to manually type previously-captured data into an online forum, as users are only able to share their tracked data by typing it in. While this may seem like a small obstacle to ask of them, this may mean that the more active users of the forum must re-enter the same information over and over again when responding to different queries or providing further detail in the same thread.

Additionally, online forums present messages (and therefore the health information contained within the messages) in a chronological and written format. These conversations may also span over multiple pages. This means that those who are trying to gain input on a question about their health must read through each message and retain the information for reflection, rather than viewing a representation of the collective information. The image below, taken from an online forum, provides an example of a community-aided reflection between three users in a forum thread (Figure 21).



Figure 21: Example of community-aided reflection taking place in an online forum

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## 2.4 Features of Systems that Support Reflection on Personal Information

Reflection requires effort and needs to be learned or supported in order to be effective (Baumer, 2015; Slovak, Frauenberger, & Fitzpatrick, 2017). By drawing on existing self-tracking systems, we can see different features that can support reflection on personal information. After reviewing 16 systems designed to support people in tracking and reflecting on their information, I identified five different types of features of tracking tools that could support reflection. Before describing those features, I will first summarise the systems that were reviewed.

### 2.4.1 Tracking systems reviewed

I reviewed sixteen existing systems designed to support tracking and reflecting on personal information. To gather a breadth of features that support reflection, not all of these systems are focused on health. Six of the sixteen were selected from popular academic publications published in the ACM or Springer digital libraries, and ten were selected from popular commercially-available systems.

Academic systems were selected based on three factors. First, the publication describing the tool needed to be on or after 2007, as technology changes significantly over time. Second, the tool needed to be used by participants in the wild to track personal information; laboratory environments and trackers used to observe participants are not representative of personal informatics technology. Third, the research needed be included in a reputable digital library, such as ACM or Springer. The number of references made to the publication also had influential power.

Regarding the selection of the ten non-academic personal informatics technology, there were also three criteria. First, the tool needed be currently available to consumers. Second, the tool needed to be popular amongst consumers (determined by the prevalence in which it was mentioned in other papers, such as that by Oh and Lee, 2015; and Rooksby et al., 2014). Third, the final selection of technology should show a broad range of technology. This meant that I would not include two systems that were intended to be used similarly (e.g. two pedometers).

Overviews of the sixteen reviewed tools are provided below. The first group listed is the six academic tools, followed by the ten industry tools. Each list is ordered alphabetically, by the name of the tool.

*Selected systems from academic publications*

*ConCap* is a mobile phone application developed and implemented with the purpose of helping diabetics understand the relationship between their daily activities and their glucose scores (Owen,

Pearson, Thimbleby, & Buchanan, 2015). **ConCap** is intended to be used alongside the existing tools used by the diabetic participants (i.e. glucometers). The diabetic participants used **ConCap** to report their glucose scores, insulin doses, location, activity, and capture photos or videos. **ConCap** then provides a representation of these data types together in order to assist users in identifying relationships and trends between their life activities and health indicators. (Owen, Pearson, Thimbleby, & Buchanan, 2015)

**Echo** was designed as a tool to encourage users to actively reflect on their past experiences (Isaacs, Konrad, Walendowski, Lennig, Hollis, & Whittaker, 2013). **Echo**, a mobile phone application, was developed to explore the benefits of technology-mediated reflection. Using this application, individuals would log daily experiences by entering short descriptions, reporting their mood, and capturing photographs. **Echo** would mediate reflection on these prior experiences by showing them to the user after several days, months, or years and asking them to report their thoughts and mood level of their memory of that event. In this way, **Echo** not only encouraged reflection but also collected data on it. (Isaacs, Konrad, Walendowski, Lennig, Hollis, & Whittaker, 2013)

**Lullaby** was developed as a means to identify causes of poor sleep quality in the context of an individual's home, rather than in a sleep center (Kay, et al., 2012). **Lullaby** is a capture and access system that is to be used in a bedroom. It consists of a number of environmental sensors, media recorders, a storage repository, and a wearable armband. **Lullaby** collects data overnight, as the user sleeps, and creates representations for the user to reflect upon and, ideally, identify why their sleep is often interrupted. (Kay, et al., 2012)

The **MONARCA 2.0** mobile application was developed to assist patients with bi-polar disorder in better understanding what affects their mood (Frost, Doryab, Faurholt-Jepsen, Kessing, & Bardram, 2013). Using this application, patients would report several bits of personal information (such as their mood, stress level, alcohol consumption, activities, and whether or not their medication was taken). The application would then find correlations between the various reported data and present the identified patterns to the user in order to improve their insight into their own disease. (Frost, Doryab, Faurholt-Jepsen, Kessing, & Bardram, 2013)

**TiY** is a mobile application that designed to provide diabetics with a more personalized way of tracking and monitoring their disease (Storni, 2014). Rather than prescribe what data can and cannot be gathered, **TiY** provides flexibility by allowing the user to enter 'tags' indicating events and capture photographs, in addition to reporting glucose readings and insulin doses. (Storni, 2014)

*UbiFit Garden* is a system comprised of a mobile phone application and an activity sensing device that can either be worn or kept in a pocket (Consolvo, et al., 2008b). The system was developed and deployed to understand how tracking technology is used in the daily lives of participants (Consolvo, et al., 2008b) and to understand how the prevalence of a user's exercise status impacts their activity (Consolvo, et al., 2008a). The activity sensing device was used to measure and infer the exercise being done by the user. The user could also add any missing or incorrect data with the mobile. The mobile phone application was mainly used to represent the user's activity through a metaphorical visualization of flowers in a garden – the more activity that was done, the more flowers would appear. (Consolvo, et al., 2008a; Consolvo, et al., 2008b)

## *Selected commercially-available systems*

Worn around the upper arm, the **BodyMedia FIT** armband is a continuously monitors the user's activity to provide information to improve weight loss (BodyMedia, Inc., 2015). The armband measures calories burned, physical activity, steps taken, and sleep quality. By connecting to the armband via Bluetooth, the collected data is uploaded to a mobile application or website. Here, the user can view their data or log food consumption. (BodyMedia, Inc., 2015)

**DAYTUM** is a commercially available website that individuals use to track personal data (DAYTUM, 2015). Unlike most personal informatics tools, **DAYTUM** allows users to decide what information should be tracked, whether it be hours spent watching television, food consumption, or time spent commuting. Users can also select which data to represent and choose from numerous pre-designed visualizations to generate representations. (DAYTUM, 2015)

The **DrinkAware** smartphone application was developed as a means to help individuals monitor their alcohol consumption and identify if it was negatively affecting their health (Drinkaware, 2015). With the application, users can report the number of units of alcohol consumed, as well as the type of alcohol (cider, wine, beer, etc.). The application represents this information in a traditional bar chart and also provides comparisons of the data through short, natural-language statements. (Drinkaware, 2015)

Consisting of a wearable patch and a small smartphone-like device, the **FreeStyle Libre** is used by diabetics for continuous non-invasive glucose monitoring (Abbott Diabetes Care Inc., 2014). The wearable patch, worn on the upper arm, captures and records the user's glucose levels continuously using small sensors.  To view their current and past glucose readings, the user holds the second device near the patch and activates the transmission of data. Their levels are then displayed on this device for them to review. (Abbott Diabetes Care Inc., 2014)

Using *Mappiness*, a smartphone application, individuals can track their happiness levels and reflect on how activities, locations, and people have an effect on their happiness. Users rate their happiness, relaxation, and exhaustion levels, input their location and activities, and note who is near them. The application represents this data in a number of charts for the end-user to reflect upon. (MacKerron & Mourato, 2015)

*MyFitnessPal* is a smartphone application used to monitor and improve healthy eating habits (MyFitnessPal, 2015). Users enter the details of each meal (what was eaten, number of servings) and the application presents the nutritional details of each meal, based on information stored in its database. Users can also record their weight. *MyFitnessPal* connects with several other health monitors, including the *Withings Pulse Ox and the BodyMedia FIT*, to enable the user to see a more holistic view of their behavior. (MyFitnessPal, 2015)

Individuals with hypertension use blood pressure monitors, such as the *QardioArm*, to measure and monitor their heart rate, systolic, and diastolic blood pressure. QardioArm is a two-part system composed of a portable blood pressure monitor and a smartphone application (Qardio, Inc., 2015). To get a reading, users wrap the monitor around their arm and initiate capture by pressing 'Start' on the app. With a wireless Bluetooth connection, their heart rate and blood pressure data is sent from the monitor to the application for them to review. This data can also be made available to friends, family members, or the user's physician. (Qardio, Inc., 2015)

An alternative to the wearable fitness trackers, *RunKeeper* is a smartphone application that uses GPS locations and time stamps to determine the distance and speed of the user during a run (RunKeeper, 2015). The level of involvement required of the user is limited – they only need to indicate the start and completion of their exercise with their phone. With the collected data, the application provides the user with a map of their run, distance, average speed, and a calculation of the calories burned. (RunKeeper, 2015)

Using the *Swarm* smartphone application, users can track their experiences around the world. Users can 'check in' to a location and add photos, comments, or list others around them. *Swarm* logs the GPS coordinates of the location, as well as the date and time of the visit. Users can review the history of their data by exploring it on a map or a list. (Foursquare, 2015)

The *Withings Pulse Ox* is a small activity tracker that can be worn on the wrist, clipped onto a belt, or kept inside a pocket (Withings, 2015a). This product is capable of tracking the distance and duration of a run, measuring the user's heart rate, and assessing the user's blood oxygen levels. If worn at night, the *Withings Pulse Ox* also tracks the user's sleep and assesses their sleep quality. The activity tracker has a small screen that allows users to see their current status,

but also pairs with their smartphone via a Bluetooth network to represent the data. (Withings, 2015a)

Whilst it appears to be the same as any other scale, the ***Withings Wireless Scale*** transfers the user's weight over a wireless connection (Wi-Fi or Bluetooth) to an application on their smartphone (Withings, 2015b). This allows them to track their weight fluctuations over time, as well as integrate this data with other Withings products. This scale also records daily weather. (Withings, 2015b)

The ***Zeo Personal Sleep Coach*** is a multi-part sleep-tracking system that consists of a bedside alarm-clock-style device and a sensor-band that is worn around the head (Zeo, 2013). The system monitors the user's sleep and, in the morning, presents a break-down of their sleeping patterns and quality. (Zeo, 2013)

### 2.4.2 Features supporting reflection

Described below, the features supporting reflection range from what data can be tracked to how that data is represented. As can be seen in Table 3, below, some features are more commonly included in a system than others.

| System | Data Options – Pre-Determined | Data Options – Free-Form | Data type – Numerical | Data type – Textual | Data type – Media | Representation Options – Fixed | Representation Options – Multiple | Representation Styles – Binary | Representation Styles – Structured | Reflection – Encouraged | Reflection – Interactive |
|---|---|---|---|---|---|---|---|---|---|---|---|
| ConCap | X | | X | X | | X | | | X | | |
| Echo | X | | X | X | X | | | | X | X | X |
| Lullaby | X | | | | X | | | X | X | | X |
| MONARCA 2.0 | X | X | X | | | | | | X | | |
| TiY | X | X | X | X | X | | | | X | | |
| UbiFit Garden | X | | | X | | | | X | | X | |
| BodyMediaFit | X | | X | | | X | | | X | | |
| Daytum | | X | X | X | | X | X | | | | |
| DrinkAware | X | | X | X | | | | | X | | |
| FreeStyle Libre | X | | X | | | | | | X | | |
| Mappiness | X | | X | X | | | | | X | | |
| MyFitnessPal | X | | X | | | | | | X | | |
| QardioArm | X | | X | | | | | | X | | |
| RunKeeper | X | | X | X | | | | X | X | | |
| Swarm | X | | X | X | X | | | | | | |
| Withings Pulse Ox | X | | X | X | | | | X | X | | |
| Withings Wireless Scale | X | | X | | | | | | X | | |
| Zeo Personal Sleep Coach | X | X | X | | | X | | | X | | |

Table 3: Breakdown of the different features supporting reflection and the systems that contain them

*Data Options*

Before collecting data (or 'information'), a user must determine what data is appropriate in relation to their intention for tracking, and what they wish to reflect upon (Li, Dey, & Forlizzi, 2010). 'Data Options' refers to whether or not a tool provides a user with the ability to select the data to capture. A tool can have a Pre-Specified Data feature, a Free-Form Data feature, or a both.

*Pre-Specified Data:*

The vast majority of tracking systems have a Pre-Specified Data feature: the data that can be captured using that tool has already been determined. One example of a personal informatics tool with the Pre-Specified Data feature is **DrinkAware**, a smartphone application with data input fields that were defined by the developer and are targeted towards the intention of monitoring alcohol consumption. Individuals who are not certain of which data is necessary may find a tool offering Pre-Specified Data useful, as it removes the need for them to decide.

*Free-Form Data:*

Some individuals may find a Free-Form Data feature to be more appealing and appropriate to their needs, though this is not a common feature. Systems with a Free-Form Data feature allow users to capture nearly any kind of information they desire. **DAYTUM**, a website which records and visualizes the data entered by users (DAYTUM, 2015), is an example of such a tool. **DAYTUM** has no pre-specified data categories; it is up to the user to determine what information they would like to collect. This feature supports individuals who desire flexibility in the data they collect or, perhaps, have not identified a Pre-Specified Data tool that they deem appropriate. Additionally, systems offering Free-Form Data features allow the user to add or change what they capture over time.

Some systems provide a combination of Pre-Specified and Free-Form Data features, which enables the user to edit or change what information they collect over time (e.g. **TiY**). Research has shown that users may identify new information to collect as a result of Insight (Whooley, Ploderer, & Gray, 2014), thus showing that Identification may occur more than once in a personal informatics journey. However, if using a tool with only Pre-Specified Data, this poses a problem as they must then re-think their capture strategy and start anew with a more appropriate tool (thus losing their data). The details of this topic have gone unexplored. Understanding *how* or *why* end-users come to decide that additional information is required would potentially lead to the design of better systems, perhaps ones that are not discarded after a few months. Studying the changes made to the data to be collected over a length of time could lead to the identification of common patterns of user behavior that occur when cycling through the personal informatics process. Potentially, these patterns could lead to personal informatics systems that can adapt and provide targeted support over longer periods of time.

The data that an individual wishes to reflect upon may come in different forms, or 'types,' and it is possible that more than one type is needed to be captured and reflected on. There are three types of data that can be captured; Numerical Data (numbers), Textual Data (words, sentences, letters), and Media Data (photographs, audios records, videos).

*Numerical Data:*

Numerical Data, as the name implies, is made up of numbers. The **DrinkAware** app captures numerical data; the user indicates the number of units of alcohol they have consumed. However, numerical data can be used for more than just counting. **Mappiness**, for example, captures the user's level of happiness using a numerical scale, with the highest number indicating extreme happiness and the lowest indicating unhappiness. Numerical data can also be temporal, meaning that a tool can capture the duration of a run (e.g. **RunKeeper** and **Withings Pulse Ox**) or the actual time of day in which information was captured (e.g. **DAYTUM**).

*Textual Data:*

Systems that capture Textual Data are those which capture words or phrases. The **Swarm** application is an example of a tool that captures words; in this case the words are names of business establishments that the user has visited. **Mappiness** also captures words, but – unlike **Swarm** – these words are referring to various activities (such as 'Working / Studying' or 'Playing with pets'). Other systems encourage the user to enter brief phrases or sentences. Users of **Echo**, for example, are able to provide brief thoughts on their situation or emotions. Additionally, after logging a run, users of **RunKeeper** can enter a few notes about their exercise or route. As such, the Textual Data that users capture can be useful as a description or reminder.

*Media Data:*

Personal Informatics systems that capture audio recordings, video recordings, or photographs have a Media Data feature. By capturing Media Data, users are able to collect information about the environment around them, context, or details that aren't easily captured using numbers or text. For example, with **ConCap** users can capture photographs alongside their insulin doses and glucose levels in order to better understand the relationship between their lifestyle and their disease (Owen, Pearson, Thimbleby, & Buchanan, 2015). **Echo** and **Swarm** also have a Media Data feature and support the user in collecting photographic data to remember their experiences. **Lullaby**, the sleep tracking device, automatically captures photographs and audio recordings throughout the night so that the user can identify what environmental factors are disturbing their

sleep. Another example of a tool with this feature is *TiY*, with which users can capture photographs and videos of their activities.

*Representation Options*

Captured information needs to be represented in a way that facilitates reflection, and many tracking systems automatically create a visual representation of the data. Often, systems provide a Fixed Representation – in which the selected data is represented in only one way – while some offer the user several visualizations to choose from ('Multiple Representations').

*Fixed Representation:*

Of the systems with a Representation Option feature, it would appear that most err on the side of Fixed Representations; the data representation is *fixed* – pre-decided by the developer and unchangeable by the user. Fixed Representations were designed and implemented by a team of individuals who determined the representation type to be appropriate for the user to reflect upon (Khovanskaya, Baumer, Cosley, Voida, & Gay, 2013). With Fixed Representations, users are given no option in the style in which their data is represented. As such, the user is removed from participating in this stage and moved straight on to Reflection (Whooley, Ploderer, & Gray, 2014). Examples of systems with Fixed Representations range from smartphone applications (e.g. *Echo, TiY, UbiFit Garden*) to wearables and devices (e.g. *Zeo Personal Sleep Coach, QardioArm, FreeStyle Libre*).

*Multiple Representations:*

When a personal informatics tool offers a user to choose from more than one style of representation, it has the Multiple Representation feature. *DAYTUM* offers a number of pre-designed displays to select from, ranging from pie charts, bar graphs, and natural language (DAYTUM, 2015). Users can easily switch between the different selections to find one that they feel is most appropriate and useful.

The prevalence of systems with Fixed Representations is distinct when compared with the low numbers of systems with Multiple Representations. Thus, these users are limited to only the representations that were defined for them; they cannot choose which data should be shown together or how. Whilst research suggests that some expert users prefer to generate their own representations (Whooley, Ploderer, & Gray, 2014), investigations have not yet explored the topic with more typical end-users.

The style in which the collected data is represented is important, as it should help the user reflect. There are two different styles in which personal informatics data can be represented: binary (the distilment of the data into one of two results), and structured (tables or graphs that show two or more variables) (Whooley, Ploderer, & Gray, 2014).

*Binary Representation Style:*

A Binary Representation means the collected data is presented in one of two ways (Whooley, Ploderer, & Gray, 2014). Personal informatics systems featuring this style of representation are often useful for showing real-time data for a user to respond to. If a user of the **UbiFit Garden** has performed a physical activity for the pre-determined period of time, the data representation will show a flower; if not, no flower will appear (Consolvo, et al., 2008a; Consolvo, et al., 2008b). The **Lullaby** system, another example of a tool with this feature, will display an icon in red if the data being collected is outside of a recommended threshold for a sleep environment (Kay, et al., 2012). This representation style is also useful for showing a user their current status or history of completing goals; **RunKeeper**'s display shows the user a timeline with each day highlighted either in red or green, depending on if they achieved their pre-set goals (RunKeeper, 2015).

*Structured Representation Style:*

Structured data representations display two or more data together to show a relationship (Whooley, Ploderer, & Gray, 2014). The majority of the reviewed systems include a Structured Representation feature. These representations range from the more traditional displays, such as charts and graphs, to textual or multimedia ones. **MONARCA 2.0**, for example, displays the user's mood fluctuations over time with a line chart whilst also displaying impact factors textually (Frost, Doryab, Faurholt-Jepsen, Kessing, & Bardram, 2013). **ConCap** displays a multimedia line chart containing photographs, locations, glucose readings, and insulin doses (Owen, Pearson, Thimbleby, & Buchanan, 2015).

Within these styles of data representation there lie innumerable visual variations, and there is no shortage of academic research seeking to design and validate a new variation of a representation style. However, within the personal informatics community there has been a notable lack of grounding these designs in the needs of users. Whilst the drive to represent data in new and hopefully useful ways is admirable, I argue that these representations should be developed in response to problems identified through user research. For example, researchers outside of the domain of Personal Informatics have shown that not all adults have high graph literacy, and that there are substantial differences in each individual's ability to understand representations (Okan, Garcia-Retamero, Cokely, & Maldonado, 2011). Perhaps through direct user observations,

researchers will be able to identify the barriers that end-users are having in understanding the representations they are provided. By combining these results with the existing theories on graph literacy, it is possible that the personal informatics community could improve end-users' abilities to reflect and gain key insights.

## *Reflection*

### *Encouraged Reflection*

Systems with this feature *encourage* the user to reflect by drawing their attention to the data representations. With **UbiFit Garden** this is done passively; the data representation is shown on the background of the user's phone so that its prevalent nature would be sure to catch the user's attention (Consolvo, et al., 2008a; Consolvo, et al., 2008b). Similarly, the **Echo** application would prompt the user to reflect by sending them prior data entries in mobile phone notifications (Isaacs, Konrad, Walendowski, Lennig, Hollis, & Whittaker, 2013). Whilst Encouraged Reflection is not common amongst personal informatics systems, it may be an important feature to include, as some users may not be aware of the data representation at all (Cohen, Keller, Hayes, Dorr, Ash, & Sittig, 2015).

### *Interactive Reflection*

With most personal informatics systems, the act of reflection takes place inside the mind of the user. However, the **Echo** application includes a feature which externalizes parts of reflection through interaction between the user and the tool. This is done by presenting the user with a previous experience that was documented and a request for them to enter new data about how their perception of the experience has changed. This interactive engagement was intended to enhance the user's level of reflection (Isaacs, Konrad, Walendowski, Lennig, Hollis, & Whittaker, 2013).

## 2.5 Summary

Despite this transfer from terminal to chronic disease, both academia and industry have failed to make progress on applications that support people living with HIV in tracking and reflecting on their personal health information. There is a lack of research regarding the information that people living with HIV wish to keep track of and what they seek to reflect upon. Indeed, related research commonly cites information-tracking suggestions made by clinicians or other healthcare providers, rather than gathering insight from the people living with HIV themselves.

This only succeeds in gathering a clinical point of view, and ignores the items which end-users deem to be important. Additionally, there is a dearth of systems available to HIV+ people for tracking their personal health information, whilst other chronic diseases (e.g. diabetes) have a broad array to choose from. For these reasons, focusing this research on people living with HIV is important. First, this research takes a first step towards exploring a real-world need and, as such, towards providing a real-world impact. Second, it allows us to explore the early process of personal health informatics amongst a population which has had limited exposure to the topic.

However, reflection is highlighted frequently in PI and PHI publications, but is often treated as a means to an end (Baumer et al., 2014). When reflection *was* a focus of a publication, Baumer et al. found that it was often tied with the assessment of a new capture tool or representation style. Some studies have tied reflection to insight, determining that it had occurred if a participant stated that they had gained some new knowledge (e.g. Mamykina et al., 2005; Owen et al., 2015). Others have analyzed reflection through time spent looking at a representation (e.g. Kay et al., 2012). Because of this, the PI and PHI communities have been described as having the opinion that merely providing access to prepared or visualized data is enough to ensure that reflection will occur (Baumer et al., 2014).

The features in 2.4.2 were described in order to provide an indication of how tracking systems could support reflection. These features show that supporting reflection does not just mean support in the actual moment of reflective thought, but also in the activities leading up to it. The gaps in research indicate that we must turn to those living with HIV to understand what they wish to track, and reflect upon, as well how they currently do so. However, there is no description of the process with which individuals engage with PHI to provide a framework for such research. In order to understand what is needed to support people living with HIV, or any chronic disease, in PHI we must first understand what the process of PHI is. With an understanding of the process of PHI, and the activities leading up to reflection, we can then turn to those living with HIV to understand how PHI systems could provide support.

# Chapter 3 The Process of Personal Health Informatics

The first objective of this thesis was to develop a process model of Personal Health Informatics.[1] The aim of this was to understand the activities involved and how they relate to reflection, and to use the process model as a lens for analysis.

The process models that were described in Chapter 2 have benefited researchers in several ways: providing a structure through which they can explore problems faced by end-users going through the process (e.g. work by Rooksby et al., 2014), allowing them to focus their research on exploring or supporting specific parts of the process through design (e.g. methods of capturing information, or prompting reflection), and understanding the context in which tracking tools are used and how the context may impact end-users.

However, I argue that none are sufficient representations of reflecting on personal health information for several reasons. First, both Cohen et al.'s (2015), and Li et al.'s (2010) processes lead to a stage in which the individual takes action or changes their behavior as a result of going through the process. Not only is this kind of shift or alteration an uncommon outcome (Prochaska, DiClemente, & Norcross, 1992), it also is not always the desired outcome, as some seek knowledge and self-understanding rather than change (e.g. the newly diagnosed diabetics described by Frost & Massagli, 2008). Additionally, both Cohen et al. and Li et al. state that their processes are iterative, but they suggest that this iteration only occurs once action/change has been taken.

The process model developed by Epstein et al. (2015), based on the work by Rooksby et al. (2014), addresses both these issues, as it describes a process for those who are not focused on changing behavior and includes several iterative cycles. However, the authors explicitly stated that their development of the model did not consider tracking for health or chronic illness, and that it may not be representative of the process for those focused on health (Epstein et al., 2015).

Finally, while the steps and overall process of Knowledge Discovery in Data are detailed and informative, they describe an approach to drawing insights from large amounts of non-personal data – this is at odds with PHI, in which individuals seek to draw understanding from often [relatively] small amounts of personal data. Additionally, KDD is focused on a process in which data is examined by a second party (Fayyad, Piatetsky-Shapiro, & Smyth, 1996). As such, the

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[1] The contents of this chapter were in part taken from Bussone, Buchanan, & Stumpf, S. (2015), and Bussone, Stumpf, & Buchanan (2016)

steps and stages described in KDD are valuable, but the process itself is not directly translatable to Personal Health Informatics.

Because of this, I felt that developing a process model specific to PHI was necessary, resulting in the following research question:

**RQ-1: What is the process of Personal Health Informatics?**

To understand what the process of PHI was, I developed a model through a comparison and alignment of the previously described processes (see Section 2.2.1) so that it would be grounded in existing theories.

## 3.1 Stages of the Process Model of PHI

The following sub-sections will detail the six stages and two iterative paths of the process model of PHI (Figure 22).
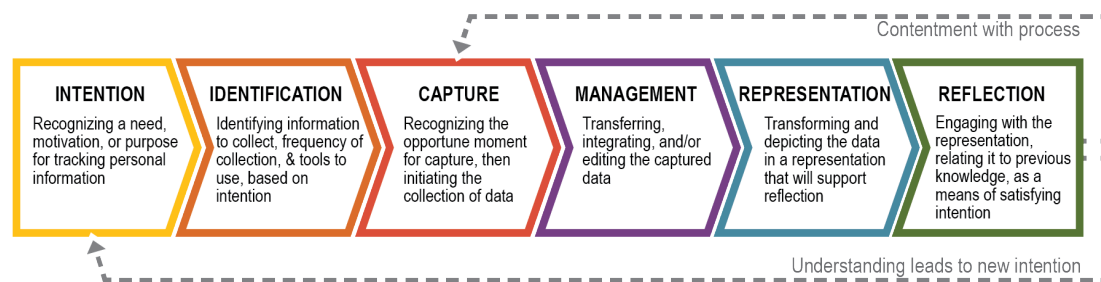


Figure 22: The process model of Personal Health Informatics

### 3.1.1 Intention

In *Intention*, the individual recognizes a need, motivation, or purpose for tracking their personal information. The intentions that drive end-users to begin tracking their personal information are frequently acknowledged in research, but may go by various other names. For example, Cohen et al. (2015) use the term 'influences', Choe et al. use 'motivations' (2014), and Fayyad, Piatetsky-Shapiro, and Smyth (1996) use the term 'goals.' While the terminology may vary, the concept remains the same. I chose to use the term 'intention' in reference to the research done by Whooley, Ploderer, and Gray (2014).

*Intention* is a crucial step in the process, as it later defines what information is gathered (Li, Dey, & Forlizzi, 2010), how it should be represented (Fayyad, Piatetsky-Shapiro, & Smyth, 1996), how the individual might need to reflect upon it and what understanding they hope to gain (Whooley,

Ploderer, & Gray, 2014). Some authors acknowledge and emphasize the importance of intentions (e.g. Choe et al., 2014; Cohen et al., 2015; Whooley et al., 2014). Indeed, a failure to identify a goal or intention before beginning the process will result in useless knowledge (Fayyad, Piatetsky-Shapiro, & Smyth, 1996).

The formation of an intention to track personal information is included in Li et al.'s (2010) description of their *Preparation* stage. However, *Preparation* also includes the determination of necessary data and tools to achieve the identified goal. By bundling these two actions together, Li et al. have underemphasized the importance of a user acknowledging their intention. As such, the process of PHI includes a step devoted solely to the formation and realization of intention.

### 3.1.2 Identification

During *Identification*, the individual determines what types of information should be collected, how frequently, and what tool(s) will support them in the process. All of this should be done in the context of their original intention. Recent studies have suggested some of the factors that may be considered during the *Identification* stage. For example, a user must identify the appropriate data for collection (Li, Dey, & Forlizzi, 2010). They also will seek to find a tool that will collect the relevant data, with little burden or usability issues (Cohen et al., 2015). They may have specific features in mind, such as social sharing of data (Oh & Lee, 2015; Paay, Kjeldskov, Skov, Lichon, & Rasmussen, 2015). Additionally, some users will consider the visibility of the tool during use, and will prefer a covert tool for privacy (O'Kane, Rogers, & Blandford, 2015) or an aesthetically appealing tool for overt use (Oh & Lee, 2015).

### 3.1.3 Capture

During *Capture*, the individual recognizes that they are in an opportune moment for data capture and initiates the collection of data. There is a wide array of systems available that support data-capture on some level (Cohen et al., 2015). Some systems prompt the user to capture information, others automatically initiate data capture. Also, some systems measure data for the user, whilst others record data that the user reports (Whooley, Ploderer, & Gray, 2014). Depending upon the user's original intention and required information, an individual may capture their data continuously (e.g. via a wearable heart monitor), routinely (e.g. taking routine blood pressure readings or documenting spending data), or sporadically (e.g. when experiencing a new symptom) (Rooksby et al., 2014). It should be noted that an individual might cycle through the *Capture* for an extended period of time before progressing on to the *Management* stage (Rooksby et al., 2014).

### 3.1.4 Management

The stage of *Management* involves preparing the captured data for *Representation.* This may involve transferring the data from the capture tool to a storage hub, integrating data from multiple sources, or editing the data. Some systems that are used to capture data are able to remove or reduce the involvement of the user during *Management* by conducting these activities for the user, seamlessly progressing them from *Capture* to *Reflection* (Li, Dey, & Forlizzi, 2010; Whooley, Ploderer, & Gray, 2014). However, some users prefer to perform the activities in this stage themselves, often when using more than one system for capture, desiring more personal control over their data, or using a tool that does not create representations (Whooley, Ploderer, & Gray, 2014).

The success of the stages following *Management* are largely contingent on these activities being carried out correctly (Fayyad, Piatetsky-Shapiro, & Smyth, 1996), yet this stage is very much overlooked by researchers (Whooley, Ploderer, & Gray, 2014). If not automated by a system, *Management* can be troublesome, laborious, and time-consuming for users (Whooley, Ploderer, & Gray, 2014). Alternatively, when *Management is* automated by a system, the user loses control over their data (Huang, et al., 2015). While Li et al. bundled the activities described in *Management* with those also described in *Representation* (to follow), I argue that the importance of the successful outcome of these activities indicates that they must be separated for appropriate emphasis.

### 3.1.5 Representation

In *Representation*, the captured and managed data is transformed and depicted in a way that will support reflection. Data representations can either be created by the tool or by the user (Whooley, Ploderer, & Gray, 2014). Personal Informatics systems that create representations may offer the user little or no control over selecting the style (Huang D., et al., 2015), often providing pre-configured or fixed representations (Whooley, Ploderer, & Gray, 2014) (refer back to Representation features described in 2.4.2). Designs created by a user offer much more control but often require the aid of a visualization software or website (Whooley, Ploderer, & Gray, 2014).

The success of *Representation* relies on the appropriateness of the representations developed. The way that the collected and integrated data is presented must be relevant to the original purpose (Fayyad, Piatetsky-Shapiro, & Smyth, 1996; Whooley, Ploderer, & Gray, 2014) and should not lead the individual to draw false insights during their reflection. By creating separate stages for each of these, I hope to draw attention to their individual importance.

### 3.1.6 Reflection

The stage of *Reflection* takes place when an individual engages with their gathered data, processes and relates it to their previous knowledge, as a means of satisfying their original intention and generating new understanding or knowledge about themselves. Reflection may occur frequently, where the user focuses on short-term data, or infrequently, where the user focuses on more long-term data (Li, Dey, & Forlizzi, 2010; Rooksby, Rost, Morrison, & Chalmers, 2014). Additionally, *Reflection* can range from a highly interactive act, where the user explores and interacts with visualizations, to a nearly unobservable one, where the user looks at a list or graph for only a brief amount of time (Li, Dey, & Forlizzi, 2010). It is not the temporal brevity that defines a reflective moment, but the mental activity in which the information found in the representation is related to the original intention (Whooley, Ploderer, & Gray, 2014).

### 3.1.7 Iterations

This new process model is not intended to be a linear one. In reviewing literature related to PI/PHI, two iterative paths were identified, both leading from Reflection. These paths indicate how the results of one stage may influence an individual to return to another stage and iterate the process. First, an individual may develop a new intention from their Reflection (Li, Dey, & Forlizzi, 2010), leading them back to the first stage of the process. Alternatively, the individual may re-join the process at the stage of *Capture.* This occurs when the user is content with the overall process and their intentions, tool, and required data remain unchanged (Whooley, Ploderer, & Gray, 2014).

Including these iterations in the model provides a more accurate picture of the process that users go through. However, it is possible that there are other iterative paths that occur that have not yet been identified. In addition, this process model is focused on what happens when an individual engages with PHI, not on what happens when they abandon it or lapse. For this reason, the paths of lapsing and resuming included in Epstein et al.'s (2015) model of Lived Informatics were not included.

## 3.2 Discussion

This chapter presents the stages and iterative paths of the process model of Personal Health Informatics. This process model was built upon existing models, each valuable in what they describe but lacking in various ways.

For the purposes of this thesis, this process model was developed as a means of understanding the activities involved in each stage of the process, and how they can affect reflection. In addition, the stages involved in the process model were intended to be used as high-level themes for analyzing data collected in the first research study (Chapter 4).

Because this process model was developed as a way of understanding the focus of the research, and using it to provide structure for the analysis of the first study, no steps were taken to validate the model, though this is an opportunity for future work. This model was developed out of an amalgamation of others, which provides a level of validity, but additional research should be conducted to determine if the stages, activities, and flow described above are in fact representative of the actual process of PHI, and if this process is truly generalizable across all purposes of tracking and reflecting on health, or if there are additional considerations to be made for particular intentions or conditions.

However, this model can still benefit other researchers. Actions that were previously understated are brought to light (e.g. Intention, Identification, and Management), allowing researchers to identify new areas of interest. Additionally, this model will help the HCI community focused on Personal Health Informatics to understand the iterative nature of the process and where PHI systems may need to offer more flexibility. With this, researchers will be able to identify new opportunities in which systems can provide support for the end-users.

# Chapter 4 Opportunities for Supporting People Living with HIV in Reflecting with Personal Health Informatics (Study One)

## 4.1 Motivation and Research Questions

In order to develop PHI systems that support people living with HIV in reflecting on their health information, we must determine where the opportunities for support lie. As described in Section 2.2.3, research has shown that people living with a long-term health condition seek to track and reflect on their health information, often as a means of self-managing and self-understanding (e.g. Mamykina et al., 2015). Research has also indicated some considerations that should be made with regards to supporting reflection for those living with a chronic disease (for example, Owen et al. (2015) and Mamykina et al. (2015) provided evidence that what is sought from reflecting on health information is linked to a person's current state of health). Still, there is little indication of where the opportunities to support reflection lie within the process of Personal Health Informatics, and how PHI systems can support those living with HIV.

This study[2] was aimed at understanding how people living with HIV currently track and reflect on their personal health information, as an approach to identifying where there are opportunities in the different stages to provide support for reflection. Each stage of the PHI process leads up to reflection, thus the activities involved in each stage will impact reflection in some way. For example, a PHI system that is not aligned with the intentions of those using them will fail to be fully effective in supporting their reflection (Whooley et al., 2014), therefore we must know what intentions people living with HIV have that lead them to tracking their personal health information. Additionally, there has been no research which identifies the personal health information that people living with HIV wish to track and reflect upon, and little indication of how they approach reflection. Therefore, we do not know how to support them in reflecting on their personal health information. By developing a rich understanding of the experiences of those living with HIV and their current approaches to tracking and reflecting on their health information, we can identify barriers and opportunities for supporting reflection.

This research study was designed to answer the following research question:

> **RQ-2: Where are the opportunities in the process of PHI for supporting people living with HIV in reflecting on their personal health information?**

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To answer this question, a qualitative research study was conducted to develop an empirical understanding of how those living with HIV currently track and reflect on their health information. The PHI process, introduced in Chapter 3, was used as a structure for analysis.

## 4.2 Method

To address the research question, a qualitative research study was conducted involving sixteen participants fitting the target population (adults living with HIV in England with an interest in tracking personal health information). Each recruited individual participated in a semi-structured interview where they were asked questions about their tracking behavior, the information they deemed important to track, and their attitudes towards tracking and tools that support it.

This section will first describe the participants and ethical considerations involved in the study. This will be followed by a detailed description of the study procedure and the materials that were used for the research. The final subsection outlines how data were collected and analyzed.

### 4.2.1 Participants and Ethical Considerations

*Target Population and Recruitment*

This research study was focused on HIV+ adults living in England who were interested in keeping track of their health information. It was not required that recruited individuals currently tracked information, nor was it required that they use or have used technology to track. However, recruited individuals needed to be adults (18+) who were living in England, spoke English, and were HIV+. Interested individuals who did not meet those criteria were not recruited.

Recruitment advertisements (Appendix 2) were sent out through sexual health clinics, social media, and HIV-specific forums. Links to the advertisement were posted on Twitter, Reddit, and Facebook. In addition, NAZ (an organization that works with Black, Asian, and minority ethnic individuals living with HIV) aided in recruitment by emailing recruitment flyers to their service users. A copy of a permission letter between the researcher and NAZ can be found in Appendix 9.

*Demographic details of the participants*

A total of sixteen people, 8 males and 8 females, were recruited for the study. All were HIV positive, and the years of diagnosis ranged from less than one to 27 (average of 11 years living with HIV). The ages ranged from 18 to 57 (average 39.87) and all lived within England. All participants stated that they were either interested in tracking health information, currently tracked their health information, or formerly tracked their health information.

A questionnaire was used to gather demographic details of the participants. The ethnicity, gender, sexual orientation, age, and year of diagnosis responses were reviewed and compared to the national average of people living with HIV in England to determine if the study sample was proportionate. These 16 presented a diverse range of demographic details such as age, gender, sexual orientation, and ethnicity (refer to Figure 23 for a visual breakdown).
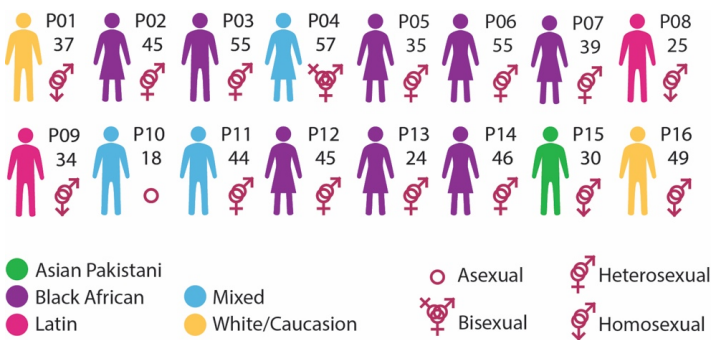


Figure 23: A visual breakdown of the sixteen participants, who ranged in gender, age, ethnicity, and sexual orientation

As a way to help identify certain traits of each participant throughout the presentation of the results, a series of letters were added to their participant number. These letters referred to their gender, sexual orientation, ethnicity, and most recent storage device, respectively. For example, the first participant (01) was a male (M), homosexual (Ho), with white British ethnicity (WB), who stored his personal health information on a digital tool (D). As such, he was referred to as 01-MHoWBD. Alternatively, the 14th participant was female (F), heterosexual (He), with black African ethnicity (BA), and stored her information both (B) on a digital tool and on paper; she was referred to as 14-FHeBAB. The initials assigned to each participant are provided alongside each demographic detail in Table 4.

There was a broad range of ages amongst the participants, spanning from 18 to 57 years old. At the time of this research study, the ages of adults accessing HIV care in England were: 15-24 years make up 3%, 25-34 make up 16%, 35-44 make up 32%, 45-54 also make up 32%, 55- 64 make up 11%, and 65+ make up 4% of the adults accessing HIV care in England (Public Health England, 2015b). The average age of the participants was 39.87; fitting into one of the two largest two age groups (35-44 and 45-54).

As for the years since being diagnosed, the participants ranged from zero (two participants had been living with HIV for less than a year) to twenty-seven. In England, a total of 128,757 HIV diagnoses have been documented (Public Health England, 2015a). 22% of these diagnoses were made between 2010 and 2014 (Public Health England, 2015a) – three of the participants were diagnosed in 2014-2015. Thus, these participants were able to share their experience in coming to terms with their diagnosis – something that can take months or even years to do. Alternatively,

nine participants were diagnosed between 2000 and 2009, a time when 48% of the total diagnoses were made (Public Health England, 2015a), and four participants were diagnosed in 1998 or earlier – from 1999 and earlier, 30% of the total diagnoses were made (Public Health England, 2015a). This means that thirteen of the sixteen participants had lived with HIV for at least five years; these individuals were in the middle of living with a chronic condition. Interestingly,

| ID | Age | Gender | Sexual orientation | Ethnicity | Years since diagnosis | Recent storage | Currently tracking? |
|---|---|---|---|---|---|---|---|
| 01-MHoWBD | 37 | Male [M] | Homosexual [Ho] | White British [WB] | 0 | Digital [D] | Yes |
| 02-FHeBAD | 45 | Female [F] | Heterosexual [He] | Black African [BA] | 12 | Digital [D] | Yes |
| 03-MHeBAB | 55 | Male [M] | Heterosexual [He] | Black African [BA] | 27 | Both [B] | Yes |
| 04-FBiWAP | 57 | Female [F] | Bisexual [Bi] | White / Black African [WA] | 14 | Paper [P] | No |
| 05-FHeBAP | 35 | Female [F] | Heterosexual [He] | Black African [BA] | 7 | Paper [P] | Yes |
| 06-FHeBAP | 55 | Female [F] | Heterosexual [He] | Black African [BA] | 10 | Paper [P] | Yes |
| 07-FHeBAP | 39 | Female [F] | Heterosexual [He] | Black African [BA] | 7 | Paper [P] | No |
| 08-MHoLD | 25 | Male [M] | Homosexual [Ho] | Latin [L] | 0 | Digital [D] | Yes |
| 09-MHoLP | 34 | Male [M] | Homosexual [Ho] | Latin [L] | 11 | Paper [P] | Yes |
| 10-MAsWCD | 18 | Male [M] | Asexual [As] | White / Black Caribbean [WC] | 18 | Digital [D] | Yes |
| 11-MHeMOB | 44 | Male [M] | Heterosexual [He] | Mixed: Other [MO] | 18 | Both [B] | Yes |
| 12-FHeBAP | 45 | Female [F] | Heterosexual [He] | Black African [BA] | 25 | Paper [P] | Yes |
| 13-FHeBAD | 24 | Female [F] | Heterosexual [He] | Black African [BA] | 7 | Digital [D] | Yes |
| 14-FHeBAB | 46 | Female [F] | Heterosexual [He] | Black African [BA] | 12 | Both [B] | Yes |
| 15-MHoAPD | 30 | Male [M] | Homosexual [Ho] | Asian Pakistani [AP] | 8 | Digital [D] | Yes |
| 16-MHoWOP | 49 | Male [M] | Homosexual [Ho] | White Other [WO] | 1 | Paper [P] | Yes |

Table 4: Breakdown of demographic data and tracking practices. 'Recent Storage' refers to the participants most recently used storage medium: paper-based, digital, or both

having this mix of individuals (those who have lived with the disease for quite some time and those who are newly diagnosed) resulted in a better understanding of the changing needs and intentions of personal health informatics over time.

The participants also represented a variety of genders, sexual orientations, and ethnicities. There was an even split of genders amongst the participants with eight males and eight females; this breakdown is disproportionate to the gender breakdown of those accessing HIV care in England: 67% males and 33% females (Public Health England, 2015b). When asked to indicate their sexual orientation, nine participants identified as straight/heterosexual, five males identified as gay/homosexual (no females identified as lesbian), one female identified as bisexual, and one male as asexual. While the sexual orientation of those living with HIV in England is not available, Public Health England (PHE) does indicate the likely source of infection, or route of exposure, which can suggest sexual orientation: sex between two men was the likely cause of 45% of the infections while sex between a man and a woman was the likely cause of 48% (Public Health England, 2015b).

Finally, the ethnicities of the participants. As can be seen from Figure 23, the participants presented an array of ethnicities that ranged from White British, Latin, Pakistani, Black Caribbean, and Black British African. With eight participants, the most common ethnicity of the recruited individuals was Black British African. This ethnic group makes up one-third (33%) of HIV+ adults in England (Public Health England, 2015b). Two participants were white, two Latin, three were mixed, and one was British Asian Pakistani.

Comparing the demographic details of the sixteen participants against the larger population does show that this sample is skewed. This sample was disproportionate to the national numbers of gender and ethnicity. The sample had a high number of Black African female heterosexuals. It is possible that this may have an effect on the data captured, but this should not be viewed as a negative outcome of the recruitment. This is because this sub-group is actually one of concern amongst HIV prevention organizations (National AIDS Trust, 2014). The reason for this is that Black African communities constitute just 1.8% of the UK population (National AIDS Trust, 2014, p. 4) but make up almost one-third of all people living with HIV accessing care (Public Health England, 2015b). Indeed, almost half of all those accessing care in 2014 were exposed to the virus through heterosexual sex – a higher portion than those exposed through sex between men (Public Health England, 2015b). Of these HIV+ and heterosexual, 60% were of Black African ethnicity. Furthermore, women make up 63% of those heterosexuals accessing HIV care in 2015, which is 30% of all adults who accessed care in England (Public Health England, 2015b). Considering the study sample in the context of these numbers, it can be said that the sample is not representative but does focus on a very important and necessary group.

The ethics and legality of this research were considered extensively. This project was approved by City, University of London's Senate Research Ethics Committee (Appendix 1).

The informed consent of each participant was an important factor for consideration. Each participant was provided with a study information sheet and consent form prior to the start of the research study. This was done to ensure that each person had ample opportunity to read through the details and ask questions. Additionally, participants were informed that they may discuss the study with their doctor if they desired. Signed copies of consent forms were given to the participants to retain for their own records.

Ensuring the confidentiality of all participants was also a major consideration. All signed consent forms retained by the researcher were kept in a locked filing cabinet, preventing others from seeing the names on the forms. All individuals who were successfully recruited into the study were assigned a unique identification number. The link between the individual's name and their unique identification number was contained on only one piece of paper (example of the key in Appendix 6), which was kept in a locked drawer in an area separate from the signed consent forms. Additionally, all audio data was stored in a locked folder on the researcher's private computer until they were transcribed in full. Once this was done, the audio files were moved to a locked folder on an external hard drive. Finally, all transcripts were examined for identifiable data. The identifiable data was then permanently edited to remove identifiable features. Examples of what is considered 'identifiable data' are names of participants, friends, family, acquaintances, and names of workplaces or locations frequently visited.

## 4.2.2 Procedure

To answer the research question, a qualitative research study was conducted using multiple materials. Each study session followed the same order of steps, which are depicted in Figure 24. These sessions involved semi-structured interviews lasting approximately 30 minutes. Of the sixteen sessions: two study sessions took place in private rooms in City, University of London, eleven took place in private rooms in NAZ, and three took place over Skype. Each part of the study procedure will be described here, in the order of the study procedure.
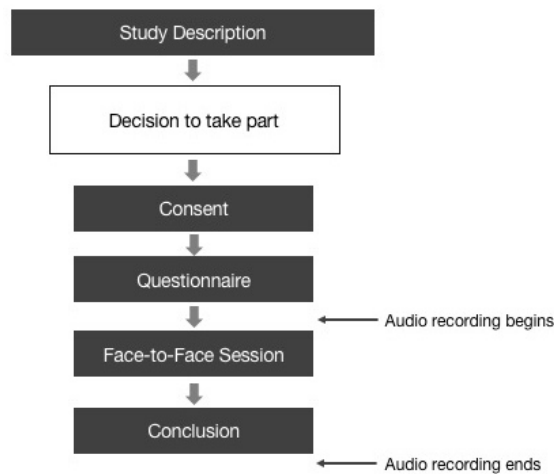
Figure 24: The study procedure

*Study Description and Consent*

Before interested individuals were fully recruited into the research study it was important to ensure they fully understood the purpose of the research and what would take place. To do this, the research and study plans were described in detail using the study information sheet (Appendix 4) to facilitate the conversation. The Study Information Sheet explained the purpose of the study and what would occur during the session. It also explained the advantages and disadvantages of taking part, how the study data would be stored, and how the results would be used. Additionally, the information sheet included detailed sections on confidentiality and sensitive or criminal information. These two sections were important to emphasize given the stigma associated with HIV and the potential for illegal behavior to be mentioned – a requirement of the University. The information sheet was read out loud, and each individual was invited to ask questions. Any questions that were brought up were answered accordingly.

Once all questions had been answered, the participants were asked to decide if they were interested in taking part. For this, the Consent Form (Appendix 5) was reviewed to ensure the interested individual understood the details of the study. Participants who chose to take part in the study were asked to sign two copies of the Consent Form. Both copies were then signed by the researcher, and one copy was returned to the participant for their records. The other was retained by the researcher. Participants who were not met in person were asked to sign and send the completed form via e-mail before the study could continue.

*Questionnaire*

Following the consent process, each participant was asked to fill out a questionnaire (Appendix 7). Those participants who were not met in person were asked to complete the questionnaire and send it via email to the researcher after the session had ended.

The questionnaire was used to gather demographic details. Recruiting a representative sample was not a focus, but gathering demographic details was done in order to describe the recruited individuals and compare the recruited sample to the larger population of people living with HIV in England. Participants were asked to indicate their ethnicity from a provided list, as well as note the country they were born in and if English was their first language. They were asked to indicate their gender and sexual orientation. The ethnicity, gender, and sexual orientation lists that were used in this questionnaire were recommended by NAZ, who also uses the list in their research. Additionally, each participant was asked to fill in their age and their year of diagnosis. The year of diagnosis was used to determine how long they had been living with HIV.

The responses to this questionnaire were not analyzed in any way, and were only used to describe the demographic details of the research participants (see 4.2.1).

*Interview session*

Once the forms were completed, the interview session began. These sessions lasted approximately 30 minutes and were audio recorded. A discussion guide (Appendix 8) was used during these sessions to guide the conversation. The discussion guide began with a script that was read to the participant, giving them an overview of what would occur. This was intended to make each participant feel more at ease before being asked to answer questions. The remainder of the discussion guide included questions to prompt the researcher and keep the session on track. The questions that were included were based around the stages of the process of PHI and the different activities that might occur, or considerations that might be made, during those stages.

The beginning of the interview involved questions aimed at understanding the intentions the participants had or tracking. All participants had an interest in tracking their health, and were asked if they currently tracked personal health information and why or why not. Those who did not currently track were asked about their former tracking practices, and ideas for future tracking, for the remainder of the interview. Participants were also asked about the information that they were interested in capturing (currently, in the past, or what they wanted to capture in the future). For each type of information, they were asked to describe the context around it (e.g. how it is obtained, the frequency at which it changes, etc.). From there, the discussion moved to the topic of technology; what they felt comfortable with, and what they perceived to be ideal tools for

supporting collection of their personal health information. Finally, participants were asked if they ever reflected on their captured information, if they wanted to, if there were visualizations available to them to explore during reflection, and if they ever edited or changed what they had captured.

*Conclusion*

Once the session had been completed, participants were given the opportunity to ask the researcher any questions they might have had, or provide any additional thoughts. In some instances, their comments led to additional insight, so the audio recorder remained on until the end of the conversation.

The participants who took part in this study did not receive any direct benefits from participation. However, as a token of appreciation for their involvement, their travel expenses to and from the session location were paid, when applicable. Additionally, all in-person meetings included baked goods, fruit, coffee, tea, and water. Every participant was thanked and told that their participation was greatly appreciated.

## 4.2.3 Data Collection and Analysis

The audio recordings from each research session were saved using the participant's ID number, then transcribed and analyzed.

The audio recordings from each session were transcribed in full; utterances (e.g. 'uh', 'umm', 'hmm', etc.), pauses (shown as '…'), and incomplete sentences were all included. This can be seen in the example below:

> *"Um. I have to think. I mean, I suppose, the thing with nutrition… But then most doctors say that if you keep a healthy diet, generally the same as everybody else's diet."* (01-MHoWBD)

In order to have a full and accurate account of the conversations that took place, the transcripts also included all of the researcher's comments. Comments made by the researcher were differentiated in the transcripts from those made by the participant. This was done by changing all comments by the researcher to a medium-gray non-italicized font, as shown in the example below:

> *So do you currently gather info related to your health?*
>
> *Yeah I do.*
>
> *Okay, what kind of information?*

Any identifiable information was anonymized by substituting the identifiable word with a generic replacement (e.g. *"I work at Starbucks in Croydon"* would have been de-identified and shown as

*"I work at [coffee shop] in [London borough]"*). No handwritten notes were taken during the study session.

Analysis of the data gathered from the study sessions began as soon as the first transcript was completed. Transcripts were imported into NVivo, a software system designed to support researchers in analyzing qualitative data. For this research study, the data gathered during the sessions were thematically analyzed using a combination of deductive and inductive thematic analysis methods.

Thematic analysis is "a method for identifying, analyzing, and reporting patterns (themes) within data" (Braun & Clarke, 2006, p. 6) and is a popular method for qualitative analysis across many disciplines – even considered by some to be a foundational method of analysis. Unlike analytical methods like Grounded Theory or Interpretative Phenomenological Analysis, thematic analysis is not tied to one theoretical or epistemological framework but is actually suitable for nearly all frameworks (Braun & Clarke, 2006). This made thematic analysis an ideal approach for this research study, which was focused on finding the motivations and experiences of the participants as they depicted them.

The analysis, described below, took a seven-step approach. From this point onward, all codes described in the text will be distinguished by using a different font (e.g. ***codes***). The codes and definitions are provided at the end of this sub-section, as well as at the beginning of each section in Results.

### *Step One: Familiarization with the data*

Immersion in the collected data is a vital step in analysis (Braun & Clarke, 2006). Familiarization with the data had already started by personally collecting and transcribing the audio recordings from each study session, but was deepened through repeated readings of the transcripts.

### *Step Two: Defining initial codes*

The next step of the analysis was to define and apply codes to sections of the transcripts. Because this study was focused on understanding the process of PHI for people living with HIV, these initial codes were 'theory-driven': there was one code for each stage of the process. The definitions of these codes, shown below in Table 5, were derived from the descriptions of each stage (see Chapter 3).

| Code | Definition |
|------|-----------|
| *Intention* | Statements portraying a need, motivation, or purpose for tracking personal health information – whether in the past, at present, or for the future. |
| *Identification* | Statements describing what information to collect, and/or how frequently collection will be necessary. |
| *Capture* | Statements regarding moments of initiating data collection, recording collected data, or storing collected data. |
| *Management* | Statements about transferring, integrating, and/or editing the captured data |
| *Representation* | Statements about transforming and depicting the data in a representation that will support reflection. References made to the data being transformed or depicted, or how it is depicted, also included. |
| *Reflection* | Descriptions of looking at their collection of data or representation of data. |

Table 5: Initial codes describing stages of PHI process

The transcripts were read through several times, each time focusing on a different code. The codes were applied to chunks of text in which participants were making statements that fitted the above definitions. For example, this comment made by 06-FHeBAP was coded as *Intention* as it shows her motivation for tracking her information. In this comment, 06-FHeBAP is explaining why she writes information down in a notebook: because she needs to track her progress and see how she is doing.

> "*The reason why I write it, I need to track it to see the progress and see how well I'm doing. If I do that, then I'm able to be on top of it as well, because it's not only for the medical profession, it's for my own benefit as well.*" (06-FHeBAP)

This process of defining and applying them to the transcripts was repeated until all had been covered and all un-coded material was determined to be irrelevant to the focus of the research. For example, this comment by 16-MHoWOP was not coded as it did not discuss anything related to capturing personal information, reflecting on health, or self-management:

> "*I lost all my friends when I moved here. I had a breaking point, a bad chapter. I'm a nice man, I think I'm normal, but when I'm in a bad mood I hate the world. So, when I said goodbye to [country], I had problems with all my friends. I came here and for me it is difficult to make new friends. When I meet somebody I always find something wrong.*" (16-MHoWOP)

### Step Three: Developing sub-codes through deductive analysis

Once the coding was applied for the stages, developing themes (or 'sub-codes') within the data began. This took both a deductive and inductive approach.

Some of the definitions of the stages indicated activities or concepts that analysis should focus on, and this allowed for the deductive analytical approach. For example, the stage of *Identification* was defined as the stage in which an individual identifies information to collect and frequency of collection based upon their intention. Within this description are pre-existing concepts that were used to develop sub-codes: the information to be collected (*information*), the frequency of collection (*frequency*).

These codes were applied by reviewing the sections of the transcripts that had been coded as a stage. While reading through these sections, phrases or individual words were highlighted and coded accordingly. The following shows an example of a section of a transcript that fitted under the *Identification* code; analysis of this section revealed several words and phrases to which the *information* code was applied (shown here with an <u>underline</u>):

> "*I do keep track of things. The first thing on the list would be <u>my lab results related to HIV</u>. Especially <u>CD4 count</u> and <u>viral load</u>. Also, if there is any <u>deficiency coming in liver or bone</u>, because those are some of the concerns that I do have related to my illness. And I do make sure that I get current information from my doctor about that.*" (15-MHoAPD)

*Step Four: Developing codes through inductive analysis*

Conducting only deductive analysis on the data would prevent unexpected codes or themes from being found. Thus, inductive analysis was required. This approach involves developing codes that are not based upon any existing theory, and is done to allow unexpected codes to emerge from the data (Braun & Clarke, 2006).

For this research, inductive coding was applied for three reasons. First, not all stage descriptions indicated smaller codes that should be used (e.g. *Intention*) which meant that there were no pre-existing themes to approach the data with. With no pre-existing themes, inductive coding was ideal to begin to understand what was happening in these sections of the transcripts. Second, it was used to find other codes that would not have been identified with a purely deductive approach. Third, many of the codes that emerged from Step Three, such as *Information*, needed to be refined into smaller sub-codes to provide a better understanding of what the data was showing. The data was reviewed numerous times before tentative sub-codes were created for small chunks of data.

For example, the definition of *Intention* (statements portraying a need, motivation, or purpose for tracking personal health information) did not include any pre-conceived notions of what intentions there might be for tracking health information, and therefore an inductive approach was needed to identify the various needs or motivations the participants had.

From the inductive coding, numerous tentative sub-codes emerged that could be combined together into more descriptive ones. This was done by comparing and contrasting them, then grouping them together repeatedly to finally form sub-codes (Braun & Clarke, 2006). The sub-codes then underwent the same process, as they were compared and contrasted to develop main codes. This continued until further grouping was not possible or obfuscated the meaning of the grouping.

| Codes for: *Intention* | | |
|---|---|---|
| Definition: Statements portraying a need, motivation, or purpose for tracking personal health information – whether in the past, at present, or for the future | | |
| Main Code and Definition | Sub-Code | Definition |
| *Monitoring*<br><br>Tracking with the purpose of having a record or reference point to look upon, particularly with the intention of having a deep understanding of themselves, without a focus on taking action or making changes. | *Future Reference* | Tracking information because it may be useful or interesting in the future, with no particular reason or hypothesis |
| | *Medication Compliance* | Tracking medication data to monitor or maintain compliance |
| | *Ownership of Data* | Tracking data to have personal control over it, or to feel like an integral part of the clinical process |
| *Acting*<br><br>Tracking data to understand what actions to take, or to observe how prior actions have made a change in the data. | *Inform Actions* | Tracking information to determine what actions (or changes) should be made |
| | *Observe Effects of Actions* | Tracking information to see how actions (or changes) have made an effect |
| *Use in Consultation*<br><br>Tracking data with the intention of using it to prepare for a clinical consultation, show a clinician, or speak to a clinician about. | *N/A* | N/A |

| Codes for: *Identification* | | |
|---|---|---|
| Definition: Statements describing what information to collect, and how frequently collection will be necessary. | | |
| Main Code and Definition | Sub-Code | Definition |
| *Frequency*<br><br>The temporal dimension of capture (e.g. 'Every Day', 'Once a month', etc.) | *Daily* | Capturing information on a daily or semi-daily basis |
| | *Monthly* | Capturing information every few months |
| *Information*<br><br>The personal information that an individual has interest in collecting, either currently, in the past, or desires to collect in the future | *Indirectly Related* | Information which may not seem to have a clear relationship to HIV, but is/was tracked (*emotions, food intake, exercise, weight*) |
| | *Directly Related* | Information which is directly related to HIV (*Lab Results, Medication*) |
| | *Potentially Related* | Information that may or may not be linked to being seropositive (*Potential Side Effects, Other Conditions*) |

| Codes for: *Capture* | | |
|---|---|---|
| Definition: Statements regarding moments of capturing data, initiating data collection, or recording collected data | | |
| Main Code and Definition | Sub-Code | Definition |
| *Storage*<br><br>Where the individual keeps, or stores, their information. Storage is where the individual can review or reflect on their information | *Paper Storage* | Any paper-based, non-digital, collection of information<br><br>e.g. Collection of loose papers, Paper diary / Notebook, HIV-Specific notebook |
| | *Digital Storage* | Any digital location in which the individual stores a collection of information<br><br>e.g. Digital document / Notebook, Health app, HIV-Specific website / app |

| Codes for: *Management* | | |
|---|---|---|
| Definition: Transferring, integrating, and/or editing the captured data | | |
| Main Code and Definition | Sub-Code | Definition |
| *Editing*<br><br>Correcting or adding detail to previously captured data | N/A | N/A |
| *Deleting*<br><br>Removing data from the stored location | N/A | N/A |
| *Integrating*<br><br>Bringing data stored in different locations together into one location | N/A | N/A |
| *Transferring*<br>Moving a corpus of data from one storage location to another | N/A | N/A |

| Codes for: *Representation* | | |
|---|---|---|
| Definition: References made to the data depicted, or how it is depicted | | |
| Main Code and Definition | Sub-Code | Definition |
| *HIV-Specific Data*<br><br>The data being represented are specific to HIV (Directly Related information, e.g. CD4, viral load, ARV medication) | N/A | N/A |
| *Non-HIV Specific Data*<br><br>The data being represented are not specific to HIV (Indirectly Related information, e.g. steps walked, heart rate, weight) | N/A | N/A |

| Codes for: *Reflection* | | |
|---|---|---|
| Looking at their collection of data or representation | | |
| Main Code and Definition | Sub-Code | Definition |
| *Community Reflection*<br><br>An individual reflecting upon data about themselves, that they have captured by themselves, with the aid of the HIV or sexual-health community | N/A | N/A |
| *Reflection with Healthcare Provider*<br><br>An individual reflecting upon data about themselves, that they have captured by themselves outside of the clinical setting, with the aid of a healthcare provider | N/A | N/A |

*Step Six: Applying codes*

Once the codes were developed, they were used in conjunction with the transcripts to describe what was occurring and why each was an interesting finding in light of the related literature or frequency of occurrence. For this study, the unit of analysis for each code was measured as the number of participants whose statements fell under that code, rather than the number of statements per participant. This was because, during the study sessions, participants may have been asked several follow-up questions; thus the frequency of statements per person may be more indicative of the questions that were asked, rather than the importance of the code itself.

A key point of research is to ensure that your work is reliable and valid (Braun & Clarke, 2013) – that what you have reported could be found again if the study was repeated by someone else. The criteria for evaluating quantitative research are well-established, but often thought to be *the* criteria for evaluating *all* research – qualitative included (Braun & Clarke, 2013). Quantitative researchers are focused on creating generalizable results, showing that the researcher did not bias the findings (Braun & Clarke, 2013). However, with qualitative research – particularly that where the researcher is interacting with participants to gather data – it is inevitable that the researcher has some influence on the results produced (Braun & Clarke, 2013). Interviews, like those conducted for this research study, result in a relationship between the researcher and the participant where not only knowledge is shared, but a social understanding is formed (Healy & Perry, 2000). Not only would conducting inter-rater reliability on such a small sample size be difficult, but a second-coder would not have experienced the conversation as it took place, nor listened to the audio recordings, meaning that they might struggle to determine how a comment was expressed, and the emotion or meaning behind it.

That inter-rater reliability was not conducted does not mean that this research study is not reliable. The approach to developing codes and applying them was an iterative process involving reflexivity. Not only did the researcher reflect upon the codes and the research questions at hand (a method recommended by Adams, Lunt, and Cairns, 2011), but the supervisors of the research project were used as reliability checks as well: for the entirety of the analysis, the researcher and supervisors met on a weekly basis to have a critical discussion about each sub-code, main code, and their definitions. Additionally, great care was taken to ensure that the study procedure, data collection, and the data analysis was documented in detail, such that others could repeat the work conducted, and the results were grounded with example quotes from participants and details of the number of instances in which that code occurred (as recommended by Elliott, Fischer, & Rennie, 1999).

## 4.3 Results

Each stage of the PHI process involves activities that may affect an individual's reflection in some way, and activities involved in each stage were mentioned by at least 4 of the 16 participants (Table 6). The results described here will follow the order of the stages of the process, beginning with Intention and ending with Reflection. Each section will begin with the code definition associated with the stage and a brief reminder of how the stage might affect reflection, before going into detail about the sub-codes developed in the analysis.

| ID# | Intention | Identification | Capture | Management | Representation | Reflection |
|---|---|---|---|---|---|---|
| 01-MHoWBD | X | X | X | | X | X |
| 02-FHeBAD | X | X | X | X | | X |
| 03-MHeBAB | X | X | X | X | | X |
| 04-FBiWAP | X | X | X | | | X |
| 05-FHeBAP | X | X | X | | | |
| 06-FHeBAP | X | X | X | | | X |
| 07-FHeBAP | X | | X | | | X |
| 08-MHoLD | X | X | X | | | X |
| 09-MHoLP | X | X | X | | | X |
| 10-MAsWCD | X | X | X | X | X | X |
| 11-MHeMOB | X | X | X | X | | X |
| 12-FHeBAP | X | X | X | | | X |
| 13-FHeBAD | X | X | X | | X | X |
| 14-FHeBAB | X | X | X | | | X |
| 15-MHoAPD | X | X | X | X | X | X |
| 16-MHoWOP | X | X | X | | | |

Table 6: Each stage was mentioned by at least four participants (indicated with 'X')

### 4.3.1 Intention

*A need, motivation, or purpose for tracking personal health information – whether in the past, at present, or for the future*

Knowing the intentions an individual has for tracking their health information is a key aspect to supporting them in reflection: the intentions inform how the individual might need to reflect, what they wish to reflect on, and what understanding they hope to gain through reflection (Whooley, Ploderer, & Gray, 2014).

All sixteen of the recruited individuals stated that they tracked their personal health information, but not every individual *currently* tracked information. Some actually fluctuated over the years, occasionally re-entering the process when they considered it necessary. Each of the sixteen participants described their intentions for tracking – either in the past, present, or future – and many participants had more than one intention for collecting their information.

Of the sixteen participants, only two (04-FBiWAP and 07-FHeBAP) stated that they no longer track their personal health information. These two participants provided reasons for their discontinuation of tracking, and statements by others explained why they would occasionally abandon and re-join the process over the years. For example, 04-FBiWAP stopped tracking her information because she felt it placed her focus on her disease and prohibited her from living her life as she should; she now chooses to let her consultant do the tracking so that she can carry on with her life. As another example, 07-FHeBAP no longer tracks her information because "*there was no change*" in her side effects or the way she was feeling. 15-MHoAPD, who was currently tracking his health, stated that he fluctuates between tracking his side effects and ignoring them because he feels that his clinician is not particularly interested. This suggests that some individuals may swing in and out of the process of PHI when feeling their health is stable or when developing a particular concern.

The reasons these participants gave for not currently tracking their information provide a conceptual segue into the three major intentions that emerged from the analysis. The most common intention, mentioned by fifteen participants, was for *monitoring*: capturing personal information so that they could keep an eye on their condition and have a collection of information to reflect upon in the future, when the need arises. The second intention, described by seven participants, was for *acting*: tracking information in order to test a theory, determine what actions should be taken, or understand the effectiveness of ongoing actions. With this intention, participants had a particular aim for what they hoped to understand through reflection. Finally, the third intention to arise was to *use during consultation.* This intention was mentioned by twelve of the sixteen participants, and it is about using the collected information during a clinical consultation, potentially for support in reflecting on what had been captured (as will be discussed later, in 4.3.6).

Five sub-intentions for tracking and reflecting on information also arose from the analysis. Three of these sub-intentions fell under *monitoring*. These were: *future reference*, *medication compliance,* and *ownership of data.* The other two sub-intentions fell under *acting*: *informing actions* and *observing effect of actions*. Each of the five sub-intentions were mentioned by at least four participants (Table 7). The third intention, *use during consultation*, was not broken down into any further sub-intentions. However, this intention overlapped with the five sub-intentions listed above; it showed that participants were also intending to use their captured data during a clinical consultation. This suggests that the data tracked was not intended just for reflecting alone.

| ID# | Monitoring | | | Acting | | |
|---|---|---|---|---|---|---|
| | Future Reference | Medication Compliance | Ownership of Data | Inform Actions | Observe Effect of Actions | Use in Consultation |
| 01-MHoWBD | X | X | | | X | X |
| 02-FHeBAD | X | | X | X | | X |
| 03-MHeBAB | | X | X | X | X | X |
| 04-FBiWAP | | | | | | X |
| 05-FHeBAP | X | | | | | |
| 06-FHeBAP | | | X | | X | |
| 07-FHeBAP | X | | | | | |
| 08-MHoLD | X | X | X | | | X |
| 09-MHoLP | | X | | | | X |
| 10-MAsWCD | | X | X | | | |
| 11-MHeMOB | | | X | X | | X |
| 12-FHeBAP | | | X | X | X | X |
| 13-FHeBAD | | | X | | | X |
| 14-FHeBAB | | X | | | | X |
| 15-MHoAPD | X | | | X | | X |
| 16-MHoWOP | | | X | | | X |
| Total: | 6 | 6 | 9 | 5 | 4 | 12 |

Table 7: Breakdown of participants and their intentions

### Monitoring

*Tracking with the purpose of having a record or reference point to look upon, particularly with the intention of having a deep understanding of themselves, without a focus on taking action or making changes*

Fifteen participants had the intention of tracking their personal health data so that they could *monitor* their situation. Statements coded with this were about keeping a record to have a reference point, a log of their personal health data that they could refer to for reflection if they desired, as a way of monitoring their health. The analysis of this category of generated three sub-codes (Table 8), with the frequency of mentions ranging from six participants to nine.

| Monitoring | |
|---|---|
| Sub-Code | Description |
| *Future Reference* | Tracking information because it may be useful or interesting in the future, with no particular reason or hypothesis |
| *Medication Compliance* | Tracking medication data to monitor or maintain compliance |
| *Ownership of Data* | Tracking data to have personal control over it, personally monitor it, or to feel like an integral part of the clinical process |

Table 8: The three sub-intentions of Monitoring

*Future Reference*

Statements coded under *future reference* were made by six participants (01-MHoWBD, 02-FHeBAD, 05-FHeBAP, 07-FHeBAP, 08-MHoLD, and 15-MHoAPD). As the name implies, these statements showed an intention for tracking various information so that in the future they could refer back and potentially gain an understanding of their health or the journey they had taken, though with no particular question for reflection: "*I dunno really, it's just sort of there to keep track of in case I ever want to look upon it*" (01-MHoWBD). This intention is at odds with the typical 'goal oriented' conception of why individuals engage with Personal Informatics and Personal Health Informatics. Additional statements made by these participants suggest that this is not just about keeping a point of reference but also about external cognition – by storing their information on paper or digitally, they are removing the burden of having to remember it themselves: "*There are so many things in my head, to be honest. I cannot keep track of everything*" (15-MHoAPD). The off-loading of information has not been previously identified as an intention or motivation for tracking, and suggests that external cognition is an important asset for reflection.

*Medication Compliance*

Another sub-intention was *medication compliance*, mentioned by six participants (01-MHoWBD, 03-MHeBAB, 08-MHoLD, 09-MHoLP, 10-MAsWCD, and 14-FHeBAB). Complying with a medication regime is particularly difficult for people living with HIV, and the anti-retroviral (ARV) drugs prescribed to them also demands a strict behavioral regime. Adherence is required not only on a daily level, like most medications, but on an hourly level as well. Because of these rigid but very serious requirements, it is no surprise that individuals would track their medication information with the intention of monitoring and maintaining compliance.

People living with HIV are prescribed anti-retroviral therapy, and taking this medication on time each day is important to prevent the virus resisting the medication. These six participants recorded when they took their medication, and for some this was done as a way to remind themselves to actually take it, as well as to reflect on their consistency: "*It's not just remembering to take it, it's*

*remembering that you took it*" (01-MHoWBD). However, ARV compliance is not as simple as making sure you take a pill each day; some medications need to be taken more than once a day and others can only be taken two hours after eating. Furthermore, people living with HIV need to make sure that they take their medication at roughly the same time of day, every day, for the rest of their lives. For example, 10-MAsWCD uses an app to track his compliance: "*Yeah, I just track that I took it, you know, it gives me a reminder*" he said, later adding "*Because I want to take it in the same hour every day. … Like, I've only missed 16 days in the last 3 years.*" Given the strict command that ARV medication has over the behaviors of people living with HIV, tracking with the intention of **medication compliance** appears to be very important.

*Ownership of Data*

Nine participants tracked their personal health information as a way of ensuring their **ownership of data**. Like **future reference**, this intention is not 'goal oriented,' and there is not explicit understanding that is sought from reflection. Instead, this intention appeared to be formed out of a desire to personally own their health data for their own reflection: "*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*" (12-FHeBAP). This aligns with the aspect of self-management that is focused on building knowledge and self-efficacy in a person's condition (Clark et al., 1991) because it was done by the participants as a way of taking control of their health and playing an active role in the clinical process: "*It feels to me like I'm managing myself*" (03-MHeBAB). The personal ownership of the data was done so that they could personally monitor the changes in their health: "*It's not only for the medical profession, it's for my own benefit as well*" (06-FHeBAP).

These statements suggest that an intention for tracking and reflecting can actually have an emotional charge. We can see evidence of this emotional aspect in many of the statements made by participants, like that made by 03-MHeBAB. These statements imply that by tracking their information, these individuals *feel* more empowered and *feel* like they are playing an important role in their healthcare: "*I'm the focal point. If people want to get a better result, what I believe is I have to be involved. I'm at the center of the service*" (06-FHeBAP)*.* These participants are showing that they want to take an active role in their healthcare and disease management, and that they are doing so through Personal Health Informatics.

*Acting*

> *Tracking data to understand what actions to take, or to observe how prior actions have made a change in the data*

A total of seven participants kept track of their information with the intention of **acting**. This intention is about personally and actively managing aspects of their disease and has two sub-

intentions (Table 9): reflecting on information to **inform actions** (an intention of five participants) and **observing the effects of actions** to determine if they were beneficial (an intention of four participants). The statements made by participants suggest that tracking and reflecting with the intention of **acting** is about maintaining health and preventing potential side effects. What is interesting about these two sub-intentions is that they actually provide evidence of the cyclical and iterative process of personal informatics, as will be discussed.

| Acting | |
| --- | --- |
| Sub-Code | Description |
| *Inform Actions* | Tracking information to determine what actions (or changes) should be made |
| *Observe Effects of Actions* | Tracking information to see how actions (or changes) have made an effect |

Table 9: The two sub-intentions of Acting

*Inform Actions*

Five participants (02-FHeBAD, 03-MHeBAB, 11-MHeMOB, 12-FHeBAD and 15-MHoAPD) mentioned the intention of tracking certain information is to reflect and **inform actions** that they should take. For each of these individuals, the information that they were tracking was not directly related to HIV but was linked. They had a question about something regarding their health and decided to monitor it so that, later, they could reflect and determine what, if any, action or change they should take. For example, 12-FHeBAD kept track of potential side effects and their progression to determine if she should take action: "*I will monitor it and see where it is going or if it is not going, and if I have to phone in for an emergency.*" Alternatively, when 15-MHoAPD described what information he wanted to track, he indicated that he had a theory that he would see a negative change: "*Also, if there is any deficiency coming in liver or bone, because those are some of the concerns that I do have related to my illness.*" With the intention of **informing actions**, we see examples of individuals attempting to prevent negative changes in their health by using PHI to track and reflect as a means of making informed choices about what actions to take.

*Observing Effect of Actions*

Tracking information to **observe the effects of actions** was the intention of 01-MHoWBD, 03-MHeBAB, 06-FHeBAP, and 12-FHeBAP, and this was about reflecting on actions that had been taken to see the effect they have had on their health. As an example, one participant (06-FHeBAP) explained that she had developed high cholesterol as a result of her medication, and because of this she tracked her cholesterol levels. When she received bad results, she would think about what she should be doing differently: "*When the GP tells me my cholesterol levels are ABCD, I'll write*

*them down. … If it's the good one then I won't worry, but if it's the bad one then I will say 'hold on a minute, I need to do more.'"* Recently, when faced with a bad result, 06-FHeBAP began eating better and cycling. When she returned to the GP to have her cholesterol checked, she used her records to compare and determined that her new actions were effective: *"Last time I went to the dietician I said I'd start cycling, so what I'm gonna do – I'll do more of the exercise I used to do and see how it goes. So I took note of that, the last time I went it was better than the last time."* This example shows how individuals are keeping track of certain information in order to see if their actions have had an effect. Sometimes they do this to see whether or not the effect was positive or negative: *"How is this impacting my health or affecting my health? Is it to the advantage or disadvantage?"* (03-MHeBAB). With the intention of **observing**, we see examples of individuals wanting to reflect on their information in order to evaluate their decisions to determine if their actions were appropriate.

### *Use in Consultation*

> *Tracking data with the intention of using it to prepare for a clinical consultation, show a clinician, or speak to a clinician about*

Twelve of the sixteen participants mentioned that they intended to use the information they tracked during a **clinical consultation**. This intention connects with the six sub-intentions previously described because participants showed that this collected data served a dual purpose. As will be explained, these participants were tracking data that occurs throughout their day-to-day lives – not data that is measured in a clinical setting. This data is then used to have an informed clinical consultation. The reasons behind the prevalence of this intention are likely related to the limited number of clinical visits a person living with HIV has each year. The examples described here suggest that this intention is not just focused about reflecting to gain understanding, but also about gaining better outcomes.

Once a person's viral load has been stabilized in the 'undetectable' zone, visits to the HIV specialist become less common. In the beginning, they occur every few weeks, then stretching to every few months. For example, 01-MHoWBD was recently diagnosed and described the shift in the frequency of visiting his HIV specialist: *"Um, it was every couple of weeks to start with and now probably every 2 or 3 months."* Over time, these visits are reduced to once or twice a year: *"I will be among the people that will see my consultant maybe… I will see him just twice next year unless I have an issue – there is an on-call doctor at the clinic. But I will see him only twice next year because my [CD4 count] is 900 plus"* (02-FHeBAD). During the span of time between visits, many things can occur that an individual may want to bring up during their next consultation.

Many of the participants reported seeing their HIV-specialist approximately once every six months, so for some this record-keeping was to serve as a reminder of points to discuss with the clinician:

"*I just write some hints in the notebook and that keeps me reminded of the questions I'm going to ask*" (15-MHoAPD). Participants also kept detailed records to show to their clinician as a discussion point and provide evidence of their experiences:

> "*That's why I have this, so I can realize oh why did this happen, or the doctor might realize 'oh maybe you are not taking your medication at the right time' and that's why I complain more about my health at that time*" (03-MHeBAB)

The types of information tracked by these participants were not available in a clinical setting; these were things that they experienced in the time between visits, mainly potential side effects.

By tracking and reflecting on health-related information outside of a clinical setting, it can be suggested that these participants are attempting to create a more holistic health record, one that not only depicts their clinical data but also how their disease is effecting their overall life. This could be seen as an informal personal health record. These participants intend to use their collected information during a clinical visit, and their goal is not just for support in reflecting on their health but also to gain better outcomes in their health care and health management.

### 4.3.2 Identification

*Searching for, or discovering, a system to use to support the process of PHI. Determining what information to collect, and/or how frequently collection will be necessary.*

When identifying a PHI system suitable for use, an individual may determine three things: what information to collect, how frequently they will need to collect, and appropriate tools to use. Different systems will have different impacts on reflection, and so the stage of *Identification* is important to understand so that suitable systems can be designed. Fifteen of the sixteen participants made statements related to Identification. **Information**, which refers to the types of information that the participants tracked / wished to track, was mentioned by 15 participants, and **frequency** (the frequency with which this information might be captured) was mentioned by 7.

#### *Information*

> *The personal information that an individual has collected, either currently or in the past*

It is important that people have access to the details, data, or experiences that they want to reflect upon. Therefore, PHI systems must support end-users in tracking the information that they deem necessary.

Of the sixteen participants, all but one mentioned the type of **information** which they capture (the exception being 16-MHoWOP, who did not specify what was on the papers he collected). Reviewing these statements revealed three main information types that highlight the directness of

the information to HIV: *indirectly related* (with four sub-codes of *emotions, food, weight,* and *exercise*), *directly related* (with two sub-codes: *medication, lab results*) and *potentially related* (again, two sub-codes: *potential side-effects,* and *other conditions*). Tracking more than one kind of data was common among twelve of the sixteen participants (Figure 25). As can be seen in Figure 26, the number of participants who mentioned each sub-code varied. *Emotions, food, weight* and *exercise* were the least frequently mentioned. *Medication* and *lab results* came up eight and seven times, respectively. Eight participants tracked *potential side effects* of the ARV medication. Similarly, seven people mentioned keeping track of health indicators related to *other conditions*, some of which developed as a result of the ARV medication. Whilst some of these information types may not immediately appear to be directly related to HIV, a closer look at the statements made by the participants show that the impact of HIV and ARV medication reaches far beyond lab results, generating a need for gathering a diverse range of information for a more holistic view. In the following sub-sections, each of the information types will be presented, along with an explanation of why it is being tracked.
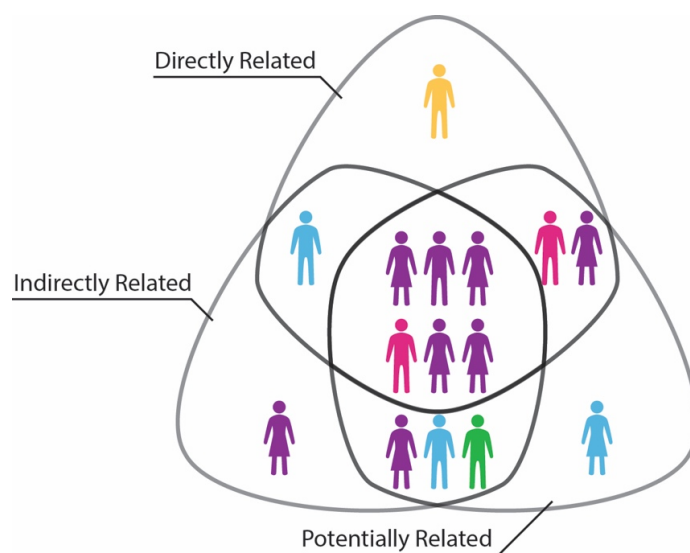


Figure 25: Twelve of the sixteen participants tracked more than one kind of information

*Indirectly Related information: Emotions, Food, Weight, and Exercise*

At first, *emotions*, *food intake*, *weight,* and *exercise* may not seem to have a clear relationship to HIV. However, statements made during the interview sessions provide some indications of the link. To begin, *emotions* were tracked by three individuals (02-FHeBAD, 05-FHeBAP, 07-FHeBAP), and their comments were rather straightforward (e.g. "*I'm feeling low this morning*" – 02-FHeBAD, "*I feel today like this*" – 07-FHeBAP, and "*The emotions, yeah. Sometimes I get emotional.*" – 05-FHeBAP). Whilst emotional well-being is not a symptom of HIV, negative emotions can be a by-product of the diagnosis ("*There seem to be more people with depression or a mental health condition that have HIV than the general population.*" – 01-MHoWBD) or

potentially a side effect of the HIV medication ("*Like sometimes if I say I feel so downbeat, I feel depressed, they brush it away and say that it's a side effect of the medication and I have to deal with it*" – 15-MHoAPD).

*Food intake* and *weight* are also related in much the same way. For example, 15-MHoAPD explained the reason why he tracks what he eats:

"*My body reacts to food in a weird way, to be honest. If I start eating more fat and all those things, I just get bulky so quick. But because of the medication, if I come back to normal eating or less eating, my body loses weight so quickly.*"

10-MAsWCD, who does not currently track his weight, provided details on why it was important for people living with HIV to do so:

"*If anything, I know that keeping track of your weight is important. Not specifically your weight, but how much fat you're holding, because the more fat you have, the more it stores, the more the virus hides in the fat cells. … You don't want to be too overweight. You also don't want to be too skinny, either, because then it replicates a lot faster. You have to keep it in a happy zone.*"
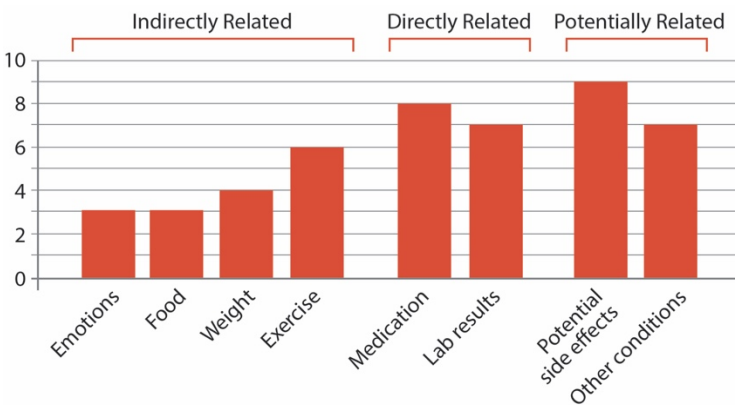


Figure 26: The type of information gathered by participants, with varying directness in relation to their HIV status

*Exercise* was mentioned by six participants. For example, 13-FHeBAD used a generic health application: "So I have the S-Health [application], the one that tracks your walking, it tracks your running, and it tracks your heartbeat as well." Like the rest of the participants who tracked *exercise*, 13-FHeBAD was capturing this information to see if she met her daily goals. *Exercise* was also captured to determine where more improvement or attention was needed: "Like, how distant or how long should I walk, or how often? Or what different kind of exercises I should do?" 03-MHeBAB. Tracking *exercise* was done by almost half of the participants. What this suggests is that people living with HIV have a desire to record the way that they are taking personal action to maintain good health.

*Directly Related Information: Medication and Lab Results*

Seven people stated that they kept track of their *lab results*, and 8 people said that they kept track of information related to their HIV *medication*. Regarding *lab results*, all 8 recorded the same two types of information: CD4 count and viral load. For *medication*, however, there was a bit more variety. For example, four people (01-MHoWBD, 02-FHeBAD, 08-MHoLD, and 12-FHeBAP) kept a record of what medications they were prescribed, and any changes in their prescriptions: "*I've got my medication on there. It keeps track of what medication I'm on, the date I started it. So if I want to change it, it will keep track of the day I changed it*" (01-MHoWBD). Three participants (01-MHoWBD, 09-MHoLP, and 10-MAsWCD) captured *when* they took their medication (noting either the day and/or time): "*For example, I just put the date and just make a tick to say I took my medication*" (09-MHoLP). The final of the seven participants, 14-FHeBAB, did not explicitly state what medication-related information she captured: "*If it's something to do with medication, I just put 'med' and then I just write it.*" By looking at the details of the information that the participants capture related to *lab results* and *medication*, it is clear that while many people may be tracking information related to the same topic, they are not always tracking the same data.

*Potentially Related Information: Potential Side Effects and Other Conditions*

Something made evident through the interviews was the drastic effect that ARV medication can have on a person's body. Participants stated that ARV can cause depression (as in the case of 15-MHoAPD), physical changes ("*My feet don't look the same, they're discolored. My feet are so black. It's because of the medications.*" 04-FBiWAP), and new conditions ("*A lot of people, as soon as they started HIV medications they developed cholesterol problems.*" – 04-FBiWAP). As a result, tracking *potential side effects* of the medication was common amongst half of the participants: "*Yeah, I write 'On this day I felt like this, I'm not sure if it's the medication or it's just a normal feeling'*" (14-FHeBAB). As was discussed in 4.3.1, Intention, keeping track of *potential side effects* was done both as a way of monitoring changes and providing evidence during clinical consultations.

Seven participants were tracking information related to *other conditions*. Not every participant explained whether their condition was developed as a result of the ARV medication or unrelated. Regardless, the data tracked about these *other conditions* ranged from blood test results ("*When the GP tells me my cholesterol levels are ABCD, I'll write them down*" – 06-FHeBAP), to physical feelings ("*I have a period tracker, so if I feel a bit weird or anything like that, it gives me options to write down if I'm feeling bloated or feeling a bit unwell*" – 13-FHeBAD), or even daily progress ("*I've kept a journal on my aftercare of my spinal operation and what's happened and how I've progressed.*" – 11-MHeMOB). The number of participants who track potential side effects and/or

other conditions shows that people living with HIV are likely to need to monitor more than just their medication and lab results. Instead, they need to constantly be aware of changes in their body and monitor these changes, as well as potentially monitoring other complex conditions in addition to HIV.

*Frequency*

> *Temporal dimension of capture (e.g. 'Every day', 'Once a month', etc.)*

***Frequency*** of capture was brought up by seven participants, resulting in two sub-codes: six of the participants mentioned tracking ***daily*** (capturing information on a daily or semi-daily basis) and three mentioned ***monthly*** (capturing information every few months). Through the analysis of the statements, it emerged that the frequency of capture was tightly linked to the availability of the information. For example, participants could only track their lab results every few months, when their doctor performed the blood test: "*Well, I just keep track of my CD4. I can keep track when I go to the doctor every 6 months. But they only take my CD4 once a year*" (09-MHoLP). Tracking medication compliance, on the other hand, could be done on a daily basis. This suggests that systems designed to support people living with HIV in tracking their health information needs to be flexible, allowing data recording to occur at various frequencies ranging from daily to monthly.

### 4.3.3 Capture

Reflection requires information to reflect upon and, as demonstrated by those participants who made statements regarding their intentions, there are clear desires to capture data for this purpose. In this section, we explore where the participants were storing their captured information.

*Storage*

> *Where the individual keeps, or stores, their information. Storage is where the individual can review or reflect on their information.*

The storage of data does not have an obvious connection to reflection if it is assumed that this storage is digital. However, there were a variety of media being used to store the health information of each participant and, as will be shown below, digital media was not always the case. Through the analysis of the statements, it appeared that participants used ***paper*** and ***digital*** systems for storing their health information (see Table 10 for definitions and examples).

| Storage | |
|---|---|
| Sub-Code | Definition |
| *Paper Storage* | Any paper-based, non-digital, collection of information |
| | e.g. Collection of loose papers, Paper diary / Notebook, HIV Specific notebook |
| *Digital Storage* | Any digital location in which the individual stores a collection of information |
| | e.g. Digital document / Notebook, Health app, HIV Specific website / app |

Table 10: Definitions of Storage, Paper, and Digital

There was a divide over the use of *paper* versus *digital* storage: more participants used paper-only than those using digital-only (seven and five, respectively) while four used both *paper* and *digital* storage. Statements made by participants produced three possibilities for the prevalence of paper-based storage: security needs, digital self-efficacy, and limited income.

It is possible that many of the recruited participants do not feel comfortable using digital devices and therefore chose to use paper instead. Whilst many of them had a smartphone, several made statements suggesting that they had a low digital self-efficacy:

> "*For some people like me it is age. Because someone who is old cannot manage to do technology. … They say this is a smart phone. It's a smart phone for a smart boy!*" *(03-MHeBAB)*

However, the choice to use paper could also be related to not being able to afford digital devices due to limited income. Indeed, in 2012 81% of the people living with HIV in the UK reported having less than £100 a week for disposable income, and 35% had no disposable income (Terrence Higgins Trust, 2014). Additionally, 40% of black Africans living with HIV in London in 2004 reported that they 'did not have enough money to cover their basic needs,' while less than 10% of white homosexual men said the same (National AIDS Trust, 2014, p. 28). Comments made by one participant provided context: when asked if she owned any devices other than her phone 04-FBiWAP said she didn't, adding that she had been seeking asylum for the last ten years.

> "*No no no, I'm not that rich. I've been living underground for ten years and I just got my papers yesterday.*" *– 04-FBiWAP*

However, another reason emerged from the data: there is a perception that paper provides more data security than digital technology: "*Paper, it cannot be spammed, it cannot be tracked. Nobody can track it unless I lose it on the bus or something. It's safe, I think it's safe*" (04-FBiWAP).

At first, it appeared that these individuals felt there were a lack of digital options available. For example, when asked if she would be interested in using a digital application, 06-FHeBAP replied:

"*Well, as of now I don't have an option, nothing is laid out for me to give me an option.*" However, digging further into this perceived lack of options showed that when their attention was brought to existing systems, such as the MyHIV website, participants showed that they actually were *aware* of such systems being made available. Turning back to 06-FHeBAP as an example, when the interviewer mentioned the MyHIV website, she acknowledged that she was aware of it but uncertain of its security: "*That's what I'm saying, I'm not sure. Because people are hacking into each other's emails!*" At this point, the second barrier to digital storage emerged: distrust of security.

The term 'security' refers to the safety of a user's personal information, and the measures taken to protect it against unwanted access (Belanger, Hiller, & Smith, 2002). When speaking about where they stored their information, twelve of the sixteen participants brought up security. This suggests that security is a feature that is considered when collecting and storing personal health information. Security was mentioned by seven participants using paper-storage and five using digital-storage. These statements show two ways in which these participants are personally ensuring the security of their data. First, by making their data difficult to access. Second, by encrypting their data in the event of a breach.

The way that users of paper-storage protect their data from unwanted access is different from the way that users of digital-storage do. The former feel that their data is secure because they are able to hide the diaries and notebooks in private places, such as in their room or in a drawer, where others should not be trespassing: "*A diary you can hide it, nobody can come in your room and take it. The best place to keep stuff is a diary*" (05-FHeBAP). To these participants, paper is more secure than digital because it is kept in a singular location away from the public eye.

Of course, if someone is using digital storage, they cannot hide it under their pillow. Instead, the five participants who spoke about the security of their information ensured it in two ways. First, they prevented others from accessing their data by requiring a password: "*My phone has a fingerprint scanner. So only I can open it. But if I didn't have that I would be nervous for my friends or family to look through my phone, you know?*" (08-MHoLD). Second, they stored their data locally, rather than in the cloud: "*One thing I don't do with my HIV, I don't put it on the cloud. I don't do that*" (02-FHeBAD). While different approaches to the same problem, these examples show that users are actually taking security measures into their own hands; personally ensuring that their data is kept secure rather than placing their trust in something else to do so. This suggests that it is not the medium itself which ensures data security, but the personal control.

In addition, to enhance security even more, four of the participants who used paper-storage also applied some form of 'encryption' to avoid accidental disclosure of their information. For example, one participant tracked his medication compliance with a subtle tick mark: "*I just put the date*

*and just make a tick to say I took my medication. So then I can see when I am doing it and sometimes I forget*" (09-MHoLP). The other three participants used initials ("*Yes, when it comes to HIV I put a lot of initials*" – 05-FHeBAP), symbols ("*I put a star, you know, an asterisk. I just put it in red like that … then I know it's, uh, HIV*" -14-FHeBAB), or a foreign language when referring to their health information ("*I have to use a jumble language which no one would understand when they see it*" – 06-FHeBAP).

## 4.3.4 Management

*Transferring, integrating, and/or editing personal data that has been captured*

Management of data is important for ensuring that the collected data is ready for representation and provides a truthful account of what has occurred. Reflecting on incorrect data may lead to an incorrect understanding. *Management* was mentioned by only five participants. During the analysis of the statements regarding *Management*, four sub-codes emerged: **editing**, **deleting**, **integrating**, and **transferring**. The statements that were coded into Management refer to both paper and digital storage types, suggesting that this stage is one that is important regardless of medium. However, the comments of the participants did not indicate any strong effect that activities in this stage might have on reflection.

### *Editing*

*Correcting or adding detail to previously captured data*

Of all the comments made in regard to Management, those describing **editing** were perhaps the most straightforward. Two participants mentioned **editing**: 02-FHeBAD and 11-MHeMOB. 02-FHeBAD wanted to edit her data to maintain proper spelling, suggesting the desire to make small corrections, even if they have little impact on the greater whole. Meanwhile, 11-MHeMOB edits his information to ensure that it is accurate. When asked if he ever looks back through the data he has recorded in his paper notebook, 11-MHeMOB confirmed that he did, and also that he edited it: "*Yeah. Yeah, I do actually. And actually sometimes I correct it.*"

### *Deleting*

*Removing data from the stored location*

**Deleting** was mentioned by two participants: 11-MHeMOB and 15-MHoAPD. For example, 11-MHeMOB described an instance where he had documented feeling quite good and realized later that it was due to the painkillers he was taking: "*so I had to revert back to that and make a big cross through.*" This participant 'deleted' his data (crossing it out) for accuracy. 15-MHoAPD also described deleting his data, but with a different purpose. 15-MHoAPD used a generic 'memo'

smartphone application to keep a list of his health concerns, and he would delete data from this list if he felt it wasn't important enough to discuss with his doctor: "*I just keep the most important ones, the rest of them I don't really ask.*" 15-MHoAPD was deleting his data as a way of removing what he considered to be extraneous, which can be viewed as a desire to filter through the collected data and highlight specific items.

### *Integrating*

*Bringing data stored in different locations together into one location*

Statements made by one participant, 03-MHeBAB, fell into the ***integrating*** sub-code. The statements made provided a very manual and literal example of integration. When asked if he writes his lab results in his paper diary, 03-MHeBAB replied: "*Yeah, yeah, that's where I write 'Last time my CD4 was this and now it is that.' And sometimes when I go to the hospital they print it out for me. I keep it in my diary so I can see that.*" This participant is saying that he actually integrates the paper-version of his lab results provided by his specialist into his paper notebook.

### *Transferring*

*Moving a corpus of data from one storage location to another*

***Transferring*** emerged from a statement made by one participant, 10-MAsWCD. This participant described the need to ***transfer*** his data because of using a smartphone application to track his medication compliance: "*My Pill Tracker. It doesn't, like, connect to any service. It just stays on your phone. And when you get a new phone you have to have the old phone and you redo all the data, or you start from new.*" 10-MAsWCD wants to transfer his entire collection of data from one location to another in order to maintain a long-term record.

## 4.3.5 Representation:

*Data depicted in a representation that will support reflection*

Reflection can be significantly supported when the data that has been captured is represented into a format that is easy to view and explore, yet only four participants – those who used a digital system to store their data – stated that they had representations ('visualizations') of their tracked information. It was these systems, rather than the participants themselves, which created the representations.

These four participants (01-MHoWBD, 10-MAsWCD, 13-FHeBAD, and 15-MHoAPD) did not provide detailed descriptions of the representation styles made by their digital devices. However, they did provide indications of the data depicted. As a result, two sub-codes emerged regarding

these data types: **HIV-specific data**, and **Non-HIV specific data**. From the analysis, it appears that representations of **HIV-specific data** are useful for reviewing data over an extensive period of time, while representations of **Non-HIV specific data** are important for facilitating insights regarding the effect of actions taken and informing future actions. Much like Management, the low frequency of mentions should not be used as an indication of unimportance, but rather a result of the systems being used. With this in mind, this sub-section will conclude with a discussion of the implications for future design and research.

## *Representations of HIV-Specific Data*

*The data being represented are specific to HIV (e.g. ARV medication, CD4, viral load)*

Two of these four participants discussed representations of data directly related to HIV (01-MHoWBD and 10-MAsWCD) and their statements suggested that representations of such long-term data facilitated a better understanding of their history with the disease. To begin, 01-MHoWBD tracked his CD4 and viral load, which he could then see represented in a graph: "*I think I use [the MyHIV site] as the main tracking thing, because you can then call up graphs. You can do it that way.*" CD4 and viral load are both numerical data, and from 01-MHoWBD's statement it appears that the website he uses generates structured data representations (refer to 2.4.2 for more detail on this representation feature), combining his CD4 and viral load data with a timeline. 01-MHoWBD, who had been living with HIV for less than a year at the time of the session, spoke about what a desirable trend would look like on such a representation: "*Um, you can see hopefully your viral load come down and your CD4 go up. Which is, again, at the beginning it's quite important.*" From his comments, it seems that 01-MHoWBD gains insight about his progression towards being undetectable and, potentially, how his medication compliance has influenced his lab results.

10-MAsWCD, who is a self-proclaimed 'techy', tracks his ARV medication compliance with a generic health-app. He stated that the app generates a representation where he can see his daily compliance over a long span of time. Because he has been using this app for three years, this representation allows him to review his compliance over the entire course of usage. His statements suggested that he receives both a structured and interactive representation of compliance and time ("*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*"), along with a numerical summary ("*Me, I have a 97% rate. … Like, I've only missed 16 days in the last 3 years*"). Additionally, it would appear that his representations include an indication of the time of day in which he reported taking his medication: "*Yes, it does show you the time, because it tries to keep you on time. Because I want to take it in the same hour every day.*" 10-MAsWCD made statements suggesting that he

appreciates these representations not only he is able to explore them, but also because they help motivate him to maintain a good rate of compliance:

> *"Well mainly the reason why is that it makes me feel like I'm completing a goal. Cause you don't want to miss, cause then you feel like 'oh no!' So it's just keeping track, every day you know 'okay I'm doing good, I'm doing good, I'm doing good.'"*

However, 10-MAsWCD also indicated that he received representations in a non-digital way as well. Like 01-MHoWBD, these representations are of his CD4 and viral load, but *unlike* 01-MHoWBD, these representations are provided to him on paper by his HIV specialist. One statement made by 10-MAsWCD implied that it was both the medium and the availability that made these representations less desirable than those on his phone: "*Well, for me right now that's in the Stone Age. I only get it when I go to the doctor, so it's on paper.*" Perhaps it is because 10-MAsWCD enjoys technology that he seems to feel that he has no place for the paper: "*Yeah, if I want them they'll give it to me, but most of the time I let them keep it because I'm not really sure what I'm going to do with a chart.*" Indeed, this could be an example of the barriers of integrating clinical data within a digital storage. Furthermore, this participant makes it clear that he finds the *information* interesting, but is hindered by format of the representation: "*Yeah, if there was an actual app to keep track of all that, I would actually like that. Because it would be more helpful for me to actually see it. Like, I see it now but the type of person I am, I need to see it digitally where I can look at the pinpoints on every graph. That's me, I need to see it digitally, pinpoint. Where I can mess with the information, look at it and expand it to see what's going on.*"

### Representations of Non-HIV Specific Data

> *The data being represented is not specific to HIV (e.g. steps walked, heart rate, weight)*

Three of the four participants (10-MAsWCD, 13-FHeBAD, and 15-MHoAPD) said that they used generic (non-HIV specific) healthcare applications which made representations of **non-HIV specific** representations of their exercise. It would appear that these applications created *structured* representations of objective personal data: "*You get little different graphs that show 'Oh you worked out this much this day, you didn't work out enough this day, this is how much you rested, this is how much standing, this is how much energy you used for the day*" (10-MAsWCD). The representations may also be numerical summaries of the data: "*It tells me how much I've walked during the day*" (13-FHeBAD). This statement also suggests that these representations do not cover the same lengthy amount of time as those previously described, therefore allowing the participants to reflect upon their activity during smaller chunks of time (such as one day).

The statements made by these three suggest that the representations of **non-HIV specific data** facilitate reflection. This seems to be due to the visual nature, which reduces the cognitive load of

the user and improves understandability: "*That gives you more of an easy information about what is happening. I'm not good with numbers, to be honest. Graphs and charts are more easy to understand what is happening*" (15-MHoAPD). Having a record of prior exercise activities presented in a manner that is easy to comprehend is useful to these individuals to ensure that they have met their goals, and to help inform future activities.

## 4.3.6 Reflection

*Looking at, or exploring, the collection or representation of data*

Reflection is the stage in which an individual looks at their collected data in order to understand or make sense of their health information, in relation to their initial intention. Throughout the interviews, fifteen of the participants stated that they did reflect on their tracked information. However, statements made by 12 of those showed that they were not always reflecting on their data by themselves, as would be expected, but actually using the knowledge of others to reflect. This section will focus on the two types of reflection identified through the analysis that involve other individuals: ***reflection with healthcare provider***, and ***community-aided reflection*** (Table 11).

### *Reflection with Healthcare Professional*

> *An individual reflecting upon data about themselves, that they have captured by themselves outside of the clinical setting, with the aid of a healthcare provider*

Referring back to Section 4.3.1 (Intention), the results showed that many participants were motivated to track their information so that they could use it during a consultation. When analyzing the statements made about reflection, it emerged that participants were not interested in just *sharing* their collection with their healthcare professional (HCP), but were also interested in using their HCP's knowledge to help them reflect and understand their health. For example, 02-FHeBAD kept track of potential side effects in an app on her phone with the intention of using the information in a consultation. She also made statements describing that she shared this information with her HCP to help her understand what it meant: "*So when I see him, we go through these, all the things that have been happening so I can find out.*"

| ID# | Reflection w/ HCP | Community-aided Reflection |
|---|---|---|
| 01-MHoWBD | | X |
| 02-FHeBAD | X | X |
| 03-MHeBAB | X | |
| 04-FBiWAP | X | |
| 05-FHeBAP | | |
| 06-FHeBAP | X | |
| 07-FHeBAP | X | |
| 08-MHoLD | X | X |
| 09-MHoLP | | |
| 10-MAsWCD | | |
| 11-MHeMOB | X | |
| 12-FHeBAP | X | |
| 13-FHeBAD | X | |
| 14-FHeBAB | X | X |
| 15-MHoAPD | X | X |
| 16-MHoWOP | | |
| Total: | 11 | 5 |

Table 11: Twelve participants stated that they reflected on their data with a healthcare professional (HCP), or within a community of other people living with HIV.

The statements made by the participants show that the information that is focused on during this reflection is *potentially related information*. This means that the participants were using the medical expertise of their healthcare professional to help them reflect upon the data that they collected *outside* of the clinical setting. It has been made clear that HIV is a complicated disease, and that it is difficult for a person to determine if changes in their health are related to their seropositive status. Therefore, the actions of these eleven participants suggest that when they are unable to draw insights about *potentially related information*, they turn to the expertise of their HCP for support. How this activity is carried out in a clinical setting, and fits into the flow of a consultation, is not yet known. Indeed, because this was not the focus of the research study, the gathered data shows only that the participants conducted this reflection with their HCP; other than knowing that this is common and important to so many, the rest is yet to be understood.

*Community-aided Reflection*

> *An individual reflecting upon data about themselves, that they have captured by themselves, with the aid of the HIV or sexual-health community*

Throughout the interviews, it became apparent that for people living with HIV, socializing with their community was very important: "*So there is that social side as well as the tracking side. I think the social side might be more important than the tracking side. The peer support, I mean*" (01-MHoWBD describing the importance of the forums on the THT website). From the analysis, it emerged that almost one-third of the participants were turning to the community to help them reflect upon the information that they had collected (***community-aided reflection***). Additionally, many participants made statements suggesting that community-aided reflection was quite common and important to reflecting:

> "*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*" (15-MHoAPD)

For example, 01-MHoWBD would ask his contacts on Twitter to help confirm or correct what he was seeing in his data: "*Again, through Twitter you go 'Right, I've seen this, is this true? Does this ring true to anybody else?' and yeah.*" With all of the complexities of living with HIV, it seems that these participants are turning to the community as a source of knowledge that can be applied to understand what their data is showing. Four out of these five turned to online communities and forums to ask their questions and, occasionally, would be able to find that others had already asked the same question:

> "*Sometimes what I do, because a lot of people are having the same sort of medication and the same sort of side effects, so you just type in the name of the medication and side effects and you get similar sort of questions that are already there and you can read their answers*" (15-MHoAPD).

The participants didn't explain what drove them to community-aided reflection, but a statement made by one participant (15-MHoAPD) may explain at least one reason for turning to the community: convenience. As previously explained, 15-MHoAPD would capture his potential side effects, ask his clinician about the most important ones, and ask the community about the rest before deleting them. With months between time-pressed HIV consultations, it may be that people living with HIV turn to their community for help in understanding their health information in the gaps of time in between.

## 4.4 Discussion

This research study was focused on identifying where there are opportunities for supporting reflection in the various stages of the PHI process, by gathering a detailed understanding of how

people living with HIV currently track and reflect on their personal health information. The use of the process model of PHI as a structure for analysis proved to be a useful approach. The statements made by the 16 participants shed light on various opportunities for support, and also indicated design considerations for PHI systems in general.

This final section of the chapter will first describe design implications related to each stage of the process. This will be followed by a deeper discussion regarding opportunities focused around information, representations, and community-aided reflection, which then motivate the later research studies.

### 4.4.1 Design Implications

*Intention*

The intentions described in this chapter show examples of people living with HIV using Personal Health Informatics as a way of personally monitoring, managing, and taking control in the treatment of their disease. These results highlight a desire to track and reflect on personal health information, even (in the case of *monitoring*) if there is no particular question or understanding that is sought. Also, HIV is a chronic condition, which means that seropositive people will find that the information types they need to capture will ebb and flow over the decades they spend living with the disease. In order to support people living with HIV in their reflection and understanding their health, PHI systems must be able to support an individual's intentions, even if they change. Systems need to be flexible and accommodate for changes of intentions over time, allowing users to track and reflect on different types of information over time. Perhaps this could be achieved through highly customizable designs, allowing the end-user to shape the system to fit their personal needs or placing temporary priority on certain information types while they are more of a focus.

*Identification*

Fifteen participants showed that eight different types of information were captured, and the directness in the relation between the information type and HIV varied. This showed not only the wide-spread impact of the disease on a person's life but also the need to capture many different kinds of information to enable a holistic understanding of how it has affected them personally. HIV effects the immune system and those living with the disease must be vigilant of potential symptoms of new illnesses or conditions. This means that, while they may not be certain of how the information they track is related to their disease, there is a need for tracking it. PHI systems *must* support people living with HIV in tracking a wide array of data.

However, the participants indicated that different types of information would need to be tracked with a different frequency. While medication compliance could be tracked on a daily basis, lab results might only be received once or twice a year. This again suggests the need for a flexible tracking system, allowing data recording to occur at various frequencies ranging from daily to monthly or even annually. Researchers should explore the relationships between the information types being captured – perhaps there is a correlation between an individual tracking their weight and potential side effects, or their emotions and their lab results.

*Capture*

The analysis of *Capture* highlighted the need for secure, covert systems, and PHI systems must be designed in accordance of these findings. A digital system should not be obvious in its relation to HIV, it must not allow others to access its contents, and it must be designed such that the data that is tracked are stored securely.

*Management*

The Management actions described occurred with both paper and digital storage mediums, showing that the desire to make alterations to captured data is not hampered by the medium of use. The participants showed an interest in ensuring that their captured data was a truthful depiction of their health, and that they wanted to maintain a comprehensive collection of their data over long periods of time. This suggests that **editing**, **deleting**, **integrating**, and **transferring** are important features that future systems should include.

*Representation*

The participants of this research study have shown that reflecting on their personal health information was of interest, yet only four of the sixteen participants had access to representations of their tracked health information to reflect upon. This means that there is currently a rather large burden in trying to reflect upon, and understand, collected data. Providing individuals with representations of their tracked data is an obvious step towards scaffolding and supporting the reflective process. In consideration of the varying frequency with which the information types were tracked, representations need to be flexible in the time-span of data being presented. While 13-FHeBAD views a daily representation of the steps she has taken, 10-MAsWCD's representation covers three years' worth of data – a good tool will meet the needs of both these individuals. However, designers should also consider if and how to include multiple data types (e.g. **HIV-specific data** and **Non-HIV specific data**) together in a representation to support reflecting on these different types of information together.

*Reflection*

The participants in this study showed that reflecting alone is not their only approach to gaining an understanding of health: turning to others for support in reflecting on health information was shown to be another tactic for reflection, particularly when trying to answer a question about a health experience. Designers should consider how to facilitate the sharing of tracked information amongst community-members and between patients and healthcare professionals. A possible design solution would be one that allows a user to compare their collected data with the data of others living with HIV, and converse about it, in order to determine if their experience was unique or shared, and if it was related to their disease.

## 4.4.2 Moving Forward: Opportunities for Supporting Reflection

The findings described in this chapter demonstrate that people living with HIV are interested in tracking and reflecting on their personal health information, but there are obstacles preventing them from reflecting. Three interrelated opportunities for supporting reflection stand out: Information, Representations, and Reflection. These will be the focus of the remaining studies in this thesis.

*Information*

The results of this research study highlighted the desire to track more than one kind of information (directly, indirectly, and potentially related), demonstrating the importance of gathering holistic data. This is at odds with current systems made available to people living with HIV, which do not support them in tracking such a wide array of information. Because HIV will cause changes in the mental and physical health of those infected over the course of their lives, the type of information that they need to track will fluctuate with the focus of their health concerns. This fluctuation is in contrast to many other chronic diseases, like diabetes, which typically have specific types of information related to their condition to track.

Systems that enable tracking such wide varieties of information are considered to have a free-form data feature (as discussed in Section 2.4.2), and systems that include this feature are rare. Given this, it is not surprising that current systems do not adequately support people living with HIV in their tracking needs, nor is it surprising that they may choose a generic option like paper that allows them to track whatever they deem necessary. A tool which does not prescribe the data to be tracked, such as DAYTUM, would allow the flexibility that people living with HIV need.

However, nearly one-third of the participants indicated that they turned to others in their community for support in understanding their health information, and additional detail is required regarding the data that is tracked and sought to be understood. We must determine what people

living with HIV are trying to understand during reflection, and which information types are the focus of their questions when turning to others for support in reflecting. With a greater understanding of the information types that are tracked and reflected upon, we will be able to develop PHI systems that are focused on supporting those needs (Chapter 5, Study Two).

*Representations*

There was a clear desire to track and reflect upon personal health information, regardless of if the intention for tracking was for monitoring or for taking action. However, less than one-third of the participants stated that they had representations of their data, and none of those combined the three different information types together. This suggests that these systems do not currently support people living with HIV in forming a holistic understanding of their health, and therefore might not adequately support reflection. Additional research is required to explore representation styles that are capable of displaying different types of information collectively. This would support those reflecting on the representation to draw connections between experiences and develop a detailed understanding of their health. Additionally, creating representations that map the individual's data to a greater sample would facilitate HIV+ people in reflecting and understanding if their experiences are shared. How these representations might look is something that needs to be explored and carefully considered (Chapter 6, Study Three).

*Reflection*

The participants of this study showed a strong desire to reflect on their collected information with the support of their clinicians' and communities' knowledge. Research outside of PHI has explored how patients and healthcare professionals reflect on a patient's health experiences, showing how different representations affect a patient's decision-making, or that patients prefer anecdotal depictions of their experiences, while clinicians prefer numerical ones (Faisal, Blandford, & Potts, 2012). These details can be used as a beginning point for further exploring the use of tracked personal health information in a clinical setting.

The number of participants who were interested in reflecting with the assistance of their healthcare provider outweighed those who were interested in reflecting with the aid of the community. However, researchers such as Mo and Coulson (2008) and O'Kane et al. (2016), have indicated the importance of community involvement in self-management, and have even begun to indicate what is asked of the community (in the case of O'Kane et al.). Still, researchers have not drawn the distinct connections between Personal Health Informatics and community-aided reflection that emerged from this study. Thus, there is much more work to be done in order to understand the details of what occurs. Given that forums and social media are used internationally, research that seeks to explore how community-aided reflection occurs, and how it might be supported, could

benefit individuals world-wide who seek support in understanding their personal health. Further work that explores what information is being shared, what is being asked about, and how the community aims to provide support is required before developing a system that can support such community-aided reflection. Addressing this knowledge gaps would not only help understand how PHI systems can support HIV+ people in self-managing through reflection, but also can be transferrable to other chronic diseases.

With these implications as a motivation, the next study of the thesis explored the use of a community during reflection on personal health information (see Chapter 5, Study Two). This study was aimed at understanding the questions that people living with HIV have about their health, the information that they are trying to reflect on, and how they seek aid from their community for reflecting and understanding their health. With this grounding, we will be able to identify what is needed in a PHI system that supports such reflection, how the information might be represented, and how communities can be involved.

# Chapter 5 Community-Aided Reflection in Online Forums (Study Two)

## 5.1 Motivation and Research Questions[3]

Within Personal Informatics and Personal Health Informatics, the act of reflecting has been seen as an individualistic act, not a social one (Baumer, 2015). PI and PHI researchers have traditionally understood reflection to occur when an individual reflects upon data about themselves, that they have captured by themselves, with no others supporting or sharing in the reflection. The results reported in Chapter 4 indicated that people living with HIV also turn to their community to aid in reflection, particularly online, which I refer to as *community-aided reflection* (see 2.3.2):

> **Community-aided reflection occurs when an individual reflects upon his or her personal health information alongside the knowledge, experiences, or health information of others who are similar, as a means for generating new knowledge or understanding about him or herself.**

Participants in Study One suggested that the activity of reflecting with the aid of their community often takes place online. When it comes to health, online support groups, forums, and communities are beneficial to people in need of information, advice, or support (Grimes, Landry, & Grinter, 2010; Roffeei, Abdullah, & Basar, 2015).

People with stigmatized diseases may find it easier or more welcoming to turn to online resources rather than in-person ones for aid in self-reflection, as there is more anonymity. Research has shown that individuals turn to online communities and forums for social support regarding their health or health behavior (e.g. Paay, Kjeldskov, Skov, Lichon, & Rasmussen, 2015; Mo & Coulson, 2008). An analysis of 123 comments made between users of PatientsLikeMe who were living with Amyotrophic Lateral Sclerosis (also known as Lou Gehrig's disease) demonstrated that those users were reviewing other people's personal information and asking questions about it to inform their own treatment (Frost & Massagli, 2008). A recent investigation of the online information-seeking behavior of people with diabetes and people with chronic migraines showed that individuals often wanted to determine whether their personal health information was typical, or 'normal,' for someone with that condition, and sought input from others to try to understand their health information (O'Kane, Park, Mentis, Blandford, & Chen, 2016).

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[3] Contents of this chapter were taken in part from Bussone, Stumpf, & Wilson (2017)

Looking more specifically at research relating to online HIV communities, a study of 85 threads on an online community forum for people living with HIV/AIDS focused on exploring how users sought support from their community. The results of this study showed that 86% of the messages in these threads contained social support, with the most frequent (44.5%) being informational support (Mo & Coulson, 2008).

Social support occurs when aid or assistance is exchanged in a social interaction (Heaney & Israel, 2008). While the receiver may not always perceive it as such, the intentions behind social support are always positive; the individual providing it is doing so with the goal of being helpful in response to a person in need (Heaney & Israel, 2008), either by providing nurturant support, or by providing support that facilitates action (Cutrona & Suhr, 1992).

Nurturant support is that which comforts or consoles the individual, but does *not* attempt to solve or eliminate their problem (Cutrona & Suhr, 1992). Three types of social support are included in this category: emotional support (expressions of empathy, love, trust, or caring), esteem support (commentary that helps the individual self-evaluate or re-appraise their situation, in the form of constructive feedback), and network support (commentary suggesting a sense of belonging to a community with similar problems or interests).

Action-facilitating support is that which aims to help the individual solve or eliminate the problem causing their stress (Cutrona & Suhr, 1992). Informational support (the provision of advice, suggestions, or information that the receiver can then use to address their problems) and tangible support (the provision or offer of tangible aid or services that directly assist a person in need) fall into this category.

The benefits of social support have been researched in the health and psychology communities, though largely these have focused on how social networks providing support can enhance health through reducing stress (Heaney & Israel, 2008; Mo & Coulson, 2008). The social support that people receive in an online community has been investigated for caregivers of children with autism (Roffeei, Abdulla, & Basar, 2015), older adults (Pfeil, Zaphiris, & Wilson, 2009), people attempting to lose weight (Hwang, et al., 2010), and (as described above) people living with HIV (Mo & Coulson, 2008; Mo & Coulson, 2014). These authors have demonstrated that social support exists in online forums and that it occurs when communities attempt to help another individual. Still, to the best of my knowledge, none have explored the social support that online communities provide with the perspective of reflection.

Reflection with the aid of a community has not yet been explored in depth within PI or PHI, leaving a gap in knowledge on the way in which it occurs. Despite the importance of online communities, forums, and social support for people living with chronic disease, no one has connected these

activities to the process of personal health informatics and the desire to understand personal data. Thus, there is little understanding of how PHI systems can better support individuals in reflecting on their personal information with the aid of their community. To advance this understanding, Study Two aimed at answering the following research question:

**RQ-3: What kinds of questions about personal health information do people living with HIV seek support in reflecting on, and how does the online community aim to address them?**

This research question was broken down into three smaller ones:

**RQ-3.1: What kinds of questions do people living with HIV seek support from their online community in reflecting on?**

**RQ-3.2: What types of personal health information are people living with HIV trying to reflect upon?**

**RQ-3.3: How does the online community attempt to address these questions?**

To address these, a research study involving both qualitative and quantitative data was conducted. Two hundred threads were scraped from an online public HIV community forum and analyzed for evidence of community-aided reflection. Analysis focused on determining the types of questions that were asked, the information that was asked about, and shared, and how the community aimed to support those who posted the questions.

The results of this research delivered one key contribution to the academic community: an empirical understanding of how online forums are used to reflect on health information, what kinds of questions people living with HIV seek support in reflecting on, and how the community aims to address the question. In addition, the results of this research will benefit those who engage in this kind of reflective activity. If the industry grows and changes to support online communities in community-aided reflection, the individuals who visit those communities also benefit. With more support of community-aided reflection, these individuals will potentially be able to draw faster or better insights. This, in turn, should lead to an improved ability to self-manage. Improved knowledge and self-efficacy regarding their personal health will hopefully then lead to more empowered patients who experience better health outcomes.

## 5.2 Method

This research study involved the analysis of threads in an online public HIV community forum.

## 5.2.1 Sampling Strategy

### The community forum

The community forum that was selected as the data source for this research study will not be named, for reasons explained in Section 5.2.4. The community forum that was selected was chosen for two main reasons. First, it is an established brand in the HIV/AIDS community. The brand has provided news, treatment updates, and a social community for people living with or affected by HIV/AIDS since for over two decades. The website is available internationally, and reaches HIV+ individuals around the world. The brand's popularity and international reach suggest that their community forums are a valuable source of data.

The second reason is that the community forums are publically available. Registration is not required to view the threads in the forums, though registration is required to post or make comments. Visitors to the forums are greeted with a privacy warning, which informs them that the forums are open to everyone and fully searchable (Figure 27). While advertising a research study on the forums is not permitted without prior permission, the website does not prohibit research of the forum content. Additional details on the ethical considerations of this research are provided in Section 5.2.4.

> **Privacy Warning:** Please realize that these forums are open to all, and are fully searchable via Google and other search engines. If you are HIV positive and disclose this in our forums, then it is almost the same thing as telling the whole world (or at least the World Wide Web). If this concerns you, then do not use a username or avatar that are self-identifying in any way. We do not allow the deletion of anything you post in these forums, so think before you post.

Figure 27: The privacy notice presented on the community forum

### Selected forum topics

Within the community forums, there are five categories and a total of nineteen forum topics. The descriptions of each forum topic were reviewed to determine if they were appropriate for the research study. Topics were excluded from the study if they were not intended for English-speakers, not intended for HIV+ individuals to start threads (e.g. 'How can I prevent HIV?'), or not intended for the sharing of personal health information (e.g. 'Forum Gatherings'). Based on this criteria, a total of eight forum topics were selected, shown in Table 12.

### Thread sampling

Two-hundred threads were selected; the 25 most recently active threads per topic. Others who have researched community forums have selected their sample of threads based on an amount of time (e.g. Mo and Coulson (2008) analyzed all threads to be added to the site over the course of one month). For the research study reported here, the threads were selected based on the

| Topic | Description |
| --- | --- |
| I Just Tested Poz | For the newly diagnosed, and the long-termers with sage advice |
| Living with HIV | For HIV+ individuals and their friends & family |
| Pre-HAART LTS | A forum for pre-HAART long-term HIV survivors |
| Positive Women | A forum for women living with HIV |
| Treatment & Side Effects | The ups and downs of antiretroviral therapy and other treatments |
| Mental Health | Stress, anxiety and depression |
| Metabolic Problems | Body, bone and blood: lipodystrophy / lipoatrophy, osteopenia / osteoporosis and lipid / glucose abnormalities |
| Nutrition & HIV | Diet, exercise, supplements and more |

Table 12: The forum topics selected and their descriptions as shown on the website.

most recent activity; this way, both newly added threads and long-lasting ones could be analyzed. Threads can continue to be messaged on far after the date of the original post, which can result in a large amount of variability in the number of messages received, users responding, and time of activity.

## 5.2.2 Working Definitions

The following terms will be used frequently throughout; their working definitions are provided below.

**Online Forum:** A website designed for individuals to meet, share ideas and views on different issues. The discussions take place in the form of messages (or responses) to original posts; discussions are contained within a thread.

**Topic:** Forums are often divided into multiple topics. These topics indicate the types of information that should be discussed, they are used to guide users on where they should post.

**Thread:** Threads are created when a user writes an original post. A thread consists of one original post and all response posts (if any), displayed in chronological order from the oldest at the top.

**Original Post:** An original post is made by a user within a topic; the original post is the start of a new thread. Original posts contain a title and a message for other users to read or respond to.

**Original Poster:** The user who creates the original post is referred to, in that thread, as the original poster (OP). There can only be one OP per thread. Using the term OP allows us to differentiate between the user who created thread and all other users who respond on that thread. Because some OPs also message on their own thread, it is important to differentiate between the two.

**Message / Response:** Any reply made to an original post in a thread is referred to as a message or response. These may be made by the Original Poster, or other users.

**Users / Posters:** The 'users' are the individuals who visit the forum and post on threads. There are other users, known as guests, who may visit the forums, but because they do not have screen names and do not make comments, they cannot be observed.

## 5.2.3 Rules which determine if a post includes a community-aided reflection question

Specific criteria were applied to determine if a post includes a community-aided reflection question on personal health information. A community-aided reflection question may be found in the original post, or in a message later in the thread. These criteria were set up to keep the research in scope to PHI.

1. The poster must share personal health information:
   a. The information must be *personal* (information about the individual themselves, not about another person).
   b. The information must be related to their *health* (e.g. the information types identified in Study 1: exercise, weight, food intake, emotions, lab results, medication, side effects, and other conditions).
   c. The information must have been drawn from a lived experience (the individual is seeking insight on health-related aspects of their life that they have gone through – e.g. not a hypothetical situation or a future scenario).
2. The poster must be seeking input based on their shared information:
   a. The post must indicate that feedback or responses are welcome.
   b. The post must indicate that the poster is seeking feedback/responses on the information that they have shared.
   c. The post must indicate that the poster is seeking feedback/responses that will help them understand the information that they have shared (for example, seeking to understand why something is occurring, rather than how to stop something from occurring).

Below are four examples of posts that were taken from existing ones found on the community forum, but trimmed to the key parts. As will be shown, two of these are examples of users seeking community-aided reflection, two are not:

**Message 1:**

*Going on day 72hrs and the migraine is still severe with no signs of letting up. My doctor said it might be a while and there's nothing I can do. The internet said it would take one*

*or two days. What causes the severe migraine? When I've woken up the last two days, I've thrown up. I'm getting cold sweats, and can't seem to do anything to help the migraine. What are your thoughts on this?*

Using the criteria listed above, Message 1 is an example of an individual seeking community-aided reflection. The information that is shared is indeed personal, related to the user's health, and has been experienced. The user clearly indicates a temporal aspect to their information by including the number of hours it has occurred. The user is seeking responses by asking questions. The questions indicate that they desire responses to their shared information.

### Message 2:

*New to the forum – I was diagnosed 10 months ago - Western Blot positive (350 CD4, 75 000 VL). I'm struggling with stigma, and fear of rejection. How did you deal? Any recommendations?*

This is not an example of a person seeking community-aided reflection. While personal health information was shared, and community feedback is desired, the user is *not* seeking responses based on their shared information.

### Message 3:

*Just started Triumeq a week ago on Oct. 23. Before that, I spent 4 years on Prezista, Norvir, and Truvada. Once I switched, I started having insomnia immediately. Every night. I've changed what time I take the pills, and I still have it. Insomnia isn't listed as a common side effect. I'm hoping it will pass. Has anyone else experienced sleeping issues with Triumeq?*

Message 3 is an example of community-aided reflection. The information shared is personal, health-related, experienced, and indicates time. Feedback is desired, and the user directly indicates that they wish the responses to relate to their shared personal information.

### Message 4:

*I was recently diagnosed (two weeks on ARV now) and for my next medical appointment my doctor wants me to get a TB test and get a PREVNAR vaccination. I understand that people with compromised immune systems are more likely to get TB, but if one is on ARV and has good CD4 numbers, is there still a higher likelihood of contracting TB being positive?*

This post is not an example of community-aided reflection. This is because the user is not asking about something that they have experienced, but something that could occur. Their desired feedback is not focused on their personal health information, but on the possibility of contracting another disease.

### 5.2.4 Ethical Considerations

This research study was approved by City, University of London's Computer Science Research Ethics Committee (see Appendix 10).

After lengthy consideration, it was determined that gaining consent from the users of the community forum was not required. As mentioned, the website and community forum is open for all to use, does not require registration for viewing, and is made fully available to search engines. All of this is made explicitly clear to the users and visitors of the forums (refer to Figure 27). While advertising for a research study is prohibited without prior permission, there is no restriction on using the forum to conduct research. As such, the community forum can be considered a place of 'public' communication and does not require consent (Eysenbach & Till, 2001).

While users were not asked to provide consent, measures were still taken to ensure their information remained confidential. All user IDs captured when scraping the forum were replaced with generic ones (e.g. 'CleverMoniker' would be replaced with 'User1') and all potentially identifiable information was replaced with generic terminology (specific locations, names, places of work, etc.). This anonymization was permanent; no records of the original data were kept. Additionally, in order to protect the culture and trust of the community using the website, future publications or presentations on this research will never name the community where the data was taken from (as recommended by Eysenbach & Till, 2001).

### 5.2.5 Materials

The study required a web scraper to gather the data. A web scraper is used to extract information from websites onto a spreadsheet that can be saved locally. The chosen platform for this research study was Import.io (https://www.import.io). Import.io is free to use for scraping a maximum of 10,000 web pages each month. Import.io allows users to gather data from websites by simply entering the web addresses into a form, rather than writing any code.

### 5.2.6 Data Collection

*Data Retrieval*

The extracted data from each thread were grouped by forum topic and exported as an .csv file, then saved on the researcher's computer with the file names indicating the topic forum.

The following data were extracted from each thread and used for analysis:

- Thread title (provided by the original poster)
- Thread link

- Original post
- Thread responses, listed in chronological order with the oldest at the top and most recent at the bottom
- User names associated with each post made

*Anonymization, User Details, Cleaning and Preparation*

After extracting all the data, anonymization began. First, all user names were replaced with generic ones (e.g. User1, User2, User3, etc.). A separate spreadsheet was used to ensure no duplicate names were created. This spreadsheet was then deleted to maintain anonymity and privacy.

The messages contained in each forum spreadsheet also had to be scoured and anonymized, as some users tended to end their message with their user name or real name. All user flair and signatures were permanently removed from the forum spreadsheets, as they may also have contained identifiable information. Once the spreadsheets had been anonymized, they were ready for analysis.

### 5.2.7 Data Analysis

A multi-step approach was taken to analyze the data set. First, every message included in the 200 scraped threads was examined to determine which contained a community-aided reflection question according to the rules described previously (5.2.3). When one was found, the responses that followed were also examined to identify those which contained a response from a community member aiming to address the question. In the 200 threads there were 2455 messages, of which a total of 252 were involved in asking or responding to questions about personal health information (10.2%). Of these 252 messages, 60 contained community-aided reflection questions and 192 aimed to address the questions. The questions were asked by 46 unique users, while 76 unique users posted messages aiming to address the questions.

Following this, all 60 messages containing questions were then examined. It was found that 11 of the 60 messages contained more than one question, giving a total of 77 different community-aided reflection questions being asked in the 60 messages. A thematic analysis was conducted to determine the types of questions asked. As described by Braun and Clarke (2006), this involved a manual exploration of the data to find instances of themes, also known as codes. The thematic analysis in this study drew partly on a set of previously defined codes for information-seeking described by O'Kane et al (2016) while also developing new codes from themes in the data. The codes were focused on describing the type of question that was being asked, rather than the information asked about. In this way, the results could be more transferable to other conditions. The development of codes went through several iterations based on discussions with supervisors.

In the end, five codes for question types were developed and defined, grouped into one of 3 main themes (Table 13).

| Question Types | | |
|---|---|---|
| Theme | Question Type | Description |
| *Causation* | *What caused this?* | A user is seeking to determine what caused a change in health, with no hypotheses. |
| | *Did that cause this?* | A user is seeking to determine what caused a change in health, with one or more hypotheses. |
| *Normalcy* | *Is this normal?* | A user is seeking to determine whether or not a change in their health is worrisome (or a 'bad sign') or a normal occurrence. |
| | *Is this normal at this point in time?* | A user is seeking to determine if something is in a normal range and/or if something is changing at a good rate in relation to diagnosis and/or start of treatment. This code is not about anticipating the future. |
| *Future* | *What's going to happen?* | A user is seeking to understand what to expect from the changes in their health in the future. This code is about anticipating the future. |

Table 13: Three main themes of questions, with five codes for question types, emerged from the analysis

Applying the codes began once they were developed and agreed upon. The unit of analysis used was per unique question asked within a community-aided reflection message, rather than per question asked. The reason behind this decision was that a user may ask the same question more than once in a message, which – if coded twice – would skew the results to suggest frequencies higher than observed. For example, User004 asked the same type of question (***Is this normal or cause for concern***) twice, focusing on the same health experience, in their community-aided reflection message (bold text indicates questions):

> *"[…] I have a lymph node under my jaw spring up. It feels tender. I can't work out any reason for that one to appear.*
>
> *I've not been particularly prone to lymph swellings throughout my life. I had a big one in my neck swell when I had tonsilitis a few months back but thats it.*
>
> ***Should i be worried about these swellings?*** *Should I be trying to get antibiotics for the bumps on my head, or just give it time (with the amount of antibiotics I've had in the last week I'd rather avoid more!)?* ***Is this all a bad or good sign, or irrelevant?****" – User004*

However, a message containing community-aided reflection may contain multiple different questions, and in these instances each different question type was coded (see example shown later, in Section 5.3.1).

The third step in the analysis was to determine the health information that was being shared and the health information that was being asked about in the messages containing those questions. In keeping with the scope of this research, only personal health information that had been

*experienced* was coded. The existing framework of 7 information types used in personal health information tracking of HIV developed in the first study (see Chapter 4, Section 4.3.2) was used as a starting point for this analysis. New information types (***Diagnosis, Start of ARVs*** and ***Sexual Activity***) were added after conducting open coding on the data. Additionally, one of the information types described in Study 1 (***Potential side effects***) evolved into a new code (***Reactions***) to denote information that could be a side effect of the medication *or* a symptom of HIV. As it would be nearly impossible for the researcher to determine whether something like a rash was a side effect or a symptom, these were grouped together under the same code. In total, 11 personal health information types were identified, the four which were not in the previous framework are defined in Table 14. The information types included in the messages were also coded to indicate if they were the focal point of the question (what was being asked about) or provided as context to the question.

| Information Types | |
|---|---|
| Code | Description |
| *Diagnosis* | User states when they were diagnosed or time since diagnosis |
| *Start of ARVs* | User states when they began taking antiretroviral medication, or the time since they began taking antiretroviral medication |
| *Sexual Activity* | User describes sexual history, recent sexual acts or recent sexual partners |
| *Reactions* | User describes changes in health that could be symptoms of HIV (seroconversion symptoms) or side effects of the medication |

Table 14: The new codes that were developed, and their descriptions

All messages responding to a post containing a community-aided reflection question were examined to determine if they aimed to address the question, resulting in a total of 192 messages. Thematic analysis was applied to these using the social support codes described by Mo and Coulson (2008) (Table 15).

| Social Support | |
|---|---|
| Social Support Type | Description |
| *Informational Support* | Providing information or advice in response |
| *Tangible Assistance* | Offering direct assistance, or willingness to help |
| *Esteem Support* | Communicating respect or confidence in the poster's abilities Providing compliments, positive assessments of the poster |
| *Network Support* | Reminders of the social network available to the poster, or offers to connect the poster with others |
| *Emotional Support* | Expressions of care or concern about the poster, expressions of sympathy or empathy |

Table 15: Five types of Social Support

Because this thesis is focused on Personal Health Informatics, and this study – in particular – was focused on the sharing of information for reflection, any message which was coded as containing informational social support was then further analyzed to identify which sub-types of informational support were present, again using the codes described by Mo and Coulson (2008) (Table 16).

| Informational Support Sub-Types | |
|---|---|
| Sub-Types | Description |
| *Advice* | Messages containing suggestions or advice for dealing with the question or taking a step back<br><br>"I think you should take 5 minutes to relax" |
| *Referral to experts* | Referring the user to some other source of help<br><br>"Go to your doctor, they'll know" |
| *Situation appraisal* | Redefining the situation, or providing a new perspective for it<br><br>"I had a viral load of A MILLION and I'm still here!" |
| *Teaching* | Providing facts, information, or news about the situation<br><br>"Actually, CD4 counts fluctuate throughout the day" |
| *Sharing own experience* | Sharing their own experience or personal information<br><br>"I took that drug" "I was diagnosed in 1985" "I had that side effect" |

Table 16: The sub-types of informational support

*Reliability*

This study was the only one in the thesis in which data were not gathered in person. Because of this, it was decided that conducting an inter-rater reliability test on the five codes for question types was important to ensure that the meaning conveyed in the posts on the forum was interpreted accurately. The other codes used during analysis (social support and information types) were not tested for reliability, as they were developed and applied previously in other research.

Two coders were used: the main researcher (Coder 1) and an independent researcher (Coder 2) with no connection to this work. Three rounds of reliability testing were performed. The second coder was sent a coding protocol sheet which described each code and when they should be applied (Appendix 12). They were also sent a short training sheet providing information on HIV-related terms and concepts in order to have contextual understanding (Appendix 11). Finally, they were sent 12 messages containing community-aided reflection questions to code. These 12 were randomly selected using a random number generating website, Psychic Science (www.psychicscience.org/random.aspx). The sample size (12 of 60, 20%) was determined based on recommendations in the literature (Riffe, Lacy, & Fico, 2008, p. 146). Selecting a higher sample size would have placed limitations on the number of testing rounds performed.

After the first round was completed and calculated, the two coders discussed some of the decisions that were made, with Coder 1 explaining some of the terms that Coder 2 was confused by (e.g. names of medication, side effects, etc.). Then, the second of testing was performed, again with 12 messages.

Agreement was calculated using two measures; the Jaccard similarity measure and the Simple Matching Coefficient. While Cohen's Kappa has been used to test for reliability similar research (e.g. Mo & Coulson, 2008), it was not applicable here due to the possibility of having more than one code applied. The result of the first round of testing was 0.63 (Jaccard) and 0.85 (Simple Matching Coefficient). The second round showed a high level of agreeability, with a Jaccard score of 0.82 and the Simple Matching Coefficient of 0.92.

## 5.3 Results

The results of the analysis will be presented here, beginning with the types of questions asked. This first subsection will briefly introduce the question types, which will be built upon and enriched in the later sub-sections.

### 5.3.1 Presence of messages containing community-aided reflection questions

In total, 60 of the 2455 messages were found to contain questions for community-aided reflection on personal health information. These messages were found in 44 of the 200 different threads, meaning that 22.0% of the threads in the corpus of data contained a post with a community-aided reflection question. All forum topics had at least two threads containing community-aided reflection posts. The data show that some topics had higher frequencies of community-aided reflection contained within threads than others. *Nutrition & HIV* and *Positive Women* had the fewest threads containing these questions (2 threads each), while *Treatment & Side Effects*, with 13 threads, had the most (Figure 28).
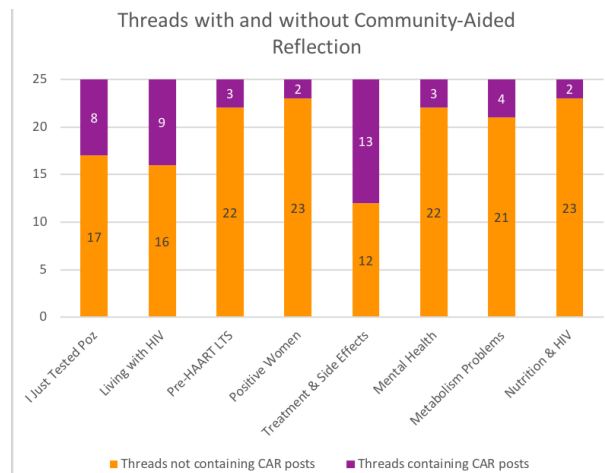
Figure 28: Threads containing messages with community-aided reflection (purple) and without (orange)

Posts containing community-aided reflection questions did not just begin threads, they also appeared within a thread (Figure 29). Of the 60 messages containing these questions, 36 were original posts (making up 18.0% of all the threads in the corpus of data). The remaining 24 were messages appearing later in a thread: less than half (11) were found in threads that did not begin with an original post containing a community-aided reflection question. Of the 24, 14 were made by users who were not the original poster of the thread. While *Treatment & Side Effects* was the forum topic with the most threads containing community-aided reflection questions, *I Just Tested Poz* was shown to have the most community-aided reflection questions asked in messages that did not begin a thread.
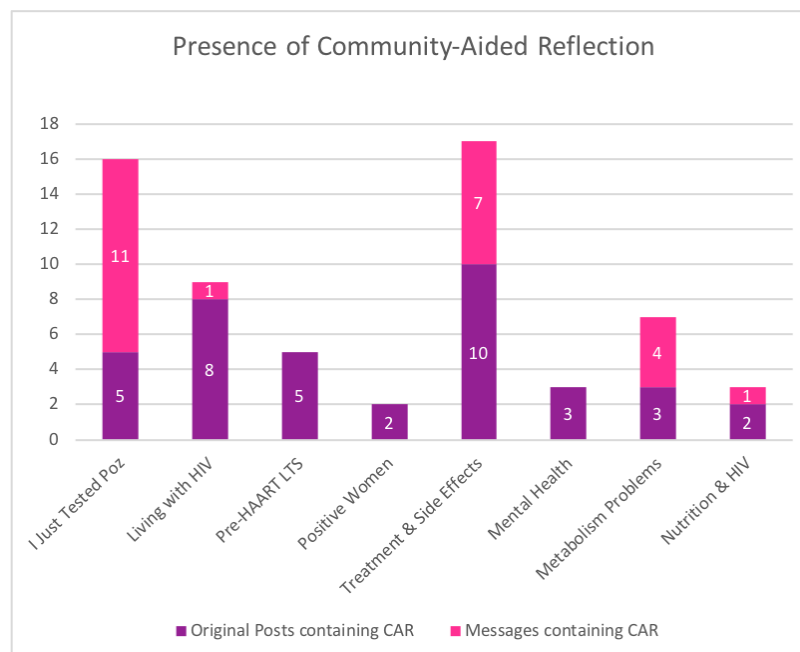


Figure 29: There were more original posts containing community-aided reflection than messages within a thread containing such questions

As discussed previously (Section 5.2.7), a post may contain more than one community-aided reflection question. Of the 60 posts, 11 contained more than one question, resulting in a total of 77 different community-aided reflection questions being asked. For example, User071's message, below, contained both a **What caused this** and a **Is this normal or cause for concern** question type (both indicated in bold):

"*Hello boys and girls!*

*After 6 months I got my last lab results today. My CD4 count was about 1100 (%31.6) but today it's 665 (%27.5). I'm not sick or having another issue about my health. I'm surprised and scared actually.* **Why did my CD4 count drop that much?**

*I haven't gotten my Viral load test result yet (hope it's still negative).*

**should I worry about it?** *I feel a bit nervous" – User071*

Of the 77 different questions asked, the majority were in the theme of causation (53.24%), followed by normalcy (31.17%) and the future (15.58%). However, **Did that cause this** and **Is this normal** were the two most frequently asked questions types (Table 17). The frequencies and differences between these question types are described in the sub-sections below in order of frequency of occurrence by theme, which can give a rough indication of how important they may be to people living with HIV.

| Question theme | Question type | No. of questions | % of total questions | % of total questions, by theme |
|---|---|---|---|---|
| Causation | Did that cause this? | 27 | 35.06 | 53.24 |
| | What caused this? | 14 | 18.18 | |
| Normalcy | Is this normal? | 16 | 20.78 | 31.17 |
| | Is this normal at this point in time? | 8 | 10.39 | |
| Future | What's going to happen? | 12 | 15.58 | 15.58 |

Table 17: Frequency in which question themes and types were observed

### *Questions about causation*

Questions about possible causation – *'Did that cause this?'* and *'What caused this?'* – were focused on determining causal relationships to explain health experiences, therefore were often associated with changes in health.

*'Did that cause this?'* was asked most frequently of all question types: a total of 27 occurrences, or 35.06% of all questions asked. In these instances, the data suggests that the person asking the question already suspected a causal relationship and was seeking input to confirm or deny it:

"*Is HIV or treatment a factor of why my cholesterol is high?" – User011*

In comparison, '*What caused this?*' (occurring 14 times) was asked when the user appeared to have no hypothesis regarding the cause of a change in health or were open to other ideas regarding what may have affected their health. These questions were typically open-ended, allowing the community free reign in their responses to help the questioner determine the source of the change:

> "*Obviously, my medication has worked if I went from 440,000 down to 82 so quickly, but why am I hovering around 82-126?*" – User040

## Questions about normalcy

Two question types were used to enquire whether health information was 'normal' – '*Is this normal?*' and '*Is this normal at this point in time?*'. Similar to findings for people living with diabetes or suffering from migraines (O'Kane, Park, Mentis, Blandford, & Chen, 2016), these questions were asked when users sought to determine if their health information was normal for someone living with the condition.

'*Is this normal?*' was the second most frequently occurring of all the question types, with a total of 16 (20.78%). This question type was focused on determining if a health experience was 'normal' for someone with HIV, something that should be worried about and, potentially, acted upon. Many of these questions were accompanied with a request for personal experiences, likely as a strategy for gauging the 'commonness' of health information as a substitute measure for normalcy:

> "*I have been living with HIV for about a year and I have had warts running rampant throughout my body and it is taking its toll on me. I am wondering if anyone else has had experience with this?[…]*" – User016

The other question in this theme, '*Is this normal at this point in time?*', focused on the normalcy of a change, or changes, over time. This question type was not focused on understanding the future, but on understanding the normalcy of the progress made to date:

> "*Results are cd4: 16! Viral load 13,027. I almost pissed my pants when the hiv specialist doc was telling me the results. That could not be right! Could I really progressed that quickly esp the fact that I was tested negative around 2 years ago?*" – User016

## Questions about the future

The final theme was about the future, with just one question type. '*What's going to happen?*' was asked 12 times in the corpus of data – 15.58% of all questions asked. With this question type, the posters appeared to want to know what to expect from the future based on their current health status. In particular, they appeared to want to know *when* or *if* a health concern would disappear or improve over time. By asking the community to respond to this question, individuals were trying

to get an understanding of a timeline for their personal information, based on the experiences of others who had lived through similar changes:

> *"[…] I'm having difficulty accepting my changed body image and need to lose about 40 pounds. Can any long term users of Egrifta share their experiences? […]"  - User349*

However, there were also more emotional aspects to some of these messages, especially when people wanted to ascertain whether fighting against a change in health was fruitless due to the disease or ARVs:

> *"[…] But one problem I'm having is somewhere about 5 to 6 years ago I began to gain belly fat. […] I've recently started trying to watch what I eat and I'm trying to get more exercise. But I need to know if this hopeless due to the meds? […]" - User351*

### 5.3.2 Types of personal health information people were trying to reflect upon

Before describing the information asked about, and shared, by question type, the overall frequencies will first be briefly introduced.

Each of the 77 questions were coded for the type of personal health information that the user was trying to understand. The coding revealed that posters were asking about just 5 types of information: *lab results, reactions, other conditions, weight,* and *emotions*. These information types were asked about a minimum of 4 times (*emotions*) and a maximum of 29 times (*lab results*). Of the five information types, *lab results*, *reactions*, and *other conditions* were asked about the most frequently – occurring in a combined total of 83% of all questions asked. A matrix (Table 18) was constructed to show the relationship between question types and information asked about.

Unlike the other information types, *reactions* and *other conditions* are rather broad terms that encompass a vast array of health information. The *reactions* that users described ranged from skin problems, fatigue, head rushes, and caffeine sensitivity. *Other conditions* also varied, with descriptions of cholesterol issues, sexually transmitted diseases, panic attacks, carpal tunnel syndrome, and menstruation.

Users posting these questions shared additional information. Overall, 196 pieces of personal health information were shared within the 60 messages containing questions, often with multiple pieces of information shared in each message (Table 19). Because some messages contained more than one question, it was not possible to divide the information shared by question type.

As suggested by the results of Study One, the information that was shared was spread across multiple aspects of health and wellbeing, not all of which are obvious in their relation to HIV (e.g. *exercise, emotions, food* and *weight*). This demonstrates that individuals attend to and share a

|  | Causation | | | | Normalcy | | | | Future | |
|---|---|---|---|---|---|---|---|---|---|---|
|  | Did that cause this? N=27 | | What caused this? N=14 | | Is this normal? N=16 | | Is this normal at this point in time? N=8 | | What's going to happen? N=12 | |
| Information type asked about | n | % | n | % | n | % | n | % | n | % |
| Medication | - | - | - | - | - | - | - | - | - | - |
| Diagnosis | - | - | - | - | - | - | - | - | - | - |
| Lab Results | - | - | 10 | 71.4 | 8 | 50.0 | 8 | 100.0 | 3 | 25.0 |
| Reactions | 8 | 29.6 | - | - | 5 | 31.3 | - | - | 6 | 50.0 |
| Other Conditions | 11 | 40.7 | 3 | 21.4 | 2 | 12.5 | - | - | - | - |
| Start of ARV | - | - | - | - | - | - | - | - | - | - |
| Weight | 6 | 22.2 | - | - | 1 | 6.3 | - | - | 2 | 16.7 |
| Food | - | - | - | - | - | - | - | - | - | - |
| Emotions | 2 | 7.4 | 1 | 7.1 | - | - | - | - | 1 | 8.3 |
| Exercise | - | - | - | - | - | - | - | - | - | - |
| Sexual Activity | - | - | - | - | - | - | - | - | - | - |

Table 18: Information types that were asked about

wide breadth of personal health information in order to provide context for the questions they ask. Some information types were shared far more frequently than others, and therefore seemed particularly at the forefront of people's thoughts when describing their situation. In particular, information about *medication* and the date of, or time since, *diagnosis* was shared in over half of the messages. *Start of ARV* – an information type that was not identified in the first study – was shared in 16 of the 60 messages, while *sexual activity* was shared 5 times.

| Information type | No. of messages | % of total messages |
|---|---|---|
| Medication | 36 | 60.00 |
| Diagnosis | 30 | 50.00 |
| Lab Results | 29 | 48.33 |
| Reactions | 25 | 41.67 |
| Other Conditions | 20 | 33.33 |
| Start of ARV | 16 | 26.67 |
| Weight | 11 | 18.33 |
| Food | 11 | 18.33 |
| Emotions | 8 | 13.33 |
| Exercise | 5 | 8.33 |
| Sexual Activity | 5 | 8.33 |
| Total: | 196 | |

Table 19: Information types that were shared in the messages

How these information types were asked about, and used to inform the queries, will now be discussed by question type.

*Personal health information in 'Did that cause this?' questions*

Of the 27 times '***Did that cause this?***' was asked, users were mainly asking about ***other conditions*** (11 times)*,* followed by ***reactions*** (8 times). Nearly every time this question was asked, the users shared what they believed to be the cause – their ***medication***:

> *"I was on [Egrifta] for about 3 months and my tongue started turning yellow I didn't have any [side effects] any change that is before my copay went up to 700 and some odd dollars but I couldn't afford it anymore but when I stop taking the [Egrifta] the yellow and my tongue went away I think it might have been having effect on my kidney I did want to try it again but I'm afraid. Anyone ever have this problem with the yellowing of the tongue"*
> *– User359*

***Weight*** – an information type not often thought of in relation to HIV – was asked about 6 times with this question type, and ***emotions*** were asked about twice. Again, the users posting these questions hypothesized the cause to be the medication they were taking:

> *"God, now i'm sure i'm not mad, i thought i was the only person in the world that suffer this.*
>
> *Last year i was on Truvada/Reyataz/Norvir in just 4 months i gained 22 pounds i told to my doctor about this also told her my appetite increased a lot! and she told me that the medication was not the reason. i had a very hard depression problem and my appearance it's very important for me, i feel very bad this way i don't want to be fat. i know this sound a little selfish but if there's people in the world with a worst condition doesn't mean that i will be ok being fat.*
>
> *i also have a worst condition Kaposi Sarcoma, and liver problems with Atazanavir for that reason i dropped the meds for a month, in that month i lost 11 pounds coincidence?*
>
> *i think this is a side effects of the Protease Inhibitors, could someone tell us something about this?*
>
> *Now i'm on Truvada/ Prezista/ Norvir ... i weight 175...20 pounds more that the last year my belly is so big and my legs and arms very thin.. so? i don't know what to do.           i'm not a very active person but since i started to gain weight i try to take healthy food 1 hour of cardio daily and i can't loss any weight it is very frustrating.]"* – *User308*

As can be seen from User308's post, sharing personal health information to provide context with this question type is not limited to medication; providing a detailed account of one's health experiences, actions, and concerns fills the post and enrichen the perspective of what that person might be experiencing. User308 does not need to describe the conditions or information that are not related to their weight gain, but chooses to – likely as a means of presenting the community with the emotional strife that everything has cost, and as proof that their struggle is not limited to a few pounds gained.

In contrast to *'Did that cause this',* the 14 instances of *'What caused this'* questions were nearly all asking about *lab results*:

> *"need you experts on here as i am waiting to hear from nurse.....CD4 count went from 570 to 522 (im now 6 weeks on med)....now ya'll know me and I am freaking out- WHY did it drop??? I dont have the VL back yet but shouldn't CD4 be rising? I did lab first thing in the morning. help!!!!!!"* – User049

> *"Hey people, am new to this and looking for support. I got diagonised recently. I did both rapid and 2 blood tests and they were positive. My CD4 count was 700 and Viral load undetectable. How possible is it to be undetectable yet not on drugs? Thank you"* – User063

Usually, when asking a question about a cause for their *lab results*, users shared their date of *diagnosis*, either by exact date or more generally. By sharing their diagnosis as well as other health information, users were providing the community with a timeline for their lab results, giving the context for their question, thus indicating that lab results may not be suitable for presentation as singular numbers, but might require an indication of time in order to be better understood:

> *"I met my HIV-specialist doctor 10days after the status came out, because I must deal with office-work and took couple days leave to capital city. [...] My first cd4 is 577, 22% (03/22/2016), I didn't check viral load at that time. Since there is no IO happened, Doctor signed me my ART (Atripla but with each dose so I must consume 3 meds daily, FDC is out of stock in my country). First week is the hardest, but lately I can handle it, though besides effect-side from the meds itself I must handle also my gastric acid problem. [...]*

> *Last weekend is my 4th consultation and doctor asked me to re-check my cd4, now with the viral load. My latest cd4 755, 21% (05/07/2016), viral load result hasn't done yet, a week is required.*

> *I want to ask, how my cd4 % get effect because it is lower than before (1%), is it okay ? [...]"* – User072

While *lab results* were asked about in 10 of the 14 questions, *other conditions* were asked about three times, and *emotions* were asked about once. These questions were not necessarily related to living with HIV, but the community was still asked for support in reflection. Potentially, the reason for this is that the online forum provides a safe space for like-minded individuals, or those who may be sensitive to the problems of others living with the same disease.

For example, User074 asked about the recovery time of a lumbar puncture and wanted to know what might have caused the migraine that had lasted days:

> *"Going on day 72hrs and the severe migraine has still not let up any at all. Doctor says it will take a while. Online info says 24-48hrs. Intern poked a few times. What causes the severe migraine? Lack of fluid in the spine? Air in the spinal cord? The past 2 mornings in a row I've thrown up. Felt like it all day. I have these weird cold sweats. Lately it seems even laying down isn't helping the migraine.*

*Thoughts?" – User074*

Lumbar punctures are not diagnostic procedures which are limited to those living with HIV, as they are often used to test for infections in the brain or spinal cord. However, HIV is known to cause damage to the central and peripheral nervous systems (Remedy's Health Communities, 2015). As such, a person living with HIV may be more inclined to ask their community about such a procedure to avoid answering any uncomfortable follow-up questions, though there are likely many other reasons.

### Personal health information in 'Is this normal' questions

'*Is this normal*' was asked 16 times, 8 questions were about *lab results*, 5 were about *reactions*, 2 were about *other conditions*, and 1 was about *weight*. For each of these kinds of health information, the messages showed that the users were surprised by a change in their health and wanted to determine if it was a 'normal' thing to happen. For example, users like User080 asked the community to share experiences with *lab results* in order to determine if theirs were normal:

> *"[…] I have been on my medication for the full 3 months since my last blood test, so I thought I would be undetectable and my normal tcell level is 750 (highest ever was 780). I got my test results back last week and I am surprised and confused. My VL was 26 and my tcells were 1006. […] Anyone ever have something like this happen?" – User080*

When asking about *reactions*, users often shared their *medication*, as their posts indicated that they usually thought their health concern was linked either to their *medication* or HIV. Sharing the precise name of the medication was important here; different medications cause different side effects, and so only community members who had taken that medication would be able to respond:

> *"Hi Ladies, I was wondering if anyone had any changes in their periods? This is the 2nd month on meds and im pretty newly [diagnosed] – my 1st month I was right [on] time. The second month now I am 23 days late….and there is NO chance of pregnancy as my husband left us months ago. Im on Triumeq" – User049*

### Personal health information in 'Is this normal at this point in time' questions

'*Is this normal at this point in time*' was the only question type to ask about just one information type: *lab results.* In all of these questions, users shared their *start of ARV* or date of *diagnosis*. By asking for the community's feedback, they were aiming to gain an understanding of how the changes in their lab results compared to what others had seen:

> *"Hi everyone! I'm in treatment since March and my CD4 are increased from 5 to 103, that is a good signal or still a low increasement? And my VL went to 10.000 to undetectable, I never thought it would be so fast. Thanks!" – User091*

*"[…] Also, why is my CD4 this low ? Shouldn't this happen with many years of being positive? […]"* – User028

*Personal health information in 'What's going to happen' questions*

In '***What's going to happen***' questions, users mainly asked about ***reactions***. Here, users were trying to determine if a ***reaction*** would go away and when:

*"I've read about anxiety issues but not much about others with sleeping issues and if and how long it took to pass."* - User388

With these questions, ***medication*** was frequently shared, as people thought it was linked to their health, and so sharing the name of the medication, as well as how long they had been taking it (***start of ARV***), was common:

*"I found out I was positive just this January. My CD4 was pretty good (750) and my VL not too elevated (150,000). […] I am on my sixth week on Truvada+Atazanavir(Norvir)+Reyataz. Overall I haven't had significant side effects except yellowing in my eyes, mostly on the parts covered by my eyelids so not too bad. […] I'd like to know if anyone has had similar symptoms and if they went away at some point or if they continued as long as on that combo and if it is a determining cause to switch meds. […] It would be great to read from someone that it will go away but if it doesn't then I might talk about switching? but what if another combo does have significant side effects? I'm a bit torn on it."* – User026

## 5.3.3 Types of support offered by the community

A total of 192 messages aimed to address the community-aided reflection questions, and these were posted by 76 unique users. These messages each contained one or more types of social support (Table 20).

| Social Support Types | No. of messages | % of total messages |
|---|---|---|
| Informational | 176 | 91.7 |
| Emotional | 56 | 29.2 |
| Esteem | 15 | 7.8 |
| Network | 15 | 7.8 |
| Tangible | 1 | 0.5 |

Table 20: Social Support types

***Tangible support*** – rarely viewed in an online setting (Mo & Coulson, 2008) – was observed one time. In this instance, User010 responded to a question about skin problems by offering to provide tips and techniques that may assuage the issue:

*"I'll post some strategies later for dealing with your skin"* – User010

*Esteem* and *Network support* were provided equally, in 15 messages each. With *esteem support*, users often made statements to relieve the question-poster of feelings of blame or made compliments about how well they were doing:

> *"You're doing great! Keep it up" – User010*

> *"User091, welcome and congratulations on turning things around. That's a fantastic increase in your cd4s and you should be very happy with that" – User003*

With the *network support*, users frequently reminded those asking the question that they had access to a group of supportive people via the forum:

> *"First off, welcome - glad you found us. You certainly have people to talk to here and a wealth of experience from all walks of life which can help you out." – User004*

*Emotional support* was the second most frequently observed – it was provided in 56 of the 192 messages (29.2%). Most of these messages were ones of empathy and encouragement:

> *"[…] After taking Truvada for several years, I began getting a fat gut and "man boobs". […] I am not an extremely vain person, but I hated seeing all those years of weight training go down the tubes. And would I take my shirt off at the beach, let alone go to the beach again? So I can relate to your concern. […]" – User318*

> *"Hi User328,*

> *It does get better as long as you continue with the therapy and working on the anxiety. And why wouldn't you have anxiety after what you've been through and not talking to anyone about this for five years?*

> *I've been dealing with HIV for 27 years and I can tell you I used to get horrible panic attacks. One time I even passed out in Kroger when I was just checking out. […]" – User069*

*Emotional*, *esteem*, and *network support* are considered to be nurturing (Cutrona & Suhr, 1992); the messages containing them may help to sooth and calm the user who asked the question, but may not help them act upon, or understand, their health information. *Informational support* is thought to facilitate action or understanding (Cutrona & Suhr, 1992), and was present in 91.7% of the messages responding to questions about health information. This suggests that the community aimed to facilitate understanding and knowledge by providing suggestions, alternative view points, or related information (Cutrona & Suhr, 1992), rather than simply nurturing and comforting the person who asked the question. This points to the role of the community as an important information source for answering these types of questions.

Given the dominance of informational support in the responses, the kind of information provided was further analyzed by applying the five informational sub-types (Table 21). The three most common sub-types across all question types were *sharing own experience*, followed by *suggestion / advice* and *teaching.* While the latter two sub-types provided more general

information about health and HIV, by sharing their own experience community members provided their own specific personal health information back to the individual posing the question – this provides further evidence that people living with HIV keep track of their health information whether or not they have a concern about it.

| Informational Support sub-types | No. of messages | % of total messages |
|---|---|---|
| Sharing Own Experience | 105 | 54.7 |
| Suggestion / Advice | 81 | 42.2 |
| Teaching | 62 | 32.3 |
| Situation Appraisal | 48 | 25.0 |
| Referral | 20 | 10.4 |

Table 21: Informational sub-types

The different ways in which information was offered in response to each question type were further investigated (Figure 30). It was found that responses to '*What caused this?*' and '*Is this normal?*' had different frequencies of the informational sub-types than those received by the other three question types. *Teaching* and *Suggestion/Advice* were more common responses to '*What caused this?*' and '*Is this normal?*' than *Sharing Own Experience*. Examples of the differences in these responses follow.
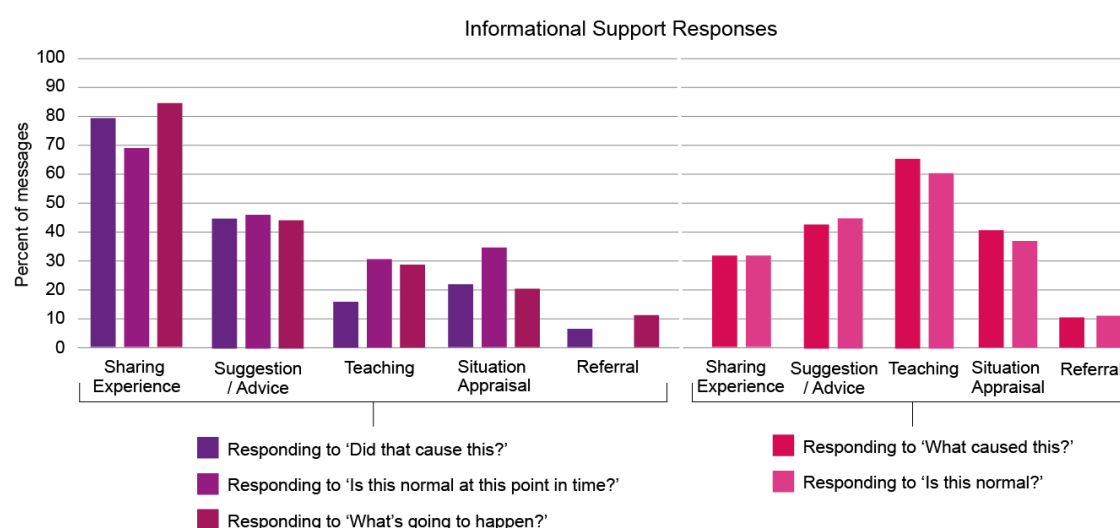


Figure 30: Informational Support responses to 'Did that cause this?', 'Is this normal at this point in time?', 'What's going to happen?' (left), and 'What caused this?', 'Is this normal?' (right)

The informational support in response to questions about '*Did that cause this*', '*What's going to happen*' and '*Is this normal at this point in time*' frequently involved a community member's own

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experience, often providing a timeline or sharing their own personal health information in response. For example:

> *"Hi, When started Triumeq I had trouble sleeping and vivid dreams when I did sleep, however this passed. I just stuck with it. […]" – User002*, responding to a question about insomnia as a reaction to Triumeq

> *"[…] I had jaundice again when I first started Reyataz. my eyes were just a little yellow tinged. I called the doc and he took a look. he agreed it was mild, warned me of other side effects or worsening side effects to keep an eye out for. My eyes cleared up a short time (a week?) later and I had no other effects. […]" – User007,* responding to a question about jaundice as a reaction

> *"ojo Hello user004 and user065, be patient, eventually you guys will get to UD level...you want to know how long it took me to get an UD level?...from November 1994 (dx) to March 2007...do the math, I have just ten fingers, and this happened because of treatment failures, my meds didn't work, resistance to all kind of meds, in your case, your med is working, so, relax and you will get there...hugs ojo" – User008*

In contrast, the responses to questions about '***What caused this***' and '***Is this normal***' mostly involved ***teaching*** informational support. Most of these questions asked about lab results, and thus general help in understanding and interpreting this type of health information seemed to suffice:

> *"CD4s fluctuate throughout the day by as many as one hundred points or so. […] Your CD4's are above 50, so [you] are in a "normalish" range." – User059*

While ***teaching support*** and ***suggestions / advice*** provides the user asking the question with facts that they can relate to their situation or suggested actions to take, ***sharing own experience*** provides them with insight on what others have gone through, so that they may reflect upon their own experiences with additional data. The frequency with which users provided ***informational support*** suggests that it is an important aspect for community-aided reflection, and the prevalence of ***sharing own experience*** highlights that users are willing to share their health information if it will assist another individual in reflecting and understanding their own.

## 5.4 Discussion

This work contributes a deeper understanding of the role of an online community in helping people living with HIV make sense of their personal health information. The results showed that causation and normalcy of their health information, mainly involving lab results, reactions and other conditions, were the most common focus of questions by people with HIV. To provide context for their questions, people shared a wide range of personal health information, with medication taken and date of diagnosis featuring most frequently. In turn, the community responded to such questions with informational support, largely drawing on their own personal health experiences. The results both confirm previous findings from Study One and other researchers, while also

highlighting implications for PHI systems to support people living with HIV in reflecting on, and understanding, their personal health information.

Because of the strict rules set up for determining if a question contained within a post was an example of community-aided reflection, only 60 messages were analyzed and used to identify question types. In addition, these findings are drawn from only one community forum. As such, the findings reported here should be taken as an indication of what occurs, but could be further developed with a larger data set.

These findings show that, like those living other chronic conditions such as diabetes, people living with HIV take an active role in self-managing their health. They pay attention to a wide variety of information types, including those that are not necessarily obvious in their relation to HIV, showing the far-reaching effects that the disease and ARVs have on the body and mind of HIV+ people. Those posting the questions and those aiming to address them both shared their health information, indicating that keeping track of this information is important to those who have questions and those who do not (reinforcing the findings of the first study regarding intentions for tracking – Section 4.3.1). Additionally, the information types that were shared aligned with those identified in the first study, supporting those earlier findings (Section 4.3.3).

The findings also show that HIV+ people seek to understand their health information by turning to their communities, again like those living with chronic migraines or diabetes (O'Kane, Park, Mentis, Blandford, & Chen, 2016), and this aligns with the statements that participants in the first study made with regards to reflecting with the aid of their community (Section 4.3.6). This study, additionally, has built upon previous research (e.g. O'Kane et al., 2016) by detailing how communities aim to address these questions: online communities provide informational support mainly based on their own health experiences to help individuals understand their health information. While this study focused on people living with HIV, the approach could be applied to research on other long-term conditions in order to determine if the question or response types seen here are transferable.

The results reported here can drive the development of much-needed PHI systems to support people living with HIV in reflection, as they also provide several implications for design. These implications revolve around information types, conversations, and representations.

Users on both sides of community-aided reflection shared a variety of personal health information, and these aligned with – and built upon – those information types identified in the first study. This again indicates the importance of PHI systems that allow people to track information that may not be considered to be directly related to HIV. These posts could indicate that a tool which facilitates tracking must be flexible in the types of information users can track, as things like reactions or

other conditions can range widely from person to person. Additionally, users rarely referred to their ARVs in broad terms, but nearly always provided the specific name of what they were taking; this indicates that systems should not just support tracking medication compliance, but also tracking the precise name of the medication prescribed.

Representations of tracked data are known to help reflection, and the content posted in the online forum suggested some key points for representations in PHI technologies for people living with HIV. First, the representations should include the various health information types – allowing users to view their medication and lab results alongside their reactions, for example. This is because the posts made by users frequently contained multiple information types, suggesting that they felt they were related and therefore should not be separated. Second, the representations should include an indication of time. Linking medication and lab results to the time of diagnosis or start of ARVs was frequently seen in posts, highlighting the importance of elapsed time for these information types. However, representations should also include space to indicate the future to come, as 15.58% of the questions observed were about setting expectations for the future.

This research study highlighted five types of questions that people living with HIV need support from their community in answering. Currently, community-aided reflection takes place largely in online forums – away from where the tracked information is stored and represented. For example, systems like PatientsLikeMe currently facilitate viewing the information of others but do not enable users to examine both their personal health information *and* the information of others in the same visualization (Frost & Massagli, 2008) – conversations about such data are held separately, in the forum section of the website. This likely places a burden on users, as they must re-enter their tracked information into a forum and then use linear, written descriptions for reflection rather than representations. PHI systems should support users in sharing various types of health information with each other, and conducting these conversations directly alongside those representations of data. Doing so may provide better scaffolding for the community-aided reflection that is already occurring around this data, enhancing conversations about health information and enable understanding of health experiences. The next study of this thesis aimed to address this by exploring how reflection takes place when using a prototype designed to support community-aided reflection.

# Chapter 6 Observing Reflection on Personal Health Information with Simulated Community Responses (Study 3)

## 6.1 Motivation and Research Questions

Analysis of the first study (Chapter 4) showed that very few of the participants had access to representations of the health information they were tracking, and none had access to representations of different information types. The analysis also showed that almost one-third of the participants had taken part in community-aided reflection This type of reflection was further explored in the second research study (Chapter 5), where the results revealed that communities converse and share a variety of personal experiences and information types as a means of supporting others in reflection. The second study of this thesis shed light on what must occur in order for an individual to reflect on his or her health information with the aid of the community, and this can be used as an indication of the requirements for a PHI system to fully support individuals in tracking and reflecting on their health information. As discussed in Chapter 2, there are no existing systems which support individuals in reflecting on their health information in a representation alongside the health information and feedback from their community-members (see 2.3.2).

In this chapter, I explored two styles of representations (referred to here as 'prototypes') intended to support the act of community-aided reflection on personal health information, and observe how reflection takes place when using them. The aim of this study was to answer the following overarching research question:

**RQ-4: When interacting with a prototype designed to support community-aided reflection, how does reflection occur?** (Study Three; Chapter 6)

This research question was broken down into three smaller ones:

**RQ-4.1: What is the process of reflection when using a prototype simulating community-aided reflection?**

**RQ-4.2: What information is used in the different levels of reflection?**

**RQ-4.3: What considerations need to be made in the design of representations intended to support community-aided reflection?**

This research study was aimed at exploring how to better support community-aided reflection of tracked health information with representations of both personal and community information alongside comments from community members. With no examples of how this might be done, this research delivered an empirical understanding of how reflection occurs when using a prototype simulating community-aided reflection.

The remainder of this chapter will first describe the design of the representations intended to support community-aided reflection. This will be followed by a breakdown of the study design, the results and implications of the research.

## 6.2 Method

### 6.2.1 Overview

In order to answer the research questions, a mixed-methods research study was conducted. This study followed a multiple-step study procedure (Figure 31) in which participants were provided with two prototypes to use during reflection. These were designed to simulate community-aided reflection: each included a representation of the participant's personal health information, a question that they had about their health, and the health information and responses from fictional profiles.

HIV+ people who had recently wondered about a recent change in their health were recruited. They were asked to complete a pre-interview questionnaire in which they described the change in their health, wrote a question that they had about that change, and provided details on their personal health information. Their responses in these questionnaires were then used to create the personalized representations, including the information and responses from the fictional profiles.

This was a within-subject study; once the representations were created, each participant was met in a one-on-one session and asked to explore one while reflecting on their question, then complete a sensemaking questionnaire before exploring the second. This counterbalancing between participants was done in order to control for bias. For clarity, and to assure the participants that their health information had not been shared, each was told at the start of the study that the profiles shown in the representations were fictional but still representative of real individuals. At the end of the study session, participants were asked open-ended questions about their experience with the representations and reflecting. These sessions were audio-recorded and screen-recorded for later thematic analysis.

### 6.2.2 Requirements of Representations

An example of the two representations that were developed for this study are shown below (Figure 32 and Figure 33). Each explores a different style of features intended to support community-aided reflection through the way the information is visualized and how questions and comments are shown. Here, the requirements that led to the features are outlined, alongside the different ways in which the features were instantiated, as well as how the fictional profiles simulating community responses were incorporated.

**Recruitment**

Materials:
Recruitment Advert
Study Information Sheet
Consent Form

Individual responds to
recruitment advert

Participant Information Sheet
and Consent Form sent

Consent Form received from
participant, signed copy returned,
Pre-Interview Questionnaire sent
and Pre-Session Scheduled

**Pre-Session**

Materials:
Pre-Interview Questionnaire

Pre-Interview Questionnaire
received

Pre-Session conducted
(Study information and question-
naire reviewed, one-on-one
session scheduled)

Personalise prototypes for
participant

Determine order in which
prototypes are shown

**Preparatory work**

**One-on-one session**

Materials:
Camtasia (data capture)
Remote Sharing Tool
Discussion Guide
Prototypes with no responses
Prototypes with responses
Reflection Questionnaires

Audio and visually recorded

Brief explaination of
one-on-one session

First Prototype

Provide prototype with
participant information,
no responses, for review

Provide full prototype, use
prompts in dicussion guide

Sensemaking questionnaire

Second Prototype

Provide prototype with
participant information,
no responses, for review

Provide full prototype, use
prompts in dicussion guide

Sensemaking questionnaire

Final questions

Conclusion (thank
and give incentive)

Figure 31: Flow chart of study procedure and materials used. Dark gray boxes indicate the researcher's activities that do not involve the participant.
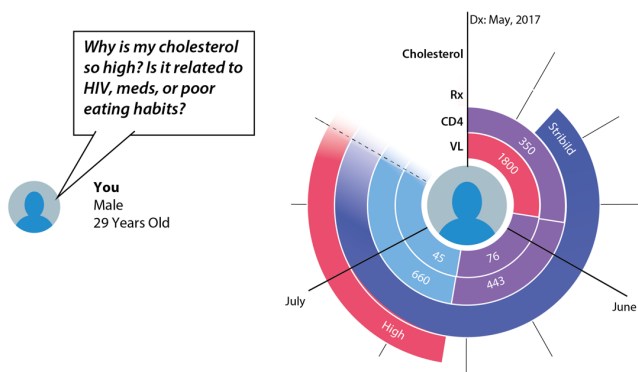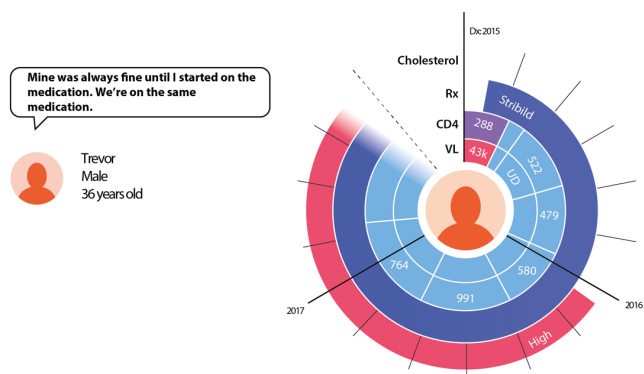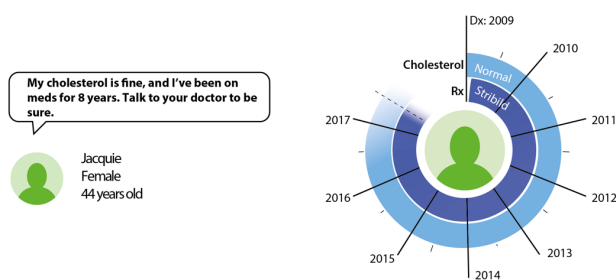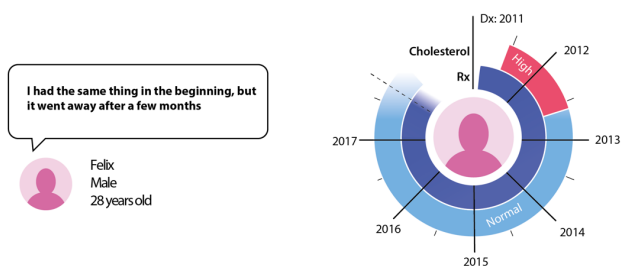
Figure 32: Example of Clock Plot Representation
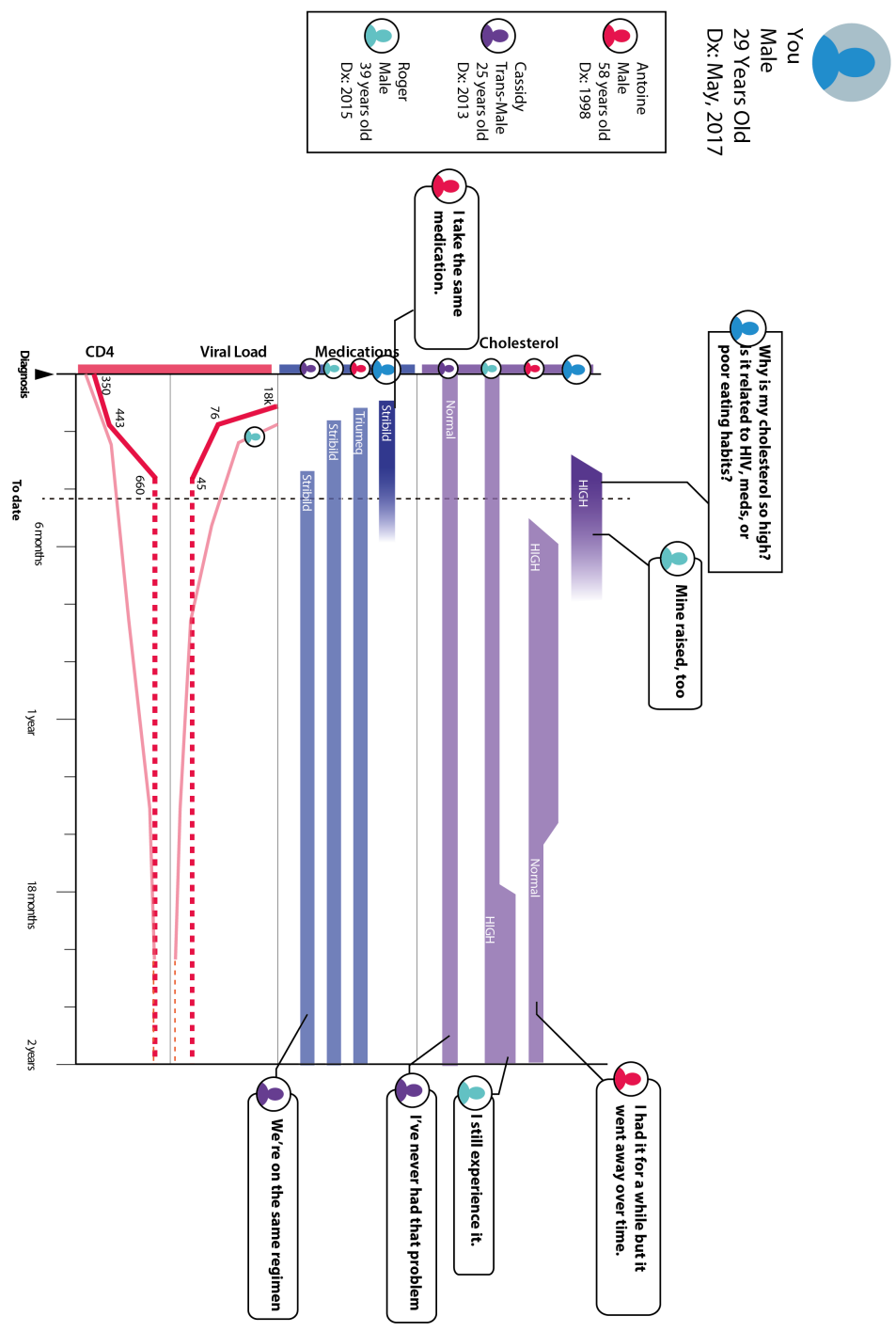
Figure 33: Example of Timeline Representation

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The results of the first and second studies indicated that people living with HIV were interested in tracking and reflecting on a variety of health information, some of which would be numerical (e.g. lab results) and some of it textual (e.g. reactions, other conditions, etc.) (see Section 2.4 for details on data types). Furthermore, despite tracking various health data, there were no representations that showed the different types together to reflect upon (as described in Section 4.3.5). Therefore, any representations intended to support someone living with HIV in reflecting on their health have to be capable of representing various types of numerical and textual data together. A familiar structured representation style, the [linear] timeline, was used for one prototype, while the clock plot was selected as a contrasting non-familiar style. The results of the second study indicated that there were at least two key points in time which must be represented – the time of diagnosis, and the current point in time. Both of these representations styles are capable of presenting both points in time.

## Clock Plot Representation: Non-familiar representation style

A clock plot presents layers of information chronologically over a radial timeline and is appropriate for representing data that occur periodically over time (Brehmer, Lee, Bach, Riche, & Munzner, 2017), which makes it a suitable choice for presenting changes in health. The clock plot was chosen as a visual contrast from the more traditional timeline style (described next), whilst still being capable of displaying the same information.

With this representation style, the personal health information is displayed around an icon representing the individual, flowing clockwise from the date of diagnosis at the 12 o'clock position (Figure 34). Rather than showing hours or minutes, the clock plot presents dates that have passed since the diagnosis was made, at even intervals. For example, the individual shown in the mock prototype had only been living with the disease for just more than 4 months at the time which the prototype was created, so his representation points out when June started, and when July started.
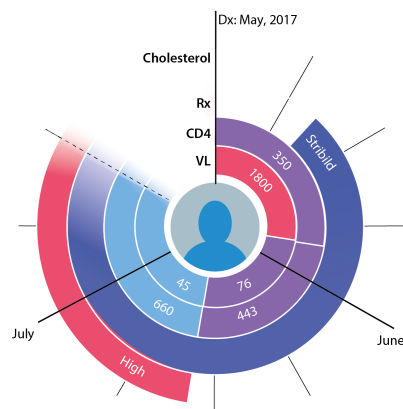


Figure 34: Non-Familiar Representation Style

The current point in time is indicated with a dashed line at approximately the 10:30 position. All information fades away after the current point in time, to signify that it has not yet occurred. Each information type is displayed in a ring, with the lab results presented closest to the icon, followed by medication, then any reactions or other conditions. Numerical data is shown with numbers and, when applicable, color-coded to indicate the severity of the data (e.g. very high viral loads are shown in red, undetectable viral loads are shown in blue).

As can be seen in the example clock plot, the rings of information may change (e.g. the lab results) or suddenly appear (e.g. medication) in line with the dates. For example, the individual shown in the mock prototype did not begin taking Stribild until mid-May, which is when that ring appears. This individual also had his labs done three times, which is why we see a change in the colors and numbers of the CD4 and VL at different periods of time.

Timeline Prototype: Familiar representation style

Presenting temporal data is traditionally done using a linear, unified timeline: one that presents one type of data over a period of time on an x/y axis (Brehmer, Lee, Bach, Riche, & Munzner, 2017). In order to display the multiple data types together, while still using a traditional representation style, a 'faceted' layout approach was taken. Faceted (multiple timelines) is effective for facilitating comparison of information over time (Brehmer, Lee, Bach, Riche, & Munzner, 2017). This style was also chosen for its similarity to graphs of lab results that participants were likely to have seen (e.g. see Section 2.2.3 for example of how BeYou+ displays CD4 and viral loud counts).

With this representation style, the personal health information is displayed chronologically from left to right, beginning from diagnosis (Figure 35). The x axis displays the time elapsed since diagnosis. Where the clock plot prototype shows the dates that have passed, the timeline shows the *time* that has elapse. To use the mock representation again, we can see that the data ends just after 4 months. The current point in time is indicated mid-way through the x axis, with a long, dashed line. Again, all information fades away after the current point in time.
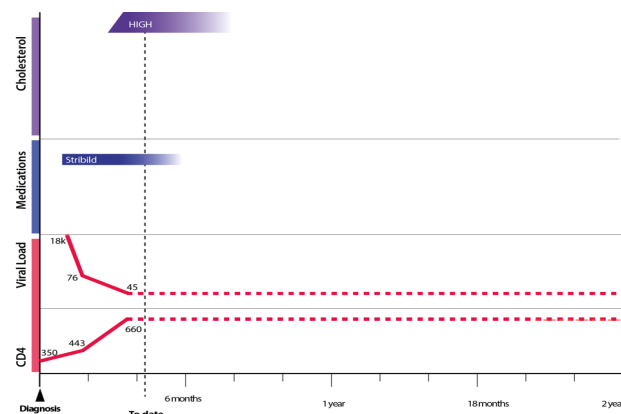


Figure 35: Familiar Representation Style

Each information type is displayed linearly on the graph. The lab results are at the bottom, with medication above, followed by reactions or other conditions on top. Numerical data is shown with numbers and changes along the y axis. Lab results are shown in a red line, while medication is shown in a blue band, and reactions / other conditions are shown in purple.

The timeline prototype presents changes in information in various ways. First, like the clock plot, information appears at the point of time in which it began (e.g. medication). Changes in lab results are represented by changes in their x/y position. Changes in reactions / other conditions are indicated through the height of the band or ending the band (if it had gone away). For example, if the high cholesterol had returned to normal after one month, the height of the purple band would decrease at that point in time.

## *Requirement 2: Asking Questions of the Community*

The results of the second study indicated that people living with HIV may want to ask about what caused a change in their health, if it is normal, and/or what to expect in the future (5.3.1). Thus, PHI technologies must support users in asking the community such questions. Each participant in the study was asked to provide the question that they had about their health, and this was used verbatim in their personalized prototypes.

### Clock Plot Prototype: Out-of-context Question

The participant's question is shown at the top of the prototype as a word bubble emerging from the top of their user icon (Figure 36). This was done as a way of linking it to their profile and making it feel more personal.
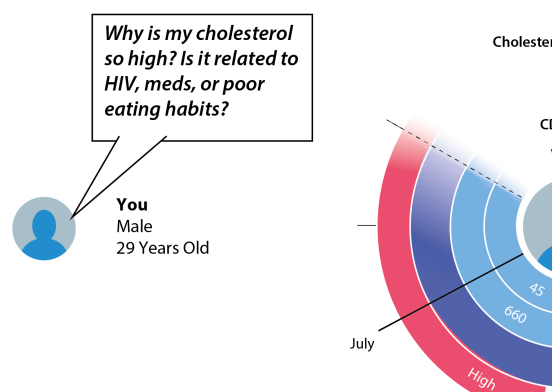


Figure 36: Out-of-Context Question

### Timeline Prototype: In-context Question

The participant's question is shown as an annotation that points to the health information he or she has a question about (Figure 37). This was done as a way of calling attention to the specific piece of information of concern.
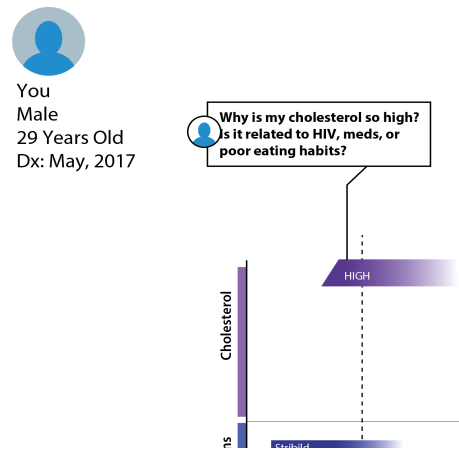
Figure 37: In-Context Question

## Requirement 3: Including Health Information of the Community

The results of the second study indicated that those asking community-aided reflection questions did not just want answers to their queries, but wanted to know about the health experiences of others in the community. Many community members provided their own health information while responding to the questions. Thus, a system that supports community-aided reflection must provide users with access to the health information of others. Additionally, this information should ideally be provided on the same page as the user's own health information (unlike platforms like PatientsLikeMe). The clock plot prototype and timeline prototype achieve this in different ways.

As shown in the examples (Figure 32, Figure 33), each prototype will contain responses from three fictitious profiles. Regarding the demographics of each profile - the age and year of diagnosis for each of these profiles will remain consistent across all participants, whilst the name and gender will vary depending on the gender of the participant. These details were chosen to represent a range of individuals living with HIV.

### Clock Plot Prototype: Separate data representations

The clock plot prototype presents the health information of the three fictional profiles on the same page as the participant's information, but not on the same representation. As mentioned, other tools (like PatientsLikeMe) allow users to see the representations of their community member's health information, but not on the same page as their own. With the clock plot prototype, we are able to explore how a design that presents multiple representations in the same place might be used. Representing information in this way is recommended as a way to support comparisons of chronology or durations between each representation (Brehmer, Lee, Bach, Riche, & Munzner, 2017).

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Three fictional profiles will respond to the participant's query with shared health information (Figure 38). The health information of each profile will be represented in a clock plot representation, resulting in 4 clock plot representations shown in the prototype (1 for the participants above the 3 for the profiles). While the name and gender of the three profiles will vary depending on the gender of the participant, the ages and years of diagnosis for the three profiles will remain consistent. For the clock plot prototype, the three profiles are:



Figure 38: The details of the three fictional profiles for Clock Plot

The profile details will be presented to the left of their respective representations. Each clock plot will present the timeline for the individual (participant or profile) that it is representing. All, however, will begin with the diagnosis at the 12 o'clock point and end at the current point in time (around 10:30). For example, Felix's clock plot will begin with 2011 and carry on to 2017, showing the years that have passed, while Trevor's will begin at 2015 and show the months that have passed.

The information shown by each profile is also predetermined:

- Felix will share medication and a similar health experience as the participant. Felix will have ceased to have that experience at some point (e.g. his cholesterol returns to normal), and this is also shown.
- Jacquie will share medication. She has not experienced the same change in health as the participant (e.g. her cholesterol, which is shown, has never been high).
- Trevor will share lab results, medication, and a similar health experience as the participant. Unlike Felix, Trevor will not have seen that health experience dissipate (e.g. he continues to have high cholesterol).

Timeline Prototype: Combined data representation

The timeline prototype presents the health information of the three fictional profiles in the same representation as the participant's information. Thus, the participants would be able to compare their information with the information of the community in the same place. Like the clock plot prototype, this representation style is recommended for comparing chronology or durations of events, but also for presenting relative synchronicities between data shown (Brehmer, Lee, Bach, Riche, & Munzner, 2017).

Just like with the Clock Plot, three fictional profiles will respond to the participant's query. In the Timeline representation, the health information of each will be represented in the same

representation as the participant's information. A small icon of each profile will be presented adjacent to the shared information, to indicate which profile it belongs to. Additionally, the information shared by the profiles will be a less opaque color than the participant's.

While the name and gender of the three profiles will vary depending on the gender of the participant, the ages and years of diagnosis for the three profiles will remain consistent. The profile details (Figure 39) will be presented together in a box on the left side of the prototype, away from the representation.



Figure 39: The details of the three fictional profiles for Timeline

The timeline will present a fixed set of time elapsing, with all information aligned by the time of diagnosis and continuing on until the current point of time. For example, Roger will only show two years of information since diagnosis, while Cassidy will show four. Each will begin at the same point, the time of diagnosis.

The information shared by the profiles in the timeline are designed to be similar to those shown by the clock plot profile:

- Antoine will share medication and a similar health experience as the participant. However, Antoine will have ceased to have that experience at some point (e.g. his cholesterol returns to normal), and this is also shown.
- Cassidy will share medication. He has not experienced the same change in health as the participant (e.g. his cholesterol, which is shown, has never been high).
- Roger will share lab results, medication, and a similar health experience as the participant. Roger will not have seen that health experience dissipate (e.g. he continues to have high cholesterol).

*Requirement 4: Showing Responses to Questions*

The prototypes also needed to allow users to view the informational support provided by those responding. The most frequently observed type of informational support in the second study was *sharing own experiences* (5.3.3), so each fictional profile was assigned a specific response describing their health experience. While it would have been possible to include additional types of informational support, it was determined that it would be safer, and therefore more ethical, to

stick to shared experiences. This decision was made to prevent accidentally providing participants with misinformation.

## Clock Plot Prototype: Consistently-located responses

The comments made by the profiles were always located in the same place on the prototypes: above the profile icon, adjacent to the profile's clock plot (Figure 40). This was done as a means of balancing out the unfamiliarity of the representation style by adding a level of consistency to the prototype.
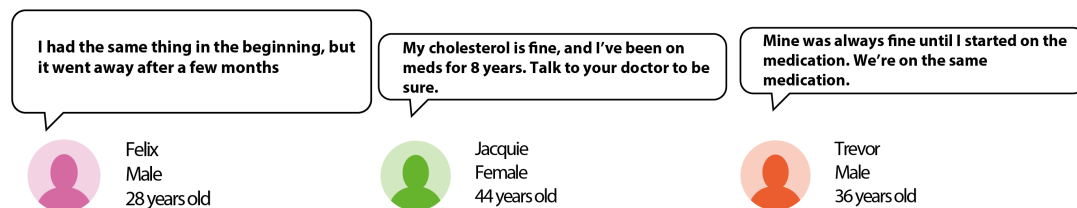


Figure 40: Consistently-located responses

The comments made by the fictional profiles were predefined. Only minor changes were made to the comments shown below (e.g. changing 'my cholesterol' to refer to what the participant was concerned about).

- Felix: "I had the same thing in the beginning. It went away after a few months."
- Jacquie: "My cholesterol is fine, and I've been on meds for 8 years. Talk to your doctor to be sure."
- Trevor: "Mine was always fine until I started on the medication. We're on the same medication."

## Timeline Prototype: Responses as annotations

The comments made by the profiles appeared in context to the data, as an annotation linking to either the participant's or profile's information (Figure 41). This was done as a means of drawing the participant's attention directly to the detail that the profile was discussing.
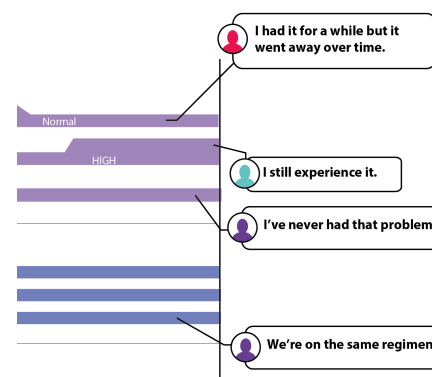


Figure 41: In-Context Comments

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The comments made by the fictional profiles were predefined, with only minor changes made (as with the Clock Plot). While the comments made in the Clock Plot comprised two sentences shown together, those made in the Timeline were two sentences shown in separate places.

- Antoine: "I had it for a while but it went away over time." "I take the same medication."
- Cassidy: "I've never had that problem." "We're on the same regimen."
- Roger: "Mine raised, too." "I still experience it."

### 6.2.3 Participants

*Recruitment*

This research study focused on HIV+ adults who have experienced a change in their health and want to know what caused it. In order to find appropriate participants, individuals were excluded from the study if they did not fit the following criteria: adults (18+) who spoke English, had experienced a change in their health within the last 6 months, had kept track of this change, were willing to share their health information for the purpose of the study, and were willing to meet the researcher in person or over a remote video connection.

Recruitment advertisements (Appendix 14) were sent out through social media (Twitter, Facebook, Gumtree, Craigslist). When given permission, recruitment posters were placed in bars, sex-toy shops, and gay clubs in London. HIV-specific Reddit forums and Google Hangout groups were also posted on, with permission where required. Sexual health and HIV clinics in the UK were also contacted and asked to disseminate the recruitment details. Unlike the first study, there were no organizations who agreed to directly recruit participants from their service users. Because of this, and the difficulty of recruiting a substantial number of appropriate individuals in the time scale required, there was no focus on recruiting a representative sample or gender balance. No individuals were contacted directly to ask for participation – it was up to interested individuals to make first contact.

Individuals who responded to the recruitment advertisements were sent a digital copy of the information sheet (Appendix 15) and consent form (Appendix 16) via email. Participants were asked to read the information sheet and consent form and, if they chose to participate, complete and return the consent form. Participants were told to contact the researcher with any questions before signing, and were told that they will also have a chance to have any additional questions answered during the pre-study session. Upon receiving the consent form, a signed copy of the

consent form was returned along with the pre-study questionnaire (Appendix 17) for the participant to complete.

The pre-study questionnaire was split into two parts. The first part was aimed at gathering demographic details to use to describe the recruited individuals. The questionnaire asked participants to indicate their ethnicity, gender, and sexual orientation from provided lists, as well as their age. These questions were the same as those used in the first study.

The latter portion of this questionnaire was used to gather the personal health information necessary for creating the two prototypes. Participants were required to write the question they had about their health, and were given examples as prompts. Participants were also asked to share the antiretroviral medication they were prescribed, when they began taking this medication, the change in health they had experienced, when this change occurred, and lab results since diagnosis. Participants were allowed to add in further information, if they desire. However, in order to avoid sensitive topics or discussions, participants were told that the personal health information they choose to share is optional, and that they should not share any information that makes them feel uncomfortable. They were reminded that the level of detail they provide will improve the level of detail in the prototypes.

*Ethics*

The ethics and legality of this research were considered extensively. This project was considered to be ethical, legal, and safe, and was approved by City, University of London's Senate Research Ethics Committee (Appendix 10). However, because of the stigma that is still associated with AIDS and HIV, it is important to describe here the extent to which ethics, confidentiality, and data protection has been considered for this research project.

Communication methods is one of the major considerations for maintaining ethics and confidentiality. As mentioned in the participants section, directly contacting any individuals to request their participation will not be done. Instead, it is up to each individual to initiate contact if they are interested. Also, only one-to-one contact was made; no mailing lists or group emails/texts were used when sending information to participants or interested individuals. Finally, all communications were conducted through City University London's provided methods, a private telephone connection, or private connections on Skype or Google Hangouts.

The informed consent of each participant is another important factor. Each participant was provided with a study information sheet and consent form *prior* to the start of the research study. This was done to ensure that each person has ample opportunity to read through the details and ask questions. Additionally, both the study information sheet and consent form will include three

important details: the participant would not *receive* any care as part of this study, nor would they be *denied* any care if they chose not to participate, and that the information contained within the prototypes is fictional. Additionally, participants were informed that they may discuss the study with their doctor if they desire. Signed copies of consent forms were given to the participants to retain for their own records.

The third major consideration is ensuring the confidentiality of all participants. All signed consent forms retained by the researcher were kept in a locked filing cabinet, preventing others from seeing the names on the forms. Second, all individuals who were successfully recruited into the study were assigned a unique identification number. The link between the individual's name and their unique identification number were contained on only one piece of paper (example of the key in Appendix 6), which was kept in a locked drawer in an area separate from the signed consent forms. Third, all recordings were stored in a locked folder on the researcher's private computer until they were transcribed in full. Once this was done, the files were moved to a locked folder on an external hard drive. Finally, all transcripts and questionnaires were examined for identifiable data. The identifiable data were permanently edited to remove identifiable features. Examples of what is considered 'identifiable data' are names of participants, friends, family, acquaintances, and names of workplace or locations frequently visited.

The recordings captured during the one-on-one sessions will only be viewed by the researcher and will never be used in any publications or presentations.

### *Recruited Participants*

Despite the efforts made in advertising the study over the course of more than two months, only 6 participants were recruited in total. This may have been partially due to the specific requirements of participation: recruiting only those who had wondered about a change in health that they experienced in the past 6 months created very narrow criteria. The low numbers were also due to the need to share personal health information in order to take part in the study. Numerous interested individuals declined to join the study after learning that they would need to share their health details with the researcher. However, a third, unanticipated, reason for the low recruitment rate emerged that indicated timing to be a factor, particularly in November and December. December is always a busy month, with holiday parties and travel, but November is a busy month in particular for those living with HIV as it includes National HIV Testing Week and the lead up to World AIDS Day. Many individuals expressed interest in participating, but did not have the time to do so in November because they were busy promoting events, and could not in December because they needed a (much deserved) break and then were busy with festive celebrations.

The participants who took part in the study were mainly male (Figure 42). One participant resided in the Philippines, while the rest resided in England. Five of the 6 identified as male, with P04 being the only female. The ages of the participants ranged from 24 to 47, with an average age of 34. Four different ethnicities were present, with two participants describing themselves as Asian or British Asian, two as Mixed, one Black African and one White / Caucasian. When asked to describe their sexual orientation, 4 responded as homosexual, 1 responded as heterosexual, and 1 as asexual. The majority or participants were diagnosed relatively recently, with P02 being diagnosed in 2017, P02 and P06 in 2016, P03 and P05 in 2015. P04 was the only participant to have lived with HIV for more than four years, as she was diagnosed in 2008.
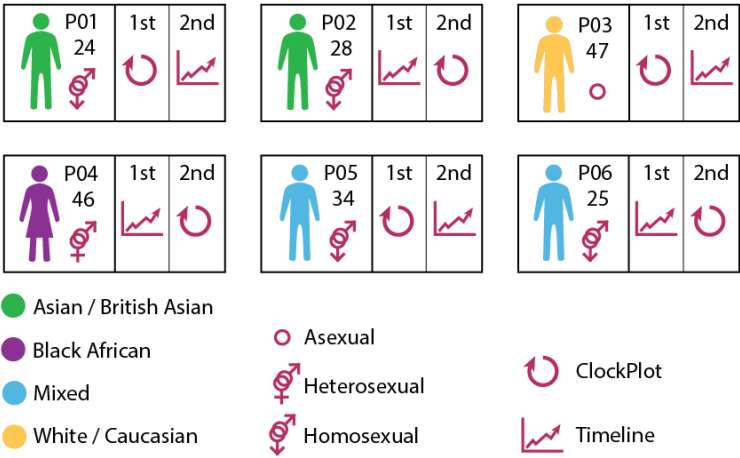


Figure 42: A visual breakdown of the six participants

For the remainder of the chapter, a participant will be referred to in one of two ways. If referring to a participant with regards to their actions or statements made while viewing a particular prototype, a suffix will be added to their participant ID to indicate the prototype being viewed and whether they saw it first or second. All other references to a participant will not include this suffix.

For example, P01's responses to open-ended questions at the end of the session will simply include "P01" at the end, while P01's comments made while viewing the timeline will include "P01-T2" as he is referring to the timeline (T) and he viewed it second (2).

Finally, it is worth noting that participants were asked to share as much of their personal health information as they felt comfortable, and that not all participants felt comfortable with sharing in detail.

Of the 6 participants, 5 shared their entire medication history, while P04 shared only the most recent. Not all participants felt comfortable sharing their lab results: P02 did not share any, P03, P04, and P05 shared only the most recent results. The levels of detail that participants provided with regards to their health concern also varied, with some providing precise details:

*"I started to notice hair falling out around the middle of December 2016. […] I was worried about what caused it and did some googling and thought it might be telogen effluvium triggered by the bad fever I got when I had acute HIV infection (first got ill on 25 September 2016). At that time I'd had a fever above 40 and was in A&E at one point and off work for two weeks. […] I continued to worry over Christmas and then in around mid-January 2017 my hair stopped falling out and since then has gone back to its normal thickness." – P06*

And others remaining vague:

*"Started to feel more lethargic." – P03*

Asking someone to share their personal health information with a stranger is uncomfortable, even if it is for research. Asking someone who may already be stigmatized because of their disease to share the details of that disease is far-reaching. No participants were pushed to share more than they felt comfortable with, but some did indicate that they struggled with the decision. Sensitivity to this should be kept in mind when conducting similar research.

## 6.2.4 Procedure

The study, from the start of recruitment to the end of data collection, took place between 11 October 2017 and 06 January 2018. The study procedure (shown previously in Figure 31) is described here in more detail, alongside the materials required.

### Pre-Session

The pre-session took place after receiving the completed pre-questionnaire, and lasted approximately 15 minutes. These sessions were held over the phone, Skype, or similar audio connection. The point of the pre-session was twofold: one purpose was to ensure the participant understood the research study and knew what to expect, while the second purpose was to review the health information provided in the pre-interview questionnaire and gather any additional details that may be required to create the prototypes. However, participants were not pressed to provide information that they did not feel comfortable with providing. Additional health information gathered during these conversations were added to the participant's pre-study questionnaire. Once neither the participant nor the researcher had remaining questions, the one-on-one session was scheduled and the pre-session ended.

### Preparatory Work

The preparatory work, during which the personalized study materials were created, took place in the time between the pre-study and one-on-one sessions. During this time, the researcher used the question and personal health information provided by the participant to develop the prototypes

and fictional responses (described in 6.2.2). Two versions of each prototype were created – one with just the participant's information (Figure 43), and one with their information and the information of the profiles (Figure 44).
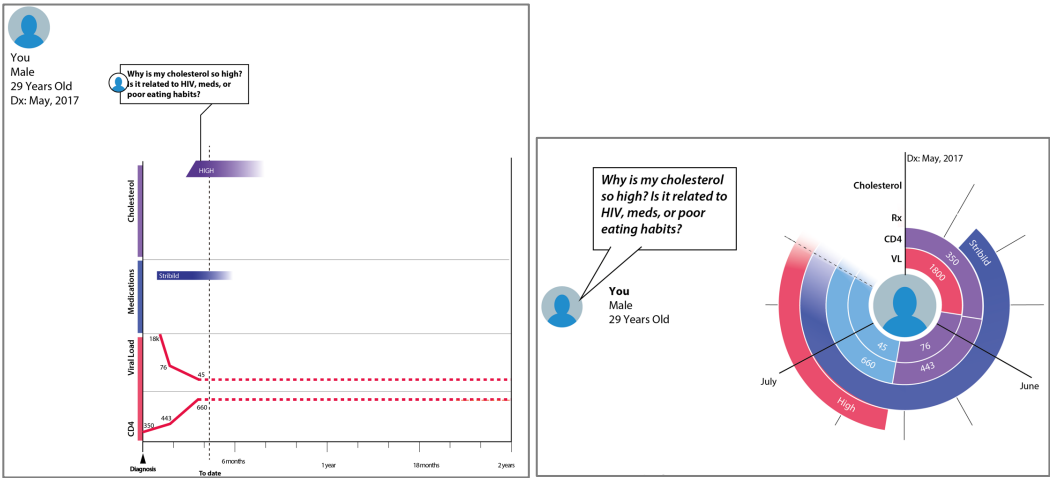


Figure 43: Version of Timeline (left) and Clock Plot (right) with no fictional profiles included
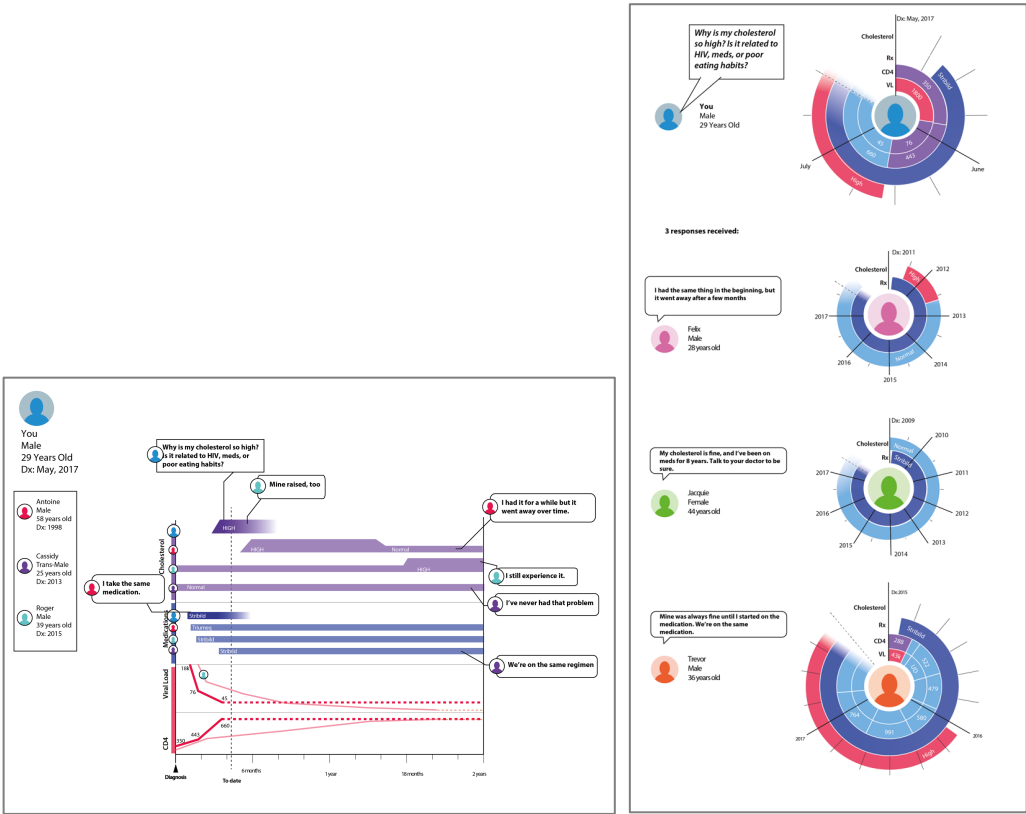


Figure 44: Version of Timeline (left) and Clock Plot (right) with fictional profiles included

The one-on-one sessions were held both in-person and remotely. Those held in-person were held in a private room in City, University of London. Those sessions that were held remotely took place over Skype. These sessions lasted approximately 45 minutes and were audio- and screen-recorded using Camtasia. The first 5 minutes of the one-on-one session involved thanking the participants for their participation, and reminding them of the purpose of the study and of what will occur. Participants were also reminded that the responses they saw in the prototypes were not from real individuals but representative profiles. The discussion guide (Appendix 18) was used by the researcher during this session to keep the session on track and guide the participant.

The discussion guide began with a script to be read to the participant, giving them an overview of what will occur. From there, the discussion guide led into reviewing the first prototype, with an explanation to the participant that the focus of the study is on how the features support reflection, rather than on the profiles or responses they receive.

Once the participant was reminded of the study purposes and procedure, the data collection began. Because this was a within-subject study, the order was alternated with each participant (e.g. the first participant saw the Clock Plot Prototype before Timeline Prototype, and the second participant saw the Timeline Prototype before the Clock Plot Prototype). Regardless of the order, each participant was first shown a view of the first prototype with only their health information (no simulated responses), as a means of familiarizing them with the visualization. They were asked to talk through what they saw, referencing the different features, and tell the researcher when they felt they were comfortable with the visualization style.

Following this, the participants were shown a second view of the prototype; the one containing the simulated responses. They were asked to use that prototype to reflect on their health and to try to find an answer to their question. They were asked to refer to what they see in on the screen while they thought out loud, and to use the mouse to indicate what they were looking at. When a participant would fall silent, they would be asked questions about what they were looking at or thinking. Once they declared they were finished looking at the prototype, or felt that they had an answer to their questions, there were asked to complete the sensemaking questionnaire (Appendix 19) for the prototype they had just seen.

The sensemaking questionnaire used in this study is a validated questionnaire developed by Alsufiani, Attfield, & Zhang (2017). It was used to measure the participant's level of sensemaking with each prototype. The questionnaire contains 14 statements, each followed by an 11-point Visual Analogue Scale which participants used to rate their agreement with the statement.

The above process, from presenting the first view of a prototype to completion of the sensemaking questionnaire, was repeated for the second prototype. Participants were asked to focus on the prototype they saw and to not compare it to the first prototype seen.

Once both prototypes were reviewed and the final sensemaking questionnaire was completed, the researcher asked final questions about what they had seen: if it surprised them, what was helpful, what they would change, and if they felt that having access to the details of other people helped in understanding their own health experiences. Participants were given an opportunity to provide feedback and to ask the researcher questions as well. Finally, the participant was thanked for their time, and the session and recording ended. All participants were given a £15 Amazon gift voucher (or equivalent in local currency) as thanks for their time and effort upon completion of the study. This amount was chosen as it provides adequate incentive for joining and compensation for time, but does not place undue interest upon participation.

### 6.2.5 Data Collection and Analysis

This sub-section describes how the data were collected, and how they were analyzed to answer the three research questions.

*Questionnaire Responses*

One method of capturing data is via the responses to the questionnaires. Both the pre-study and sensemaking questionnaires were online, so the data that were entered into them were automatically captured alongside the participant's unique identification number and readily available to be downloaded as a spreadsheet.

The pre-study questionnaire responses were used only to describe the demographics of the recruited participants, these details were not analyzed in any further way.

The responses to the sensemaking questionnaires were used to determine the level of sensemaking achieved with each instantiation. The responses were entered into a spreadsheet and then analyzed according to the methods described by Alsufiani, Attfield, & Zhang (2017): the Likert responses to each statement were tallied for each prototype viewed by a participant. No statistical analysis was conducted. According to Alsufiani et al., a 'high' level of sensemaking would be a score of over 100 (maximum 154).

*Recordings from One-On-One Sessions*

Data about the participants' thoughts and what features they were looking at during the one-on-one sessions were captured using Camtasia. The audio from each one-on-one session were

transcribed in full; utterances (e.g. 'uh', 'umm', 'hmm', etc.), pauses (shown as '…'), and incomplete sentences were all included. In order to have a full and accurate account of the conversations that take place, the transcripts also included the researcher's comments. Comments made by the researcher were differentiated in the transcripts from those made by the participant. This were done by changing all comments by the researcher to a medium-gray non-italicized font.

Any identifiable information was anonymized by substituting the identifiable word with a generic replacement (e.g. *"I work at Starbucks in Croydon"* would have been de-identified and shown as *"I work at [coffee shop] in [borough]"*). No handwritten notes were taken during the one-on-one study sessions. Once the data were suitably anonymized, each participant's transcript was entered into an Excel file and separated into three different sheets: one for the viewing of the Clock Plot, one for the viewing of the Timeline, and one for the responses to the open-ended questions. Once this was done, the data were ready to be 'chunked' into smaller sections and analyzed.

The transcripts describing the responses to the open-ended questions were chunked by question type – one cell showed the question asked, one cell showed the response. The transcripts regarding the prototypes being viewed were chunked differently, following the method described by Grigoreanu et al. (2012): each time a participant made a statement regarding a piece of information or feature, a chunk was made. If multiple pieces of information or features were described in the same sentence, they were kept together in one chunk. These statements varied in length, from unfinished sentences (e.g. *"Her labs are… oh, okay…"*) to multiple sentences (e.g. *"So you can see his labs, they went up at this time, but then they came back down. That's really good to know, you know? That gives me some assurance."*).

The transcripts describing the prototypes were also marked with a black line to indicate the point in which the participant went from viewing the prototype with just his/her information, to the prototype with the profiles included.

Following this, four sets of codes were defined: one for coding health information, one for features, one for stages of sensemaking, and one for levels of reflection. As will be described below, these codes were applied through thematic analysis of the videos and transcripts (with the exception of the open-ended questions) in the spreadsheet.

All codes were assigned a color scheme as a means of visually identifying differences and patterns – these will be shown in the tables describing each code, below. An excerpt from Participant 04's spreadsheet, who viewed the Timeline first (hence 'P04-T1'), is provided in Figure 45, as an example of how the codes were applied to each chunk of data.
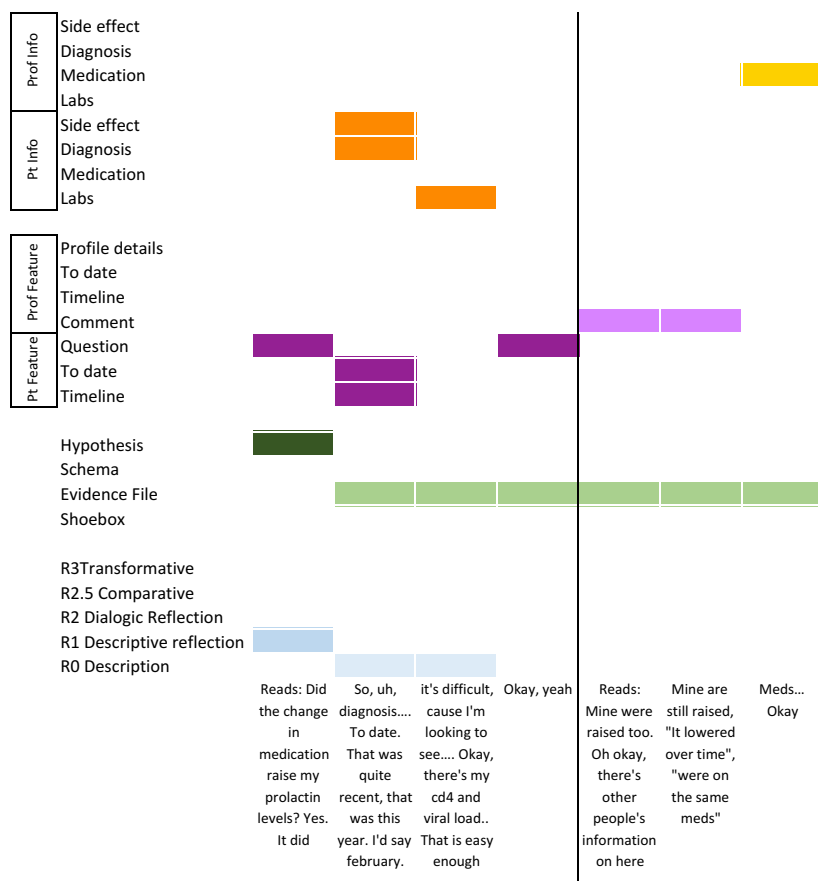
Figure 45: Example of coding applied to P04-T1's transcripts

A completed analysis of P06-T1's session is shown in Figure 46, without the transcripts. Creating a visual depiction of the codes was done as a means of identifying patterns in the data.



**P06 Timeline 1st**
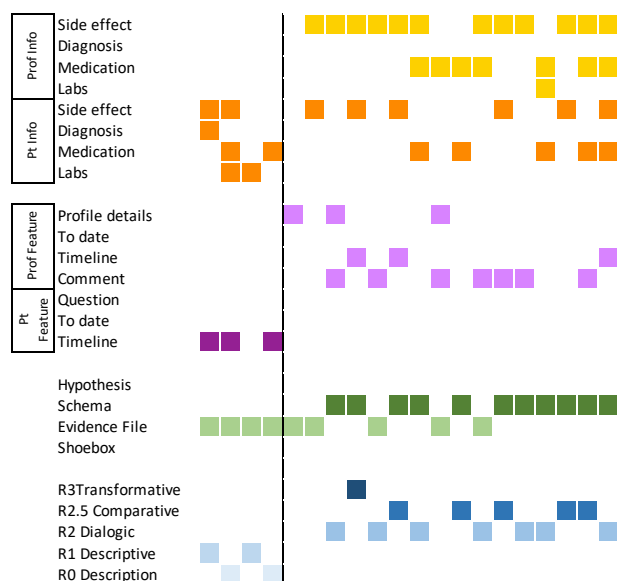
Figure 46: Example of coding for P06-T1. The black line indicates when the participant moved from viewing the prototype of just his information ('solo version'), to the prototype with the profiles ('full version').

*Sensemaking Code Set*

Sensemaking refers to how individuals manage and consider information and make sense out of their experiences (Dervin, 1998). Because the participants in this study each had a question about their health that they wanted to make sense of, we used sensemaking as one way of exploring how they did so. While the reflection codes (described later) were used as a way of understanding how participants considered their experiences alongside those of the fictional profiles, the sensemaking codes were used to understand how participants manipulated the information they were presented with while they were reflecting.

Codes describing the stages of sensemaking (Table 22) were the first to be applied to the transcripts. These codes were based on those descriptions provided by Pirolli and Card (2005) and the definitions used by Grigoreanu et al., (2012) in their own coding exercise. These descriptions / definitions from previous researchers were altered slightly so that they matched the scenario of community-aided reflection. Each chunk in the transcripts was analyzed to determine which level of sensemaking was occurring.

Because of the way the transcripts were chunked (by descriptions of information or features), and because the sensemaking codes focus on information usage, a sensemaking code was applied to every chunk in the transcripts. Because these codes describe levels, there cannot be more than one code applied for any individual chunk of data.

Once the sensemaking codes were applied, analysis turned to the coding features and information types. First, the codes were created, then the video recordings were watched again to identify instances when a participant was circling information or a feature with the cursor. This way, both the verbal and physical uses could be coded.

*Information Type Code Set*

The codes describing the information types were taken directly from the previous research studies, so did not need re-defining. However, in order to highlight the instances when participants referred to their own health information, versus the health information of a profile simulating a community response, these codes were split (Table 23). If a participant was speaking about, or indicating with the mouse, their medication, the cell in the Participant Medication row would be marked. If speaking about a fictional profile's medication, the cell in the Community Medication row would be marked. Occasionally, participants would regard multiple types of information together, and these would all be marked.

*Feature Code Set*

Rules were set up for determining when to apply a code for the features of the representations. If a participant looked at, read, referred to, or circled one of the features, it was coded. Like the information types, the feature codes were split to highlight if a participant was referring to a feature about themselves or about a profile simulating a community-member (Table 24).

| The Sensemaking Model for Analysts (Pirolli and Card, 2005) | The Sensemaking Model for End-User Debuggers (Grigoreanu et al, 2012) | The Sensemaking Model for Computer-supported Community-Aided Reflection |
|---|---|---|
| *Shoebox* (node 4): Much smaller set of data, relevant for processing | Shoebox: Data that a participant deemed relevant enough to "touch" in the spreadsheet or study environment Examples: Particular cells selected, spreadsheet description handouts read, menus of features perused, help documents accessed, etc. | ■ Shoebox: Information or features of the prototype deemed relevant enough to mention looking at Examples: Expressions of looking at callouts, visualizations. Comments read, etc. e.g. "I see a lot of comments, the data of other people" |
| Evidence File (node 7): Snippets of data extracted from the items in the shoebox | Evidence File: Extracted from the shoebox, data that attracted a participant's interest enough for follow-up Example: Wanting to find out more information about a suspicious cell | ■ Evidence File: Snippets extracted from the shoebox: considering smaller, more specific pieces of information Example: Looking into specific pieces of information, rather than overview of what is available e.g. "Jacquie says it's this" "I'm just looking at Trevor's cholesterol" |
| *Schema* (node 10): A re-representation or organized marshalling of the information for easier conclusion drawing | Schema: A structure or pattern a participant noticed as to how cells or information related Example: Declaring that all cells in an area were behaving properly or that a cell(s) did not fit the pattern. | ■ Schema: A structure or pattern a participant noticed as to how pieces of information in the prototype related Example: Declaring potential patterns, similarities or differences in information available e.g. "Neither Trevor nor Jacquie had my problem" "Jacquie didn't have high cholesterol, but she's much older than me" "Felix had it and we have been on medication for a similar amount of time" |
| Hypotheses (node 13): A tentative representation of the conclusions with supporting arguments | Hypothesis: A tentative idea about how to fix a particular bug based on the participant's schema Example: "So it's saying that the group average is higher than it really was. I would say that is a mistake, since the formulas below it include all of them, this formula should include all" | ■ Hypothesis: A tentative idea about the answer to the participant's original question, based on the participant's schema Example: "Maybe the medication causes it, since Felix and I both have it and are at similar stages" |

Table 22: Definitions of codes for stages of sensemaking

| | | |
|---|---|---|
| ■ Participant Health Information | Side Effect | 'Side Effect' refers to the change in health that the participant is concerned with |
| | Diagnosis | 'Diagnosis' refers to the date that the participant was diagnosed with HIV |
| | Medication | 'Medication' refers to the name of the medication(s) taken, as well as the start/end/duration of that medication being taken |
| | Lab Results | 'Lab results' refers to the CD4/viral load of the participant |
| ■ Community Health Information | Side Effect | 'Side Effect' refers to the change in health that the participant is concerned with, which the fictional profiles refer to |
| | Diagnosis | 'Diagnosis' refers to the date that the fictional profile was diagnosed with HIV |
| | Medication | 'Medication' refers to the name of the medication(s) taken, as well as the start/end/duration of that medication being taken |
| | Lab Results | 'Lab results' refers to the CD4/viral load of the fictional profile |

Table 23: Codes of health information were split to indicate if the information referred to the participant or a fictional profile

| | | |
|---|---|---|
| ■ Community Feature | Profile Details | Reading out, or looking at, the details of a fictional profile<br><br>Ex: "This is Roger, he's 39" |
| | To date | Stating, or looking at, the 'to date' mark when referring to a fictional profile<br><br>Ex: "Oh, okay, so this is him up to the current date" |
| | Timeline | Stating, or looking at, the timeline when referring to a fictional profile<br><br>Ex: "You can see the time go around since the start" |
| | Comment | Reading, or looking at, an in-context or out-of-context comment<br><br>Ex: "[Reads] I found out mine was high…" |
| ■ Participant Feature | Question | Reading out, or looking at, their in-context or out-of-context question<br><br>Ex: "So this is my question" |
| | To Date | Stating, or looking at, the 'to date' mark when referring to their personal information<br><br>Ex: "So this line is where I'm at now" |
| | Timeline | Stating, or looking at, the timeline when referring to their personal information<br><br>Ex: "You can see the months along the bottom" |

Table 24: Definitions of Features Codes

*Reflection Code Set*

Finally, thematic analysis of the participants' comments while viewing each prototype was conducted to determine the level of reflection that had occurred. For this, codes describing levels of reflection were used (Table 25), based on those defined by Fleck (2012). One of the levels of reflection that Fleck defined was divided into two (R2 and R2.5). This was done to separate the instances in which individuals merely stated that similarities were present (R2) and when they displayed deeper thought on those similarities and what they might mean. Each chunk in the transcripts was analyzed to determine *if* it showed an example of reflection and, if so, what level of reflection was occurring.

| Levels of Reflection (Fleck, 2012) | Levels of Reflection (codes for this study) |
|---|---|
| **R0: Non-Reflective Description**<br><br>A description or statement about events or other interpretation of the image without further elaboration or explanation. Can be of/about images, or just from memory of events. | **R0: Description (Non-reflective)**<br><br>A description or statement about the participant's experience shown in the prototype, without further elaboration or explanation. Does not include or link to the data of others, or mention data or experiences not represented in the prototype.<br><br>Ex: "This is when I was diagnosed" |
| **R1: Reflective Description**<br><br>Description including justification or reasons for action, but in a reportive or descriptive way. No alternate explanations explored, limited analysis and no change of perspective. May include discussion of things to change in future.<br><br>Examples include description and explanation, description and theory, evaluation, or storytelling. | **R1: Reflective Description**<br><br>Description about experience or information in prototype, but providing contextual detail not included in visualization. No alternate explanations explored, limited analysis and no change of perspective. Does not include or link to the data of others.<br><br>Ex: "This is showing the period where I experienced hair loss. I had a very bad fever of about 40 degrees and was in the A&E" |
| **R2: Dialogical Reflection**<br><br>A different level of thinking about. Looking for relationships between pieces of experience, evidence of cycles of interpreting and questioning, consideration of different explanations, hypothesis and other points of view. May include discussion of suggestions for change. | **R2.0: Dialogical Reflection**<br><br>Stating similarities between pieces of personal info/experiences, and/or similarities between personal info/experience and the info/experiences of others. No evidence of interpreting and questioning, consideration of different explanations, hypothesis and other points of view.<br><br>Ex: "Antoine had it too", "This is Roger, we are on the same regimen" |
| | **R2.5: Comparative Reflection**<br><br>A different level of thinking about. Describing relationships between personal info/experience, and/or relationships between personal info/experiences and the info/experiences of others. Evidence of interpreting and questioning, consideration of different explanations, hypothesis and other points of view.<br><br>Ex: "I can check their progress on my medication", "Roger still experiences it, so I'm not an outlier", "This person had the same thing, but at the beginning" |
| **R3: Transformative Reflection**<br><br>Revisiting an event with intent to re-organize and do something differently. Asking of fundamental questions and challenging personal assumptions leading to a change in practice. | **R3: Transformative Reflection**<br><br>Asking of fundamental questions and challenging personal assumptions about person experiences or personal information, suggesting hypotheses or reasons.<br><br>Ex: "Does that mean there is a link between these medications and weight gain?" |

Table 25: Definitions of Levels of Reflection codes

## 6.3 Results

The results of this research study will be described in the following order. First, the visual depictions of the codes applied to each participant's transcripts will be provided to provide a general overview of the results. These depictions will be referred to throughout the remainder of the results section beginning with how reflection occurred with the representations (RQ-4.1), followed by how information was used during reflection (RQ-4.2), and ending with the design considerations for supporting reflection (RQ-4.3).

### 6.3.1 Visual depictions of results

Below are the visual depictions of each participant's results. Alongside each are the total number of instances of sensemaking that was coded, and the total instances of reflection. As mentioned in Section 6.2.5, the way that the transcripts were chunked meant that a sensemaking code was applied to every 'chunk' of data, but that not all chunks were instances of reflection. Therefore, the frequencies of sensemaking and reflection differ.

P01-C1 - 16 instances of sensemaking, 10 of which were also reflection:
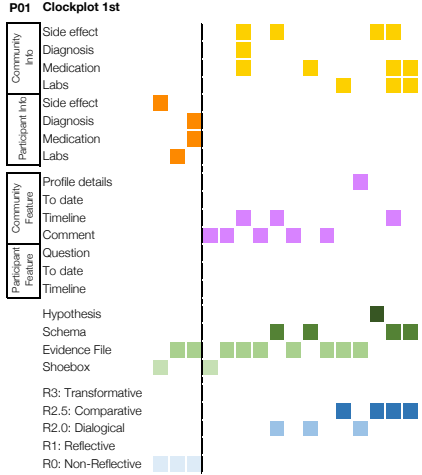


P01-T1 – 23 instances of sensemaking, 22 of which were reflection:
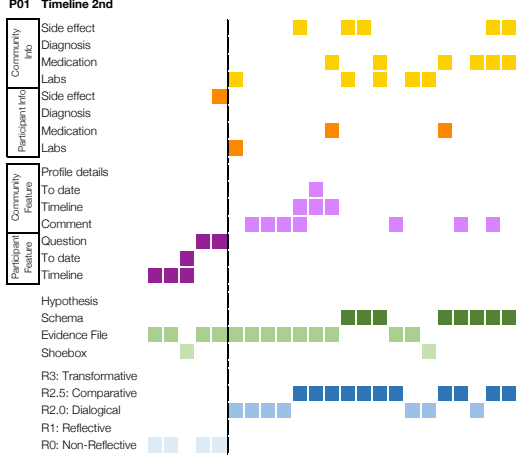
## P02-T1 – 11 instances of sensemaking, 9 of which were reflection:



## P02-C2 - 13 instances of sensemaking, 10 of which were reflection:
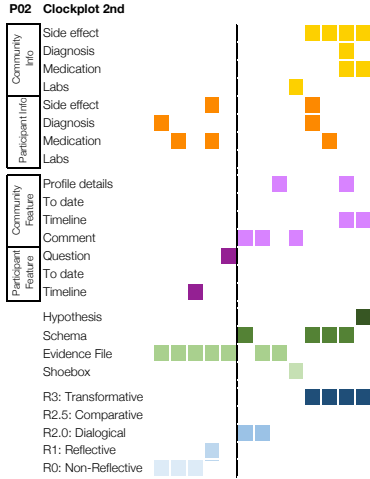


## P03-C1 - 21 instances of sensemaking, all of which were reflection:
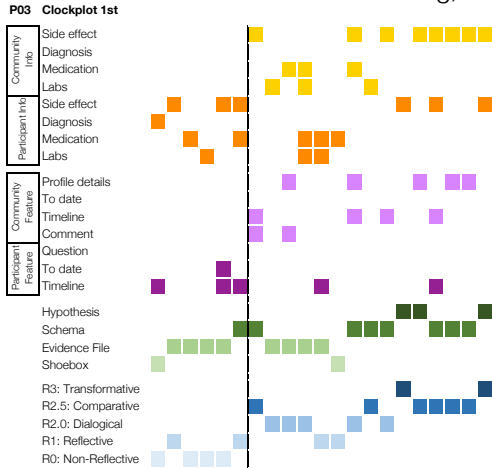
## P03-T2 – 22 instances of sensemaking, 17 of which were reflection:
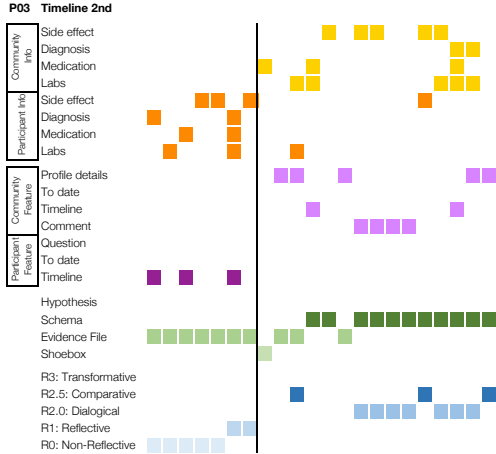


## P04-T1 – 13 instances of sensemaking, 8 of which were reflection:
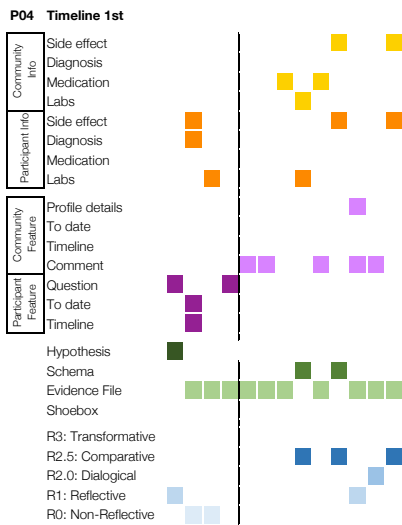


## P04-C2 – 10 instances of sensemaking, 6 of which were reflection:
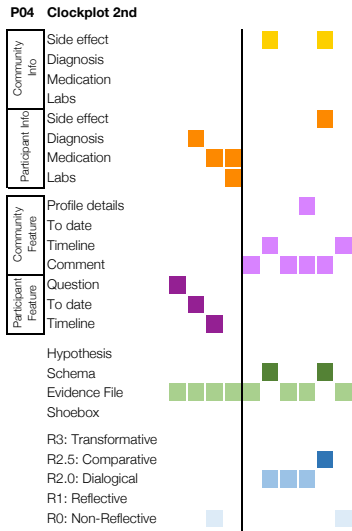
## P05-C1 – 12 instances of sensemaking, 10 of which were reflection:



**P05    Clock Plot 1st**
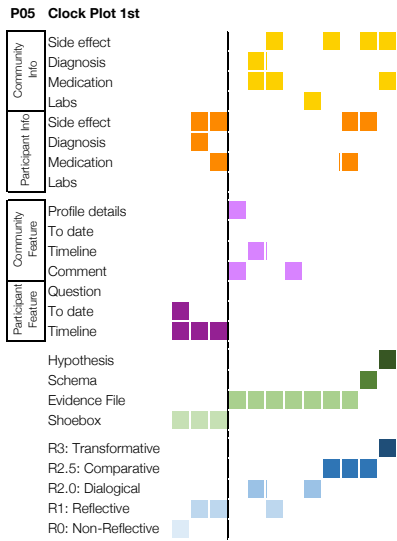
## P05-T2 – 10 instances of sensemaking, 3 of which were reflection



**P05    Timeline 2nd**
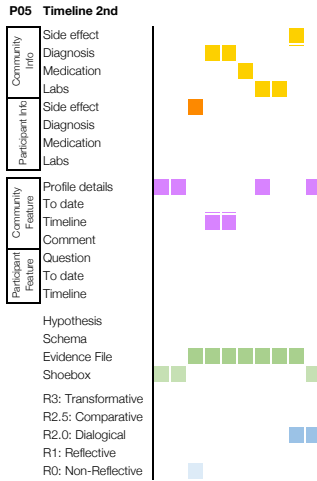
## P06-T1 – 20 instances of sensemaking, 17 of which were reflection:



**P06    Timeline 1st**
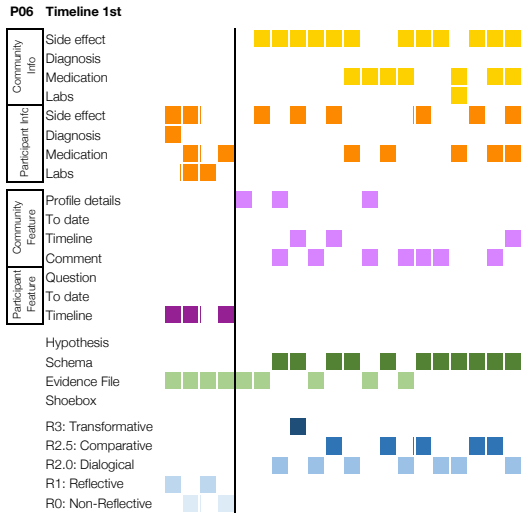
P06-C2 – 14 instances of sensemaking, 9 of which were reflection
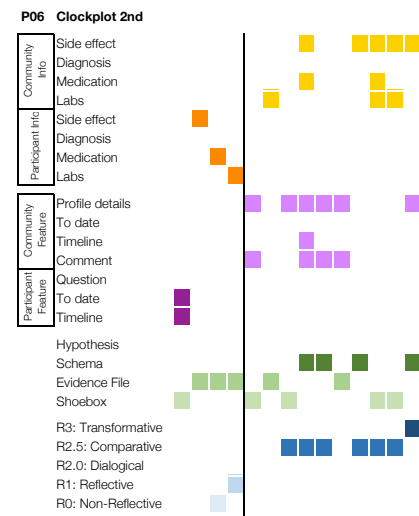


## 6.3.2 The process of reflection

**RQ-4.1: What is the process of reflection when using a prototype simulating community-aided reflection?**

To answer this research question, reflection was measured in three ways. First, with the responses to the sensemaking questionnaire, then through the stages of sensemaking that were observed, and finally through the levels of reflection. This sub-section will present the results to RQ-4.1, in that order.

*Sensemaking Questionnaire*

Five of the six participants completed the online sensemaking questionnaire (Appendix 19) after viewing each visualization. Table 26, below, displays the overall scores of the sensemaking questionnaire for each prototype and each participant. One participant, P05, could not complete the online questionnaire due to an internet failure. As such, P05's data is missing from the table below. The full results of this questionnaire are provided in Appendix 20.

| Participant ID | P01 | | P02 | | P03 | | P04 | | P06 | |
|---|---|---|---|---|---|---|---|---|---|---|
| View | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 |
| Prototype | CP | T | T | CP | CP | T | T | CP | T | CP |
| Average score per question | 7.5 | 9.2 | 3.4 | 8.1 | 9.4 | 9.9 | 10.9 | 11 | 6.4 | 7.2 |
| SUM | 105 | 129 | 48 | 114 | 132 | 139 | 153 | 154 | 90 | 101 |

Table 26: The results of the sensemaking questionnaire

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The highest possible score to achieve would be 154 (achieved by answering each question with 11). P04's results suggest that she achieved the highest level of sensemaking with each prototype. The lowest score was given by P02 on his first prototype view (3.42 average, 48 altogether). All participants scores improved when viewing the second representation style.

According to Alsufiani, Attfield, & Zhang (2017), scores of over 100 indicate a 'high' level of sensemaking. Each of the participants who were able to complete the questionnaire scored over 100 after viewing a prototype. Three of the participants scored over 100 after viewing both prototypes, while P02-T1, and P06-T1 only scored over 100 with one prototype.

P06's responses to the questionnaire after viewing the Timeline resulted in a total score of 90, which Alsufiani et al. consider to be a 'good' level of sensemaking. However, P02's responses to the questionnaire after viewing the Timeline resulted in a low score, 48, which is considered to be a low level of sensemaking. His transcripts indicate that the reason for this score was that he found it difficult to draw connections between the community's information and his own, he struggled to identify similarities or pull out what might be important for his concern while reflecting:

> "The timeline was easy to understand, but with all the information on the commented version it was too much. It was hard to understand the relevance it has." – P02-T1

Still, P02's sensemaking score with the second prototype indicates that he did end up achieving a high level of sensemaking, and the results of all the participant's scores suggest that the prototypes are supportive of sensemaking as a whole, and largely of higher levels of sensemaking.

### Levels of Sensemaking

The sensemaking questionnaire was used as a way of measuring the level of sensemaking, and therefore reflection, that occurred as a whole after using the prototypes. However, the sensemaking questionnaire does not indicate what occurred while the participants were viewing the prototype. By looking at the frequency with which each stage of sensemaking was achieved when using the prototypes, we can gain a better idea of how supportive they are.

In total, there were 175 instances in which sensemaking occurred when participants were exploring the prototypes. There were four codes for sensemaking, and these are hierarchical. Shoebox is the lowest level, followed by Evidence File, then Schema, and finally – the highest level – Hypothesis.
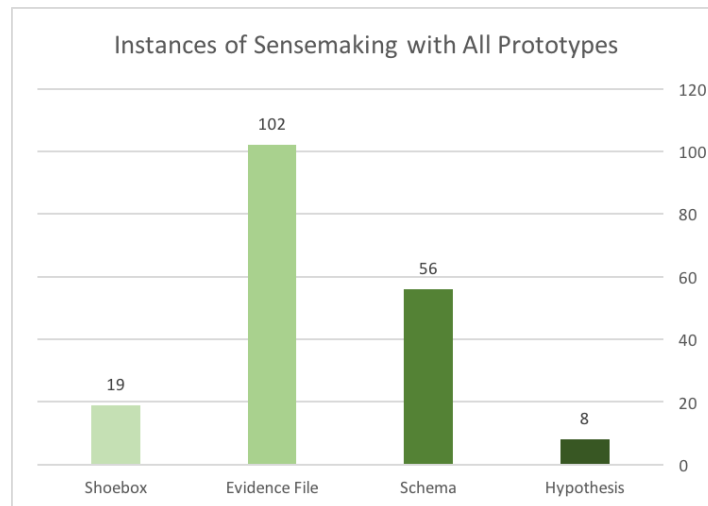
Figure 47: Total instances of sensemaking

Shoebox, which occurs when individuals glance over information, was coded just 19 times (Figure 47). Few instances of Shoebox could be taken as an indication that participants found the prototypes accessible, and that they were able to spend more time focusing on information (Evidence File) than on understanding what was available to them in the prototype.

The Evidence File was the most frequently coded stage of sensemaking (102 instances), but the high frequency should not be taken as a negative indication. The Evidence File occurs when individuals are focusing in on pieces of information, seeking to determine if they are relevant or not. The Evidence File occurred most frequently when participants were first provided with the prototypes (both the version with only their information, and the version with the community responses). This shows that the participants were exploring the prototype, focusing in on the different pieces of information made available to get an idea of what might be relevant to them before seeking out patterns.

Schema, which occurs when a participant found patterns in the information shown, was coded 56 times. This indicates that participants found the information shown in the prototypes to be useful, and that they were seeking relationships between the community's information and their own. Participants often bounced between Evidence File and Schema: they focused in on a piece of information, found it relevant, and then sought to determine a pattern or connection. For example, P01-C1 moved from Evidence File to Schema, before returning to Evidence File to find further information of relevance:

*"[reads] "I had the same thing in the beginning but it went away after a few months""* *[Evidence File]*

*"Okay, that's nice to know, although his side effects were only for the year of 2011 to 2012. Okay, that's nice to know" [Schema]*
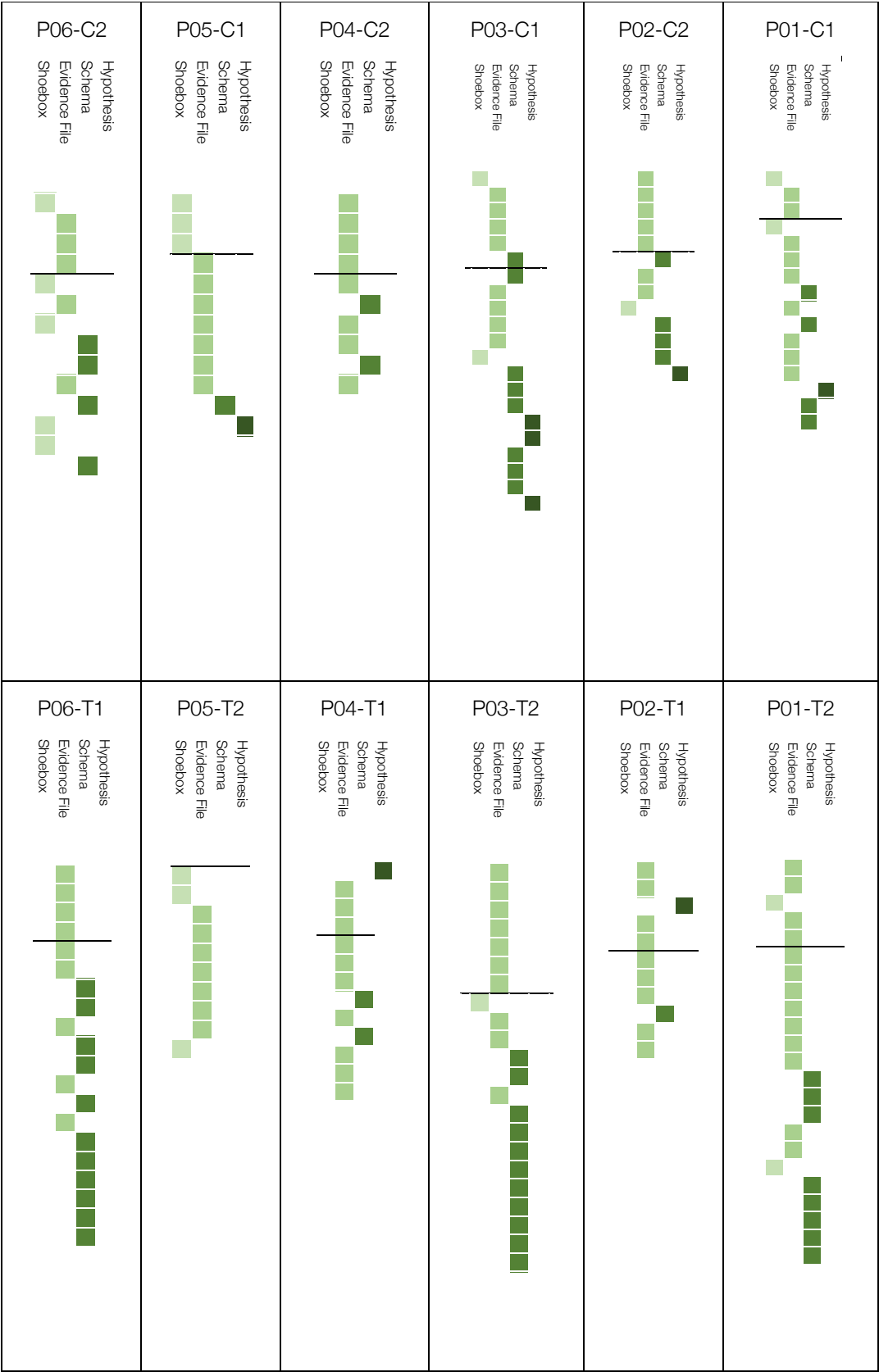
Figure 48: Breakdown of instances of stages of sensemaking. Separation of solo and full versions indicated by black line.

*"[Reads] "I've never experienced any dizziness or sleepiness, and I've been on meds for 8 years. Talk to your doctor to be sure.""" [Evidence File]*

Finally, there were 8 instances in which Hypothesis occurred; 5 of the 6 participants had an instance of Hypothesis at least once. Such a low number of occurrences is not necessarily a bad thing – Hypothesis is the highest stage of sensemaking, so this suggests that most participants were able to move through the previous stages, draw connections and patterns, and ultimately achieve a hypothesis.

Two participants (P04 and P02) actually had a hypothesis early on in viewing the prototypes. These two participants seemed to already have pre-conceived hypotheses with regards to their question: their hypothesis did not appear to form in that moment, but instead it formed how they viewed the prototypes – seeking confirmation:

*"[Reads] 'Did the change in medication raise my prolactin levels?' Yes. It did." – P04-T1*

*"It just shows that the medication could have a significant impact on a condition, and there is a possibility that the medication could have caused a side effect of the health condition." – P02-T1*

These participants then proceeded to explore the information available in the prototypes, placing potentially relevant information in the Evidence File, and drew on patterns from the information (Schema) that supported their Hypothesis.

*Levels of Reflection*

There was a total of 142 instances in which reflection was coded. Reflection levels 0-3 were coded between 9 and 43 times (Figure 49). There were no instances in which participants reached the highest level of reflection, Critical Reflection, although this was not surprising as it seems to rarely occur (see Fleck, 2012).
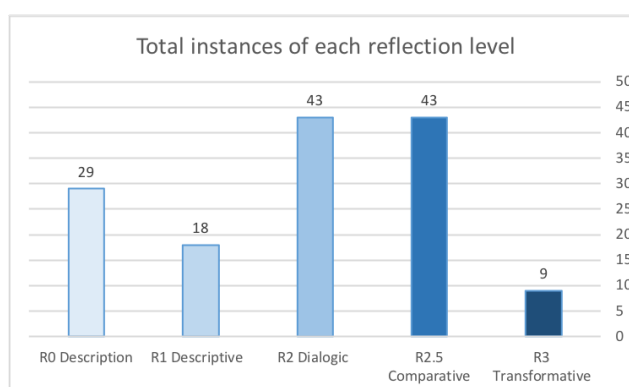


Figure 49: Total instances of reflection

Of all the instances of reflection, 29 were coded as R0 – Non Reflective Description and 18 were R1 – Descriptive Reflection. These are the lowest levels of reflection, as defined by Fleck (2012). R0 occurs when a participant describes or states their health experiences shown in the prototypes provided, but do not elaborate further. Reflective Description (R1), occurs when a participant describes what is shown in the prototype, but also provides contextual detail not included.

The instances of R0 almost always occurred when the participant was viewing the version of the prototype that had only their information shown, and this was nearly always the first reflective occurrence with each participant (Figure 50, to the left of the black line). R0 is not considered to be reflective thought, but it is a starting point for reflection – before diving deeper into reflecting on their experiences or describing events that were not included in the health information represented, participants were first providing an overall description of them when viewing the prototypes. For example, P03-T2's comments below first show him making two statements about his health information shown in the prototype, then following them with a detailed description [R1] as he reflected on his experiences and what was not shown:

> *"The medication, when it started after six months" [R0]*
>
> *"And my side effects, okay." [R0]*
>
> *"All these figures are pretty steady, but if you were to start it here [at the diagnosis] and you'd see that the CD4 is very low and the viral load is very high, and the medication and the change, then you could see the comparison and how long it took for the medication to kick in, when the figures started to change." [R1]*

Reflection level R2, Dialogic Reflection, occurs when individuals state similarities between their own information/experiences and/or the information/experiences of the fictional profiles, and was coded 43 times. This is still not a deep level of reflection, as it does not involve comparing, interpreting, questioning, or exploring connections between information/experiences. We can see, from the transcripts, that chunks that were coded as R2 involve rather straight-forward statements of similarities, unlike those in R2.5:

> *"So this is Trevor, 36. okay he started on the medication and has had the tiredness as well. From September 2015 he has basically been on the same stuff [as me]." – P03-C1 [R2]*
>
> *"These people have been on similar medication to me." – P06-T1 [R2]*
>
> *"Okay, they have the same medicine, Sustiva and 3TC, as here…" – P01-C1 [R2]*
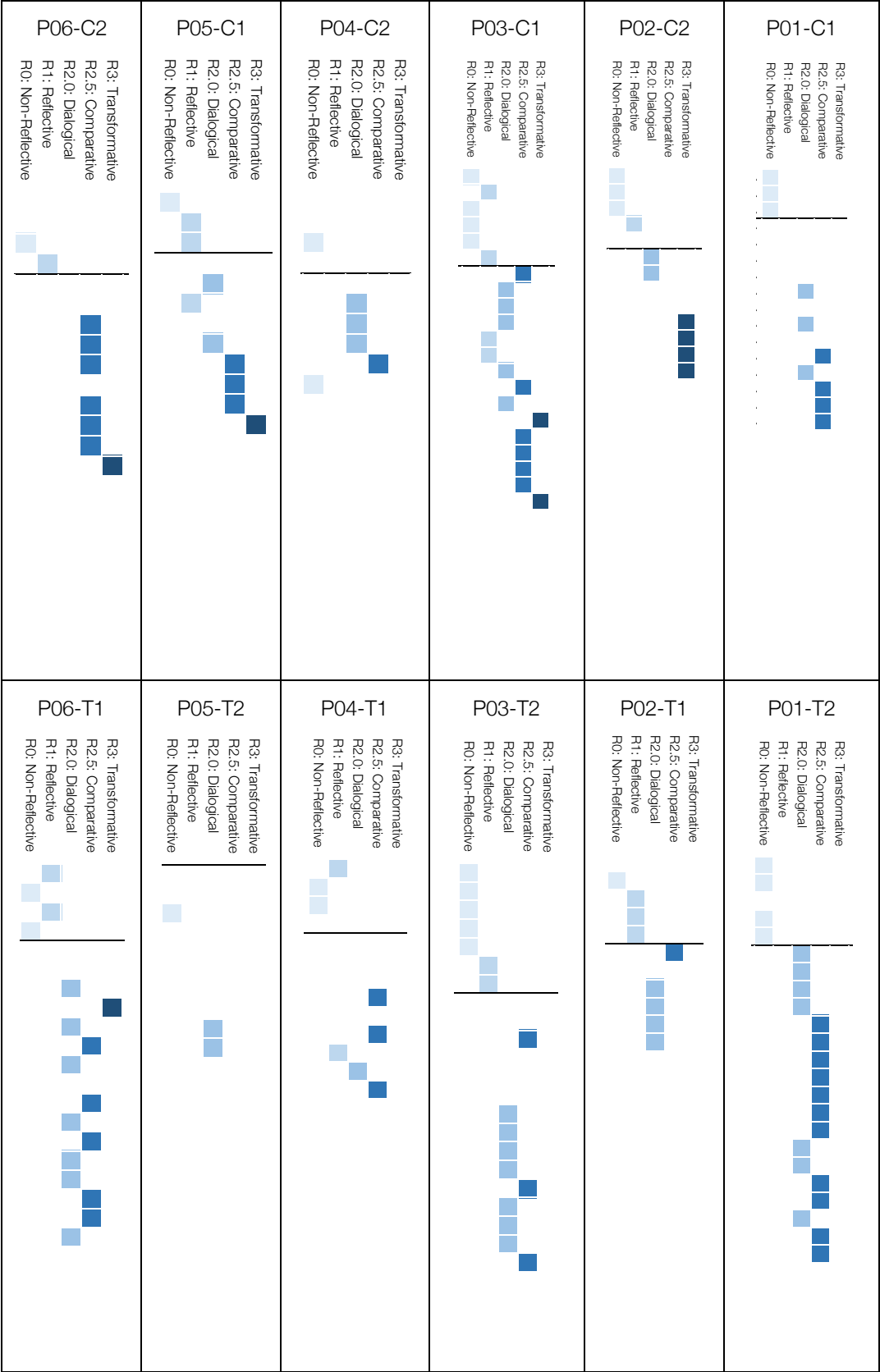
Figure 50: Breakdown of instances of levels of Reflection. Separation of solo and full versions indicated by black line.

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The number of instances Comparative Reflection, R2.5, was coded was the same as Dialogic Reflection: 43 times. Comparative Reflection occurs when an individual moves beyond stating links or similarities to describing, questioning, and interpreting relationships between other information / experiences and their own:

> *"So this person has the same thing as me but felt it at the beginning of their diagnosis."*
> *– P03-C1*

P03's comment shows that he is not only describing a similarity, but is also describing a mismatch or difference of experiences. As the quote above shows, P03 describes a connection in health experiences ('the same thing as me') but then points out a difference ('but felt it at the beginning of their diagnosis'). This shows that R2.5 does not just mean that individuals are searching for what is the same as they reflect, they are also searching for what is different. This highlights that community-aided reflection does not always involve finding positive connections; mismatches of experiences, like that shown above, are also used to reflect and understand personal health information.

The deepest level of reflection observed in this study was R3, Transformative Reflection, and this was coded 9 times across four participants: 4 with P02-C2, 2 with P03-C1, and 1 with P05-C1, and 1 with both prototypes P06 viewed. In R3, individuals ask fundamental questions or suggest hypotheses for their experiences. From the transcripts, we can see that these participants were drawing on the information shared by the fictional profiles as they considered potential reasons for their own experiences:

> *"Yeah, it puts it into perspective – maybe as you get older the medication works in a different way." – P03-C1*

> *"The first example, where I've got Felix and he's male 28 years old […] it really makes you think. […] It just makes me think that the medication has had a significant impact, and the weight loss and headaches have been present." – P02-C2*

### 6.3.3 Health information used during reflection

**RQ-4.2: What information is used in the different levels of reflection?**

The prototypes were designed to simulate and support community-aided reflection; by observing the participants while they reflected we are able to better understand how the information represented in these prototypes were used during reflection. Across all of the instances of reflection, there was a total of 84 times in which Participant Information was coded, and a total of 101 times in which Community Information types were coded. In this section I will break down the information types that were used in each stage of reflection.

The graph below, Figure 51, provides an overview of how participants referred to their health information ('Participant information') and the 'Community information.' Because the amount of

Community information outweighed the Participant's (refer back to 6.2.2 for details on what information was shown by the fictional profiles), the Participant and Community information frequencies will each be presented as a percentage of the total number of instances. For example, of the 84 instances in which Participant information was referred to during reflection, 6 of those instances occurred in level R3, or 7.14%. Of the 101 instances in which Community information was referred to, 12 occurred in level R3, or 11.88%.
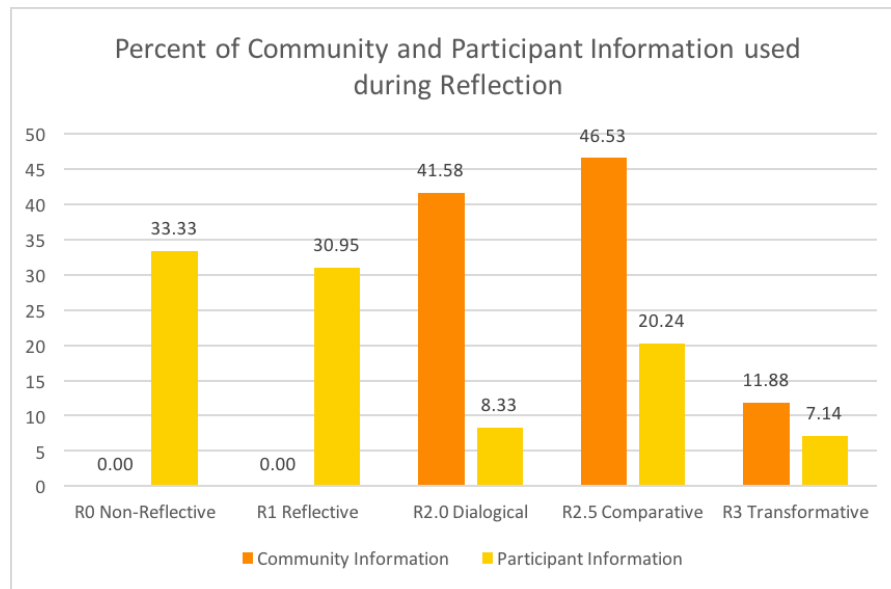


Figure 51: Percentage of instances of Community Information and Participant Information in each level of reflection

Figure 51 shows that Participant information was referred to in every level of reflection, but most prominently in the first two levels (R0, R1), as the participants were recalling their experiences and beginning to reflect on them. Then, in level R2.0 (Dialogical Reflection), participants are more interested in the Community information than their own. They are touching upon the various details made available to them by the fictional profiles as they look for similarities or differences. However, Participant information increases again in R2.5, because this is when they begin to draw out the connections between their information and the Community information. They are still referring to the Community information more than their own, but this shows that they are using the additional information to reflect deeper. Finally, in Transformative Reflection (R3), Participant and Community information are both referred to in relatively similar rates as the participants state potential reasons for their change in health, based on both their information and the community's.

### Information and R0: Non-Reflective Description

By definition (see 6.2.5), R0 only involves the consideration of the *participant's* information. As such, none of the instances in which these two reflective levels occurred involved any information relating to the Community information.

In R0, each type of Participant Information was touched upon at similar rates (Figure 52). The statements that were coded as R0 show little evidence of deep thought – the participants were simply stating what they were seeing and what they had experienced:

> "So, I can see the diagnosis of my condition, and the two different types of medication I've taken over time." P02-T1

> "I see my CD4 levels and how they increased over time." – P01-C1

> "So that's the timeline, so I'm going around, it's about two years, and I've got my antiretroviral, my cd4 and my viral load." – P05-C1

> "The medication, when I started after six months." – P03-T2
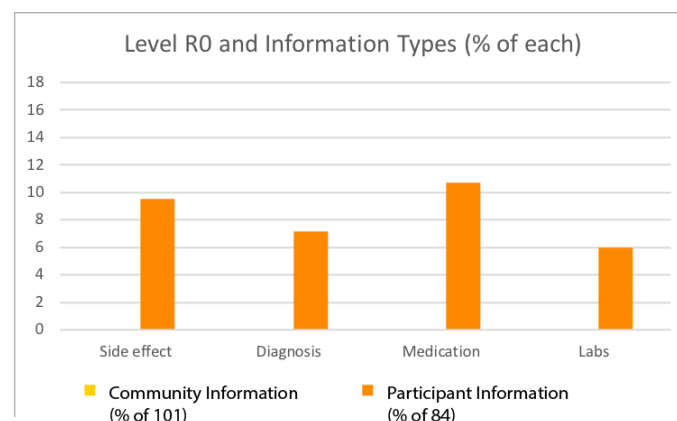


Figure 52: Percent of all information types coded with Reflection Level R0

As mentioned previously, in 6.3.2, R0 nearly always took place when the participants were first shown the prototypes, and this (in conjunction with the transcripts) suggests that R0 occurs when an individual is familiarizing themselves with a representation. Before reflecting on what they see, they first state what is there to reflect upon. As such, R0 could be considered a stepping stone for approaching deeper reflection.

*Information and R1: Reflective Description*

Like R0, R1 does not involve the inclusion of Community information, only the participant's.

With reflection level R1, the very beginning of reflective thought, participants described their experiences in detail. Each type of Participant Information was touched upon, but participants referred to their health concerns (the 'side effect') and medication more frequently than their lab results or date of diagnosis (Figure 52), and this is likely because that is the focus of their question and their reason for reflecting. Participants embellished on the information they referred to, providing additional details as they reflected. For example, P06 discusses the information he was concerned about – his hair loss – and gives more context about when it occurred:

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*"So, this visualization shows the date at which I started noticing some hair loss, about three months after the diagnosis. I had a very bad fever about a month after being infected. I had a fever of about 40\* and was in the A&E and stuff." – P06-T1*

Participants also reflected on information that they did not have a question about, even pointing out where detail was missing as they recalled their experiences:

*"Well, it's a good way of mapping the changes, so I'll be able to see - if I had given you my weight… because I was really emaciated. Obviously after my [family member] died [one month before being diagnosed], and then I had a month long seroconversion, i could not eat or hold anything down. and nobody knew what it was. Obviously my immune system was weak, but everyone thought I was having a breakdown because of my [family member's death]. So I was confined to a bed and trying to eat a little bit of melon every day, but I couldn't hold anything down. I think I was like 11 stone then." – P05-C1*
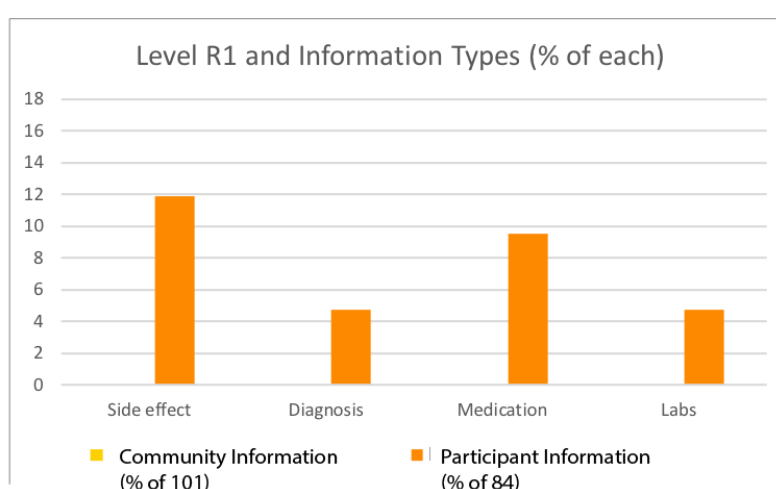


Figure 53: Percent of all information types coded with Reflection Level R1

While R1 is the lowest level of reflective thought, we can take from the analysis that the presentation of the information in the prototypes support individuals in recalling their experiences – even those experiences which were not the focus of their question. Achieving Reflective Description is important as it provides a grounding for conducting further reflective thought.

## Information and R2: Dialogic Reflection

Here, we can see that Participant Information was referred to far less frequently in Dialogic Reflection than R0 and R1 (Figure 54). This drop is likely due to the participants having become familiar with their own information and not needing to look at it, or highlight it, while regarding the information of the profiles:

*"These people have been on similar medication to me" – P06-T1*
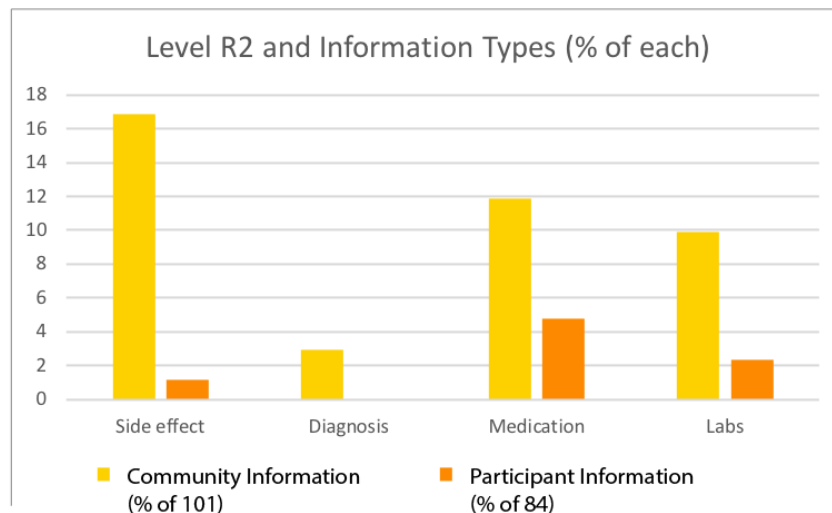
Figure 54: Percent of all information types (Participant and Community, separately) coded with Reflection Level R2

Figure 54 also shows that each type of Community information was referred to in R2, although some more than others. The least frequently mentioned was the Diagnosis shown by each fictional profile, which was often mentioned in passing alongside other information:

*"Okay, so this person has been taking his medicine for like, 7 years? 6 years?* [Participant circles diagnosis date with cursor] *6 years, and this is the part here he is now." P06-T1*

However, other comments did show that the time of diagnosis could be of importance to individuals, particularly if there was a vast difference in time. As P03 describes, this is because of the medical advances made: someone diagnosed ten years prior to someone today would have different medication, different side effects, and a different lab result trajectory – therefore limiting the similarities to be found:

*"Someone who was diagnosed 20 years ago is going to have a different set of results, because the medication was different then – they were still trying to tweak it." – P03-T2*

The comments made by participants show that the Community lab results were of interest, even if not completely relevant to their question at hand. For example, P01 shared only his latest CD4 results, but still regarded the viral load of a fictional profile: *"The green one is Roger, this is his CD4 compared to mine, his viral load"* P01-T2 stated, later commenting: *"It's nice to know that his viral load is going down, but it's not really that important to me, because I didn't give information on that."* As mentioned, only one fictional profile on each prototype displayed a CD4. Despite this, participants still commented. *"They don't have their information on here regarding viral load or CD4"* P03-C1 commented on one profile, later stating that he felt it was *"important to have the CD4 and viral load"* because it is an indication of the medication working. *"Everybody reacts differently to the virus and medication."*

The Medication and Side Effects displayed by the fictional profiles were also used quite frequently with Dialogic Reflection, making up just under 30% of all Profile Information codes in total. In these instances, participants made statements relating to the medication taken by the profile to their own, and the presence – or lack of presence – of the side effect:

> *"So, this is Trevor, 36 [years old]. Okay, he started on the medication and has had the tiredness as well. From September 2015, he has basically been on the same stuff." – P03-C1*

> *"[Reading profile comment] 'I never experienced any change in my levels and I've been on meds for 8 years. Talk to your doctor to be sure.' That's so interesting." – P04-C2*

Participants explored all Profile Information types during Dialogic Reflection, showing that exploring connections between their own experiences and that of the profiles was of interest for all information types. While Medication and Side Effects were regarded more frequently than Lab Results and Diagnosis, comments indicate that these still held value and meaning.

### *Information and R2.5: Comparative Reflection*

While the use of Participant Information in R2 Reflection made up less than 10% of all Participant Information codes, the use in level R2.5 made up 20.23% (Figure 55). Participants referred to their Lab Results and Medication at similar rates in R2.5 as R2, but referred to their Side Effects far more frequently. The instances in which these personal details were mentioned frequently coincided with similar information shown by a fictional profile. For example, P04-T1 compares her lab results to those shown by a fictional profile in the prototype: *"It's interesting to have others with their levels with mine, it's good to see we're on the same wavelength."*
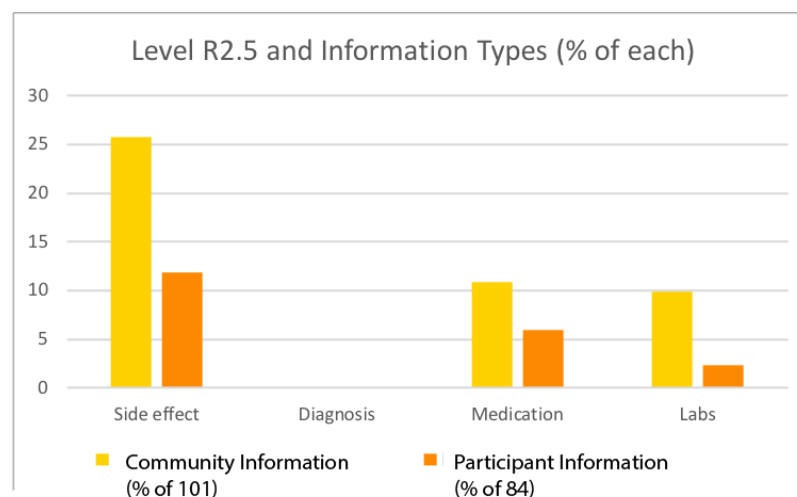


Figure 55: Percent of all information types (Participant and Profile, separately) coded with Reflection Level R2.5

Out of all the instances in which Community Information was coded, nearly half (46.53%) occurred when participants were making Comparative Reflection statements. References to Medication and Lab Results were referred to with relatively similar rates (approximately 10% each), showing again that participants were as interested in comparing their medication with the fictional profiles as they were in comparing their lab results.

As was shown in P04's quote, above, the lab results of the fictional profiles were used by some participants to compare journeys. For some, this comparison allowed for reflection on what they had already gone through:

*"Oh, his viral load started at… Okay, it's undetectable. That's quite unusual for it to be undetectable after a short period of time. It took me maybe nine or ten months. So, I guess in his case he got [medication] very early on."* – *P03-C1*, who wasn't prescribed medication until several months after diagnosis.

For others, it was an indication of what might to expect in the future:

*"The first two don't have their CD4 levels, so I can't compare that, but this one shred his CD4 and viral loads. 43 thousand… Wow, he's undetectable already!"* P01-C1 commented, then later mentioning *"I can see that his CD4 and Viral Load is getting better. Even though there is a fluctuation here, it's getting better. So that is a sign to look forward to, and this one is only in the span of three years, so that is something to look forward to for me."*

P01 made an additional comment that suggested that seeing the lab results of others was rare, but highly appreciated:

*"Yeah, even though all three of them are not directly related to my question, I appreciate that this is here so that I can check on other people's progress on my same medication. That's really good to see, even though they didn't answer my question directly. So, I appreciate this [profile's information], the one with CD4 and viral load. Being able to compare with other people… I know normally people don't share information like that very easily, so seeing that on this table, where it is visualized for me, makes a lot of sense."*

When discussing the Community medication, this frequently coincided with comments about the fictional profile's lab results (as demonstrated in the quote above) or the fictional profile's Side Effect – or lack of. For example, P06-T1 compares his medication and side effects with those of a fictional profile named Cassidy, and debates whether Cassidy's medication is of interest he hasn't experienced the same issue:

*"Perhaps Cassidy's medication [is extraneous] because… well, even that… Because she hasn't – sorry,* he *hasn't – experienced any hair loss. But even then, I guess it is kind of a nice thing to know because he's been on the same regime but hasn't had any hair loss."*

References to the Community Side Effects comprised just over a quarter of all instances in which Community Information was coded (25.74%). These statements were a mixture of participants

making connections or questioning what they saw. For example, P01-T2 described the connection between his experience and that of Roger, a fictional profile who still continues to have the side effect: *"For example, Roger still experiences it. So, I'm not an outlier in the sense of my question."* Meanwhile, P03-C1 deliberated over profile Trevor's age and continued experience of lethargy: *"Trevor is ten years younger and he's had this all the time. Strange. But it effects everyone differently."* P03-C1 then began factoring in the time in which the lethargy began occurring as he pondered: *"See, he had it at the beginning, I have it at this period, and he has had it all the way long. Everybody is at a different stage of it."*

These statements suggest that – to those living with the disease – medication is inextricably linked to other aspects of living with HIV and likely a required piece of information for most community-aided reflection. In addition, the statements regarding lab results suggest that this may be extraneous information if not the focus of a question, but desirable and informative nonetheless – perhaps more so for those who are newly diagnosed, like P01. Additionally, we see that the occurrence of a side effect alone is of interest, but that individuals may explore the lack of occurrence, or time span, as a means of making sense of their own question.

*Information and R3: Transformative Reflection*

Of the 9 instances of Transformative Reflection, both Participant and Community Information were referred to, although not the lab results of either (Figure 56).
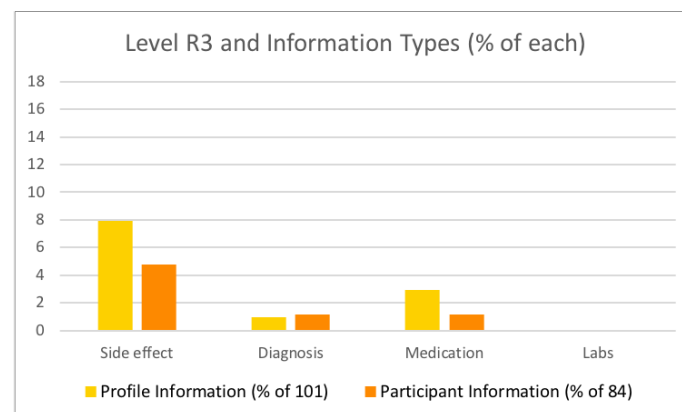


Figure 56: Percent of all information types (Participant and Profile, separately) coded with Reflection Level R3

For P03-C1, Transformative Reflection involved contemplating the effect that age may be causing his lethargy, or that the effects of his medication are altered by age:

> *"I can see that I experienced this quite recently for some unknown reason - nothing has changed - maybe it's an age thing. That's a thing that happens as people get older."*

*"Yeah, it puts it into perspective – maybe as you get older the medication works in a different way."*

P06 also considered age and how it factored in to his change in health – heavy, but temporary, hair loss:

*"I guess also there is kind of like an age element as well. I'm 25. Obviously, for men, hair loss will quite often set in in the 30s. So, I'd rather that it was this - that the 28 year old had just brief hair loss and the 36 year old had long term hair loss." P06-C2*

P02-C2's statements of Transformative Reflection showed that he was convinced by his own experience and that of the fictional profiles that the medication was the cause of his change in health, and he wondered what his next actions should be.

*"The first example, where I've got Felix and he's male 28 years old […] it really makes you think. […] It just makes me think that the medication has had a significant impact, and the weight loss and headaches have been present."*

*"In terms of my diagnosis and the impact on my health, this makes me worried - what actions do I have to take? What questions should I ask in my review?"*

Finally, P05-C1 also connected the medication to his weight gain, questioning the veracity of his hypothesis as he did so:

*"I think it is one of the main questions, one of my exes did gain quite a bit of weight when he started his regime, so it seems like a trend that I've spotted. But does it mean that there is a link between these medicines and weight gain? Because they don't really tell you that when you start taking it."*

### 6.3.4 Considerations for designs supporting community-aided reflection

**RQ-4.3: What considerations need to be made in the design of representations intended to support community-aided reflection?**

This research question was approached in two ways – first, by gathering feedback on how the prototypes provided support or could be improved, and second, by determining how the features intended to support reflection were used in the different levels of reflection. In this sub-section, I will first discuss the design considerations that were gathered from the feedback, then present the usage of features in the levels of reflection.

*Responses to Open-Ended Questions*

All participants were asked open-ended questions at the end of the research session as a means of gathering feedback on the prototypes they viewed and to capture their thoughts on viewing the health information of others. This sub-section will first cover the thoughts of the participants on each prototype and their feelings on seeing visualizations of their health in general. Then, their

thoughts on viewing the health information of others will be presented: how they felt about what they shared, how they felt about seeing the information of others, and how they might want to change what they were able to see.

*Representations:*

Clock Plot:

Participants were drawn in by the Clock Plot prototypes, finding them unique and aesthetically appealing:

> *"That looks like a nice way to display it. Yeah, it's a good visualization. It's a good way of mapping the changes." P05-C1*
>
> *"The clock plot was really helpful, it helps you see your information and what changed over the years." – P02-C2*

However, they had difficulty viewing them when the information was displayed far from the labels (e.g. if they had not started medication for six months since diagnosis) – there was too much white space, making it hard for them to understand:

> *"I can see this is my starting time and as I go through I can see all my medicines laid out and then, oh interesting, what is this? Why are there gaps here?" – P01-C1*

Clock Plots, therefore, should be avoided for those who have lived with the disease for several years, or have experienced numerous changes in their health or medication, as those which contained a large amount of information became unwieldy.

Timeline:

When viewing their own personal data, it seemed that the Timeline was preferable, as it was aligned to what they were anticipating or used to seeing.

> *"I like this format. It's slightly easier to read when it is in this graph form because you have a better understanding of the pattern." – P03*
>
> *"I'm used to seeing time as a standard on the x axis." – P05*

However, several participants were daunted by the amount of information shown on the timeline prototype with the profile information included.

> *"The timeline was easy to understand, but with all the information on the commented version it was too much. It was hard to understand the relevance it has." – P02*
>
> *"[Sighs] Yeah, it's like, too much information." – P05*

Unlike the Clock Plot, participants were not confused by the Timeline visualization style. However, participants did point out that they would like to choose what to see, suggesting that they would prefer to toggle on and off different data.

*"So, I think it's all useful but perhaps... Maybe if it was more interactive, where you could see the categories. Maybe it came in a more compressed version and you could open up lists of the hair loss section, or the medication section, or the CD4 and viral load section. Rather than seeing it all at once. That would be good." – P06-T1*

Toggling information on and off with the Clock Plot would be tricky, but much more feasible with the Timeline. Allowing users to do so would support them in focusing in on specific pieces of information of interest, while also giving them access to a wider array of information types.

*Health Information*

Visualized Health Information

Many of the participants were excited by viewing the prototypes. They expressed that they had never seen their information represented before, and that it helped them understand more about their health and journey with the disease:

*"They don't offer patients anything like that. We're just getting numbers and lists and columns and tables." – P05*

*"You never see it like this when you go to hospital. You just see numbers. It's confusing" – P04*

*"I mean, I never get a print out from my consultant. They never give it to you. It's on their screen and they just tell you. And you have to try to remember what it was before. It doesn't mean very much, it's almost like someone tells you that you have £2000 in your account but when you actually see the statement, then you get it much more." – P03*

The participants – without prompting – also stated that they wished their consultants would use a tool similar to the prototypes they saw.

*"But I like it, I like it. Will the doctors be using this soon? You gotta implement it. I like it. I like it." – P04*

*"I actually wish my consultant had one of these and that he could just fill it in every time I went to see him, and then he could print it and say: 'this is where you are at the moment' and you could track it, you could follow it. […] Then you'd have a reference point to know what is going on inside you." – P03*

Sharing

As mentioned, some participants did not feel comfortable sharing all of their information, particularly their lab results. However, the information 'shared' by the profiles (specifically Trevor and Roger, who 'shared' their full history of labs) did not vary based on this, and this was met with an interesting reaction. Some participants were very excited to view the lab results of others, stating that it was rare to see, or that it gave them an idea of what to expect. Others, however, seemed to find this annoying, and questioned why a person would share information that they had not shared or asked for. However, because the lab results were frequently viewed, and

because they were used by some as a means of comparing their personal journey with others, it seems an important piece of information for PHI systems to support users in tracking and sharing.

> *"I didn't fill out the viral load […] So maybe I would filter that out - let me have the option to see that if I want." – P01*

### Access to Community Information

The inclusion of health information from community members – even if fictional – was highly praised, and participants stated that it made them feel less alone – it made them feel like they were going through a journey with other people who understood them. For example, P06 stated that the inclusion of comments made him feel supported, while P01 said it made him feel less alone:

> *"Something which I quite like is that it says there are responses - it suggests that this is a small community who has gone to the trouble to respond. […] This seems more personal, that three people have actually taken the time to respond. That feels more supportive." – P06*

> *"However, seeing information from other people gives me a way to compare my progress with others, and that's really satisfying and empowering to have, to know that you're not alone. You can see other people's progress and they can give you their thoughts on what is going on and what is happening to them. I think being able to compare is the main point. That's really good for me. I like to compare my situation with others." – P01*

Other comments from participants suggested that access to the information of other people helped them understand their own experience:

> *"Yes, definitely. I think that definitely makes the tool a lot more meaningful, because you can compare different people's experiences at a glance. That is the meaningful bit. You can see that you aren't alone and that different are experiencing this weight gain." – P05*

Finally, participants also stated that the ability to compare experiences with others helped them understand their own experiences:

> *"Yeah, yes, so that you just feel, either you're going good or you're going bad... Just to see that little bit saying - even that comment 'I have the same thing,' then you can kind of visually relate. Anonymously relate. Yeah, it's good. I like that. – P04*

> *"Yeah I think it helps in understanding the diagnosis and referring to case examples of other people's information. It really makes you think about the impact it has, and the consequences of the medication on side effects. Yeah, referring to other people and different cases gives you more scope and understanding." – P02*

### Interest in Similar Individuals

Some participants – particularly the newly diagnosed – pointed out that they would like to view only the information of those who were most similar to them in terms of time since diagnosis or medication taken. P01 initially suggested that this would help him focus, but later explained that it is an issue of relevance:

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*"I think having information that is similar to what I provided would be better, so that there is less information to be distracted by." – P01*

*"Let me filter out other people who are not as similar to my profile. […] Since I provided this information, I'd like to see people that are similar to me. It's like finding someone to date - you filter out people with common interests" – P01*

Filtering responses based on time of diagnosis, medication, or even age was not an anticipated desire, but it is clearly one that should be incorporated in a PHI system that supports community-aided reflection. In addition, it seems plausible that individuals would like access to the data of others and explore it themselves, asking questions and starting conversations with users they deem relevant if they wish. Potentially, a platform designed to support community-aided reflection could facilitate this as well.

### *Features Used in the stages of Reflection*

Of all the instances in which reflection occurred, there were 94 different features referred to: 67 of them were Community features (profile details, 'to date' marker, timeline, comment) and 27 were Participant features (question, 'to date' marker, timeline).

In the instances in which Descriptive (Non-Reflection), or R0, occurred, the Participant's Timeline feature was referred to far more frequently than any other feature (Figure 57). Participants used the timeline as they explored their information presented in the prototype, linking what occurred to the dates or time elapsed. References to the Participant's Timeline almost always included references to information at the same time. For example, P06-T1 traced his cursor along the timeline as he referred to different pieces of his health information, while P05-C1 followed the timeline as he described what he was seeing:

*"So, I can see the date at which I started to notice the hair loss, as well as the medications I've been on, and then the viral load and CD4 count." – P06-T1*

*"So that's the timeline, so I'm going around, it's about two years, and I've got my antiretroviral, my cd4 and my viral load." – P05-C1*
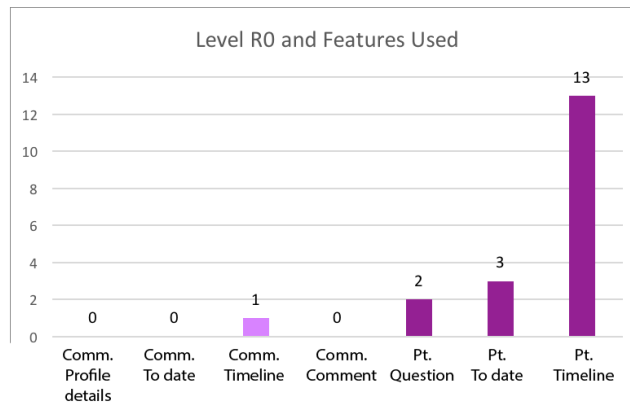
Figure 57: Frequency with which Features were referred to in reflection level R0

This trend continued in R1 (Descriptive Reflection): out of just 9 instances in which features were referred to with R1, only four types of features were touched upon. Again, the Participant's Timeline was referred to far more than any other type. As with R0, participants referred to their timeline while exploring their health information. However, in R1, they used their timeline to expand upon their experiences. P05-C1, below, traced his cursor along the timeline around the Clock Plot as he reflected upon, and described, his experiences during that time:

*"I was really emaciated. Obviously after my [family member] died in [month] before being diagnosed, and then I had a month-long seroconversion. I could not eat or hold anything down, and nobody knew what it was. […]" (P05-C1).*
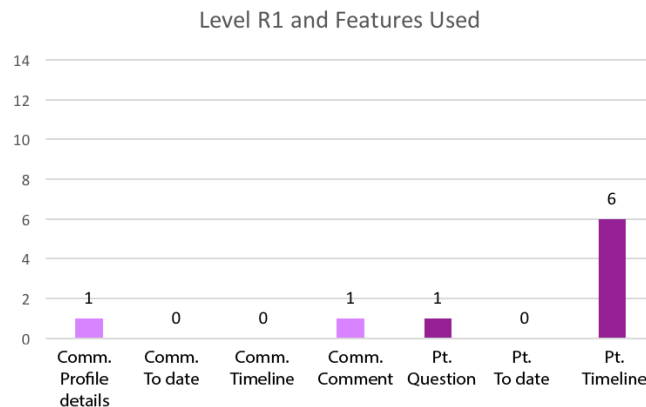


Figure 58: Frequency with which Features were referred to in reflection level R1

After R1, the Participant Timeline feature lost importance, alongside all features relating to the participants. A total of 33 features were referred to in R2 (Dialogic Reflection), and all were Community Features (Figure 59). Out of the three different types of features referred to, the most common was the comments. Participants often read the comments from the fictional profiles out loud, word for word, before drawing a connection to themselves:

*"I have three responses received. [Reads] "I had something in the beginning but it went away" - that's another example of it happening with an individual" – P02-C2*

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However, participants also referred to the profile details while reading through the comments or referring to the information shown. For example, P04-C2 observed the medication taken by a fictional profile, circling back to the comment, then details to the profile's name:

*"Yeah, her levels have changed, we're on the same medication. Trisha. Okay." – P04-C2*
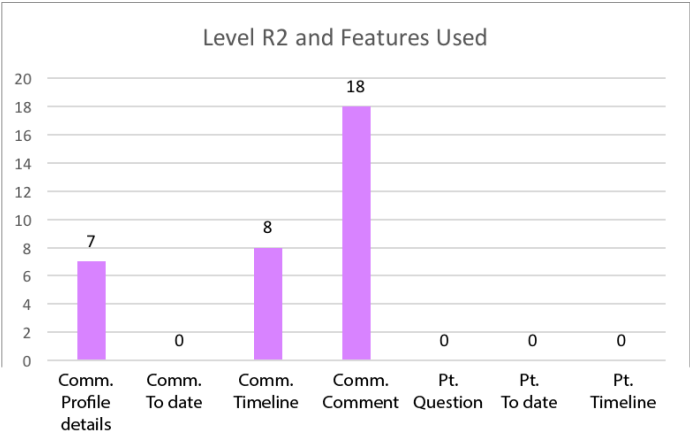


Figure 59: Frequency with which Features were referred to in reflection level R2

The timelines were again used to explore and understand the information seen (e.g. *"So, this is Trevor, 36. Okay, he started on the medication and has had the had the tiredness as well. From September 2015, he has basically been on the same stuff"* – P03-C1), and comparing the durations of their experiences to the profile's (e.g. *"Okay, that's nice to know, although his side effects were only for the year of 2011 to 2012. Okay, that's nice to know"* – P01-C1).

However, it was the use of the Profile Details during R2.5 that was the most surprising. Out of the 33 instances in which features were referred to in R2.5, 9 of them involved Profile Details. Participants drew on the ages of the profiles as additional sources of information that they could compare and contrast to develop meaning from. For example, P03 was concerned with lethargy and fatigue. Being a middle-aged man, P03-C1 began to seek meaning out of the ages of the fictional profiles and whether or not they had a similar experience, as shown in the comments below:

*"Whereas Trevor is ten years younger [than me] and he's had this all the time. Strange. But it effects everyone different."*

*"I mean, she's around the same age [as me] and she's never had it."*

*"…And he's a lot younger and had it a little bit."*
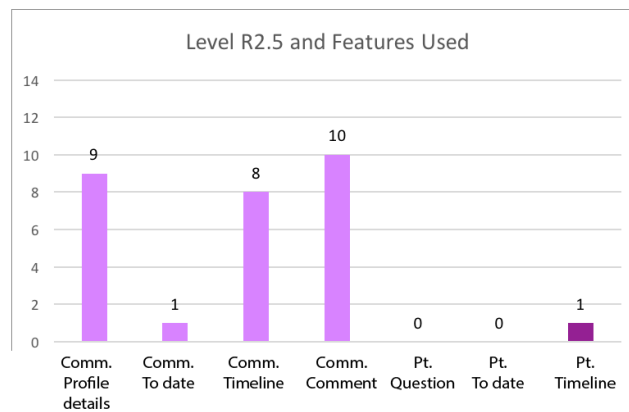
Figure 60: Frequency with which Features were referred to in reflection level R2.5

Finally, there were only 5 instances in which features were used during R3, Comparative Reflection (Figure 61). This, however, should not be taken as an indication that the features do not support reflection or reaching higher levels of reflection. Once an individual has reached R3, they do not necessarily require features to reflect. The use of features throughout all levels of reflection indicate that they do support individuals in reflecting on their experiences, and what the experiences of others might mean for them.
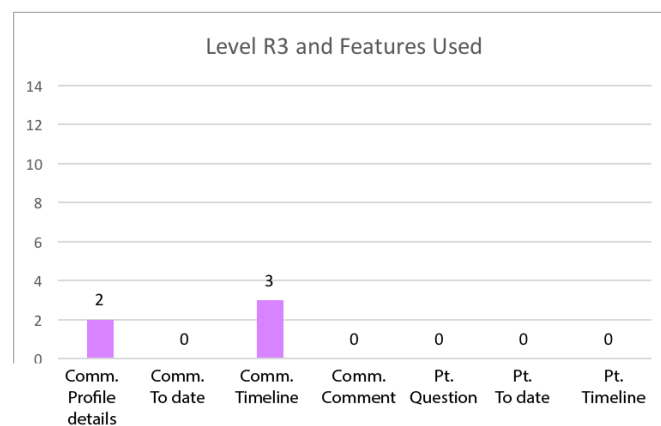


Figure 61: Frequency with which Features were referred to in reflection level R3

## 6.4 Discussion

This research was the first to explore how reflection might occur when using a system that supports community-aided reflection. While a difficult recruitment led to low numbers of participants, the results of this research are the first to suggest how reflection occurs with such a system, how information is used in the different levels of reflection, and what design considerations need to be made for supporting community-aided reflection. The statements made by the participants show the importance of having access to such PHI systems that support community-

aided reflection, and also suggest that it does not only support reflection, but also provides a sense of community.

The results described here show evidence of the participants reflecting on their health experiences and achieving high levels of sensemaking and reflection. From the analysis and the transcripts, we can see that the participants often began in the lowest stage/levels by exploring what was available in the prototypes and remembering their experience. They then built upon this by reflecting deeper – touching upon the various pieces of information available as they recalled their experiences in more detail. From there, they progressed to drawing connections and describing similarities between themselves and the fictional profiles, ultimately leading several to develop hypotheses or critical thinking.

Every information type – participant or community – was used in at least one level of reflection. The statements made from the participants showed that they focused in on different details, stating similarities, comparing, and – for many – developing a hypothesis or new perspective from the prototypes. While not all information types were directly related to the questions that the participants had (namely diagnosis and lab results), they were still points of interest for the participants. This highlights the importance of these types of information, and suggests that systems designed to support community-aided reflection should allow users to include these information types at a minimum.

From the analysis, we can see that features were not just used by participants as a way of understanding what they were looking at, but also as an additional form of information. Overall, the findings suggest that all of these are important features for technologies that support community-aided reflection, and that they should be included in future designs.

Even though the profile's lab results were not relevant to the participants' questions or health experiences, they were often still regarded. While participants did make comments showing that they were not necessarily interested in this information, they also stated that it was a nice option. It emerged from the interviews that access to the lab results of other individuals was rare, and that being able to see how others had progressed to undetectable, or experienced a 'blip', was useful knowledge and – for some – provided a source of hope. Based on this, it is recommended that any PHI tool that connects to community information for people living with HIV include the opportunity to track and represent lab results – particularly for those who are newly diagnosed and have not yet reached undetectable status.

The results also provide evidence that representations of personal health information – alongside the information of the community – is highly desirable. Each participant was able to reflect on his/her experience while considering the experiences of other individuals, and each participant

stated that it made them feel supported, connected, and have a better understanding of their journey. The statements that participants made about having access to a system such as this should be a driving factor for designers and developers of healthcare systems across all chronic conditions – both in academia and in industry.

While the findings here can be used to develop PHI technologies that supports tracking, representing, and reflecting on personal information alongside the information of the community, they also can be used as the basis of additional research. This research study was conducted in a rather controlled way, it would be useful to understand how such a system is used in the wild, from multiple aspects. To monitor the frequency with which individuals track different pieces of information, explore their representations, and converse with their community would help uncover additional considerations and behaviors not currently understood or supported.

# Chapter 7 Discussion and Conclusion

This thesis provides a detailed account of how PHI systems could support people living with HIV in reflecting on their personal health information. In this final chapter, I return to the research questions that were laid out in the first chapter and the contributions of the work. I then address the overarching research question by summarizing the design implications which arose from each research study. The transferability of these design implications are then discussed in reference to other conditions. I then revisit and reconsider several of my concepts and my approach before concluding with a section on the limitations of the work, and opportunities for future research to build on what was done.

## 7.1 Contributions

The overarching contribution of this thesis is a detailed understanding of how Personal Health Informatics systems can support people living with HIV in reflecting on their health information. This contribution is comprised of smaller ones, each achieved in addressing the research questions introduced at the beginning of the thesis.

### RQ-1: What is the process of Personal Health Informatics? (Chapter 3)

Before conducting any research, it was important to have a framework through which the activities involved in PHI could be viewed. With no existing process models that related to tracking and reflecting on health information specifically, I developed a process model of Personal Health Informatics that was based upon existing models of tracking and reflecting on information (Chapter 3).

The resulting six-stage process model of Personal Health Informatics is the first contribution in this thesis. Unlike the models by Cohen et al. (2015), Epstein et al., (2015), Fayyad, Piatetsky-Shapiro, & Smyth (1996), the PHI process model is focused specifically on Personal Health Informatics and does not emphasize behavior change or action as an end-goal or result of reflection. Researchers of PHI or self-management systems can benefit from the PHI process model. The model can be used as a means of understanding Personal Health Informatics, of exploring PHI systems and their features, and as a tool for analysis (as demonstrated in Chapter 4).

### RQ-2: Where are the opportunities in the process of PHI for supporting people living with HIV in reflecting on their personal health information? (Study One; Chapter 4)

Chapter 4 includes details about the findings associated with each stage of the process model, but the key findings of the research showed the following design implications for supporting their reflection:

- In contrast to the tracking systems designed for people living with HIV, participants were interested in tracking more than just their medication compliance and lab results. There was a strong interest in tracking a variety of information, not all of which is obvious in its relation to HIV. This highlights the need for PHI systems that support users in tracking various information types.

- Very few participants had access to representations of their tracked information, and there were no representations which presented different information types together for reflection. This highlights the need for PHI systems to include representations that display various information types together.

- Despite the lack of representations, participants did reflect on their tracked information. However, the participants showed that they were not just interested in reflecting on their information alone, but also sought support in reflecting from their HIV+ community. This highlights the need for PHI systems to support community-aided reflection.

One of the contributions from this research is an empirical understanding of how people living with HIV currently track and reflect on their health information. Both within HCI and the medical domain, this research was the first to engage with people living with HIV for the purpose of understanding their motivations and approaches for tracking personal health information, what information they were interested in tracking, and how they attempted to reflect upon it. Furthermore, this research was one of the few that approached PI and PHI from a user-centered perspective, rather than a technology-driven one (see Mamykina, Mynatt, & Kaufman, 2006). The results of this study highlight the gaps between what is currently available and what is needed, and by highlighting the current gaps, I have also highlighted areas for future work for researchers to focus on. For example, the data visualization community could explore new ways of representing a wide variety of information types together, while PHI or self-management researchers could explore what other patient groups are in need of more flexible tracking systems. Healthcare professionals can also use this new knowledge by encouraging their patients to collect more information about their condition for later discussion, or by pointing them in the direction of already-existing systems that they might not be aware of.

The design implications are another contribution. These implications detail different features or design considerations for PHI systems that, if developed, would provide better support for those living with HIV in tracking and reflecting on their health. Many of these design implications were acted upon in the design of the two prototypes simulating community-aided reflection in Study Three. Healthcare organizations can take these design implications to developers, who can then easily apply them to improve or create systems which support people living with HIV in tracking and reflecting on their health information, and this will benefit those who use them. It is likely that

some of these design implications are transferrable to the design of PHI systems for people living with other diseases or conditions as well; it is not a far stretch to imagine, for example, that a person living with a chronic disease will want the ability to manage their tracked data, or share it with their community as a means of reflecting on it (further details on transferability can be found in Section 7.2.2).

### RQ-3: What kinds of questions about personal health information do people living with HIV seek support in reflecting on, and how does the online community aim to address them? (Study Two; Chapter 5)

After conducting an analysis of 200 threads in an HIV-specific forum, the above research question was answered with the following findings:

- There were five different types of questions about health information that users on the forum sought help in reflecting upon and understanding the answer to. Two of these were focused on understanding the cause of a change in health, two were focused on determining if what they saw in their health information was normal, and one was focused on setting expectations for the future.
- The health information that those users were seeking aid in reflecting upon were not limited to lab results; the questions were also focused on reactions, other conditions, their weight, and their emotions.
- The online community attempted to address the questions that were asked by providing informational support, most often sharing their own experiences and health information.

Researchers have shown that forums for chronically-ill individuals are often used to gain social support (e.g. Mo & Coulson, 2008), or to determine if what was being experienced was 'normal' for that condition (e.g. O'Kane et al., 2016), but my research was the first to connect these activities to Personal Health Informatics and the use of the community as aid in reflecting on personal information. While O'Kane et al. (2016) demonstrated that individuals sought feedback from forum-members for understanding if their experiences were normal, they did not identify the types of questions asked, the health information shared and asked about, nor how their community responded. The research study reported in Chapter 5 was the first to address those points, and the first to explore the activity of community-aided reflection in depth.

The contribution resulting from this study is empirical. Healthcare professionals, particularly those focused on HIV, can benefit from this contribution. Informational materials (posters, pamphlets, online resources) could be tailored to directly address the questions identified in this study, providing individuals with instant responses to their concerns. Other researchers of chronic conditions can also use the question types as a basepoint for a coding scheme to identify if their

target groups share similar concerns about causality, normalcy, and the future. Additionally, developers of PHI systems should consider the importance of community-input for those living with a chronic disease and begin designing features that support end-users in achieving this easily.

### RQ-4: When interacting with a prototype designed to support community-aided reflection, how does reflection occur? (Study Three; Chapter 6)

The results of Study One highlighted that people living with HIV tracked various types of personal health information, but had no access to visual representations that presented those various details collectively. Study Two provided evidence of how information was used in an online forum to aid in reflection, and showed that community members shared their health information in an attempt to address the questions being asked. The final study of the thesis sought to understand how reflection occurred when interacting with a prototype designed to support community-aided reflection.

The analysis of observing 6 participants using the prototypes provided insight on how various information and features were used, resulting in the following findings:

- Participants achieved high levels of reflection when exploring the prototypes. They often began in the lowest levels of reflection while they explored what was there and recalling their experience, then began to find similarities and draw connections between their information and the fictional profiles before developing a hypothesis or questioning their assumptions.
- The information shown in the prototypes were used throughout the levels of reflection. All information types were used in at least one level, but the side effects and medication (both the participant's and the community's) were regarded the most frequently, as they were most relevant to the participant's question.
- The features of the prototypes were used as a way of understanding the prototypes, but some participants also found meaning in the ages and years since diagnosis displayed in the profile details, highlighting that these were important details that provided additional context and fodder to consider.
- Having access to representations of health information – both personal, and that of a community member – was stated to be helpful in reflecting and understanding, but also produced feelings of support and connectivity.

The overarching contribution of Study Three is an empirical one. This research was the first to observe how people reflected when exploring a prototype designed to simulate community-aided reflection. While researchers have demonstrated that individuals do explore the health information of others to inform their own personal care (Frost & Massagli, 2008) or understand if their own

experiences are normal (O'Kane et al., 2016), none have explored means of supporting community-aided reflection, nor how it might occur if provided with a system intended to support it.  The results described in Chapter 6 gave detail on the ways the features and information shown in the prototypes were used in each level of reflection, and also included design implications that should be considered. That this research study was focused specifically on supporting those living with HIV in reflection should not be taken as an indication that the results are not transferrable, but should instead spur other researchers to explore how similar designs could support other communities in reflecting on their health information. The statements that participants made about having access to a system such as this should be a driving factor for designers and developers of healthcare systems across all chronic conditions – both in academia and in industry. Developers can directly draw from the requirements described in Chapter 6 to create similar systems that support community-aided reflection. Data visualization specialists can also take these requirements and explore other styles of representations that would also work. Researchers could also expand on this work by exploring how such a system might be used if deployed in the wild.

## 7.2 Implications of the Work

### 7.2.1 Design Implications

In this thesis, I aimed to answer one overarching research question:

> **How can Personal Health Informatics systems support people living with HIV in reflecting on their personal health information?**

The answer to this question is threaded throughout the thesis in the results and discussions of each chapter. In this section, I summarize those design implications that using the structure of the process model.

*Intention*

In order to be effective and useful, PHI systems must be designed to meet the intentions that users have for tracking (Fayyad, Piatetsky-Shapiro, & Smyth, 1996). The results of Study One showed that people living with HIV are interested in tracking their information as a means of taking action, and as a means of monitoring their condition. Thus, PHI systems must serve both needs simultaneously. As an individual's condition changes over the years living with HIV, their intentions will too, and a good PHI system should support this. This could potentially be achieved through personalizable designs which allow end-users to continuously shape the system to fit their needs.

*Identification*

In order to be adopted and used, systems must match the user's needs with regards to the types of information to collect (Li, Dey, & Forlizzi, 2010) and the frequency with which they need to collect that data (Cohen et al., 2015). Information was an important focal point in each of the three studies conducted, as it was shown that people living with HIV are concerned with much more than their medication compliance and lab results. Designers must ensure that PHI systems intended for people living with HIV are able to capture a wide array of personal health information, from lab results to emotions, weight, other conditions, potential side effects, etc. Additionally, these various information types are a mixture of numerical (e.g. lab results, weight) and textual (e.g. emotions, other conditions), which has an implication on how a user inputs the data. Furthermore, system designs should not assume the frequency with which these details will be captured. With HIV being a lifelong condition, with some aspects being taken into account daily (e.g. medication compliance, emotions, exercise, etc.) and others occurring sporadically over months or years (e.g. other conditions, lab results), a well-designed PHI system will be flexible enough to allow data recording to occur at various frequencies and avoid notifications or requests for data input that do not align with the actual frequency of occurrence.

*Capture*

Research focused on diabetes indicated that some individuals seek out covert self-management systems to avoid awkwardness and potential discrimination (O'Kane, Rogers, & Blandford, 2015). The results of Study One indicated that people living with HIV also seek covert systems, in addition for secure data storage. Participants expressed a distrust of digital security and a fear that their data might be viewed by unwanted parties, whether those are hackers, friends, family, or even strangers on a bus. Thus, designs should seek to assuage the fears that users have by providing choice and clarity on data storage, strong protection against unwanted individuals accessing the data, and appear covert in as many ways as possible (e.g. avoiding logos that relate to HIV). In addition, designers should consider allowing users to choose if and what data is shared with others, and potentially enable them to encrypt their data as further protection.

*Management*

Some PHI systems take away the users' control over their own data, not allowing them to transfer, edit, or even delete their personal information (Huang et al., 2015). However, participants in the first study showed evidence that they do desire authority over their data, as they wish to ensure that their captured data provides a truthful depiction of their health. Additionally, participants wanted to maintain a comprehensive collection of their data over long periods of time, and thus should not be tied to using one particular PHI system but instead be allowed to have complete

ownership of the information that is rightfully theirs. In short, systems should allow users to correct, delete, transfer and/or integrate their personal health information however they see fit.

*Representation*

Representations of captured data should take a form which is appropriate for the user to reflect upon – the form must be relevant to their intention and reason for reflecting (Fayyad, Piatetsky-Shapiro, & Smyth, 1996; Whooley, PPloderer, & Gray, 2014), and the research studies conducted in this thesis lead to multiple design implications for data representations.

Study Three explored different design styles to support individuals in reflecting with the aid of their community and an aim of understanding a change in health. However, that is only one of the intentions identified in this thesis. Additionally, participants of Study One indicated that there individuals may have more than one intention at the same time. As such, PHI systems for people living with HIV should focus on supporting users in all of their intentions and reasons for reflecting, and this might be best done by providing multiple representation styles – each aimed at addressing a different intention – that users can explore during reflection.

Throughout each of the research studies, participants showed an interest in tracking and reflecting on a wide array of personal health information – both textual and numerical – and that these may occur at various frequencies (daily, weekly, monthly, yearly). Representations should be capable of presenting these different pieces of information together to facilitate users in drawing connections between different experiences in their health, taking inspiration from those designs presented in Study Three. In addition, PHI systems should allow users to select which data they want to see in a representation, to allow them to focus and explore different aspects of their journey.

This ability to select data does not apply strictly to users' own information, but also to their community members'. As was shown in the three research studies, there is an interest in reflecting on personal health information with community members, which indicates that this is something a PHI system should support. However, such systems should not *just* allow users to share and converse about their data, but also (as was made evident in Study Three) allow them to filter who and what they see in those representations.

Finally, designers of PHI systems for people living with HIV must be cognizant of the implications of a life-long condition. As was shown to be a pitfall of the Clock Plot representation in Study Three – representations should support users in reflecting on years' worth of data. However, participants in Study One also wished to reflect on much shorter periods of time (e.g. 13-FHeBAD

wished to reflect on her daily step-count). With regards to this, PHI systems should allow users to not only filter and select what they see and share, but also how and how much they see.

*Reflection*

Ideally, if the above design implications are met, people living with HIV will find themselves much more supported in reflecting with PHI systems than before. However, one further point should be stressed, and that is one that relates to my notion of reflection itself (which will be expanded upon later, in Section 7.3.1). While Study Three was focused on supporting individuals in reflecting deeply as they attempted to understand a change in health they had experienced, this will not always be the level of reflection that is desired or required. Some individuals may have specific questions which they seek to address in their reflection, and those will likely involve a longer engagement or interrogation of the data (Li et al., 2010; Rooksby et al., 2014). Others, like 13-FHeBAD (above) may seek to gather an updated understanding of their current status, and this often involves a much more brief – potentially even unobservable – form of reflection (Li et al., 2010; Rooksby et al., 2014). PHI systems for people living with HIV should support all levels of reflection, allowing users to interrogate the data when needed, but also providing users with snapshots of their current status when desired.

## 7.2.2 Broader Implications

As stated throughout, HIV is now considered a chronic condition (Gifford and Groessl, 2002), and chronic conditions each come with individualized triggers, symptoms, and treatments (O'Kane et al., 2016). These differences between each person are subtle, and make self-management difficult, but despite the differences between conditions, their characteristics, complexity, and challenges are the same (O'Kane et al., 2016). Thus, the specific details (e.g. information types) between conditions may differ, but broader concepts are still transferable (Swendeman, Ingram & Rotheram-Borus, 2009). With regards to this, the implications described throughout this thesis are likely to hold true for supporting others living with a chronic condition in reflecting on their personal health information. In this subsection, I provide examples of how those design implications could carry over to other chronic conditions.

Participants of the Study One indicated that their intentions fluctuated depending on their condition, and many were interested in *monitoring* their condition and *acting* on a particular aspect of it. The notion that intentions change over time is not limited just to those living with HIV; researchers of other conditions have shown examples of the same. For example, people who live with diabetes will find their understanding of their condition fluctuating between states of understanding their health and wishing to *monitor* it, and states of needing to make change and wishing to *act* upon it (Owen, Pearson, Thimbleby, & Buchanan, 2015). The same holds true for

those conditions which gradually progress throughout the years – people living with Parkinson's, for example, will need to continually adjust and adapt to their changing condition, resulting in changes in their intentions over time (Nunes & Fitzpatrick, 2015). This suggests that these individuals would also benefit from a PHI system that can meet their changing intentions.

One of the main design implications derived from the work described in this thesis is about the need to track multiple types of information – both numerical and textual, related and seemingly unrelated, and each with its own frequency of occurrence. Again, HIV is not the only condition for which this relates to. Researchers have shown that individuals suffering from bi-polar disorder may be better able to monitor their condition and identify their triggers by tracking a variety of data – beyond medication compliance and emotions – such as the weather, alcohol consumption, activity levels (Frost et al., 2013). Also, it has been suggested that people living with diabetes have a better self-understanding of their condition when they are able to track their nutritional intake, health decisions, and/or activity levels (e.g. Katz et al., 2016; Mamykina et al., 2008; Owen et al., 2015). Keeping track of various kinds of information, beyond that which is deemed medically important, is an important means of gathering context and a holistic view of one's wellbeing and PHI systems should allow users to track the information they deem important.

The need for covert and secure tracking systems also extends to other conditions – even those which are considerably less stigmatized than HIV. Wearable trackers, in general, can bear the stigma of illness or weakness (Liolios, Doukas, Fourlas, & Maglogiannis, 2010). Even using life-critical tools, such as inhalers (Pickles, et al., 2018), glucometers (O'Kane et al., 2015) or blood pressure meters (O'Kane et al., 2014), can cause social discomfort and lead people to try to conceal their systems and their use of them. Additionally, Nunes & Fitzpatrick (2015) described systems which allow healthcare providers and carers to view the tracked information of their patients who have Parkinson's; but those 'patients' – just like those people living with HIV – should be given the ability to choose what data is shared with what individual.

Autonomy over data has emerged as a theme in research on self-management systems (Nunes & Fitzpatrick, 2015). The desire for editing and deleting information was brought up as a crucial feature tracking systems aimed to support people who suffer from poor sleep (Kay, et al., 2012). Furthermore, integrating and/or transferring data has emerged as an issue not just for the chronically ill, but for healthy users as well (Choe E. K., Lee, Lee, Pratt, & Kientz, 2014). The ability to own and use personal health information as users please is not something that is singularly connected to chronic conditions, but – I believe – a basic right for any individual capturing their personal information.

Because of the ranging intentions and information types tracked, another major design implication that I have highlighted is the need for representations which allow users to combine different

information types into different representation styles and portions of time to best support them in reflecting on all different aspects of their health. Again, this can be transferred over to various different chronic conditions. For example, people with asthma may seek to identify a trigger for a recent attack, and will therefor wish to reflect upon their wellness indicators (inhaler usage, peak flow readings) alongside their environmental context (presence of pollen, animals, smoke, allergens, etc.) (Finkelstein & Jeong, 2016). However, given the irregularity with which these attacks occur, they may only need to do this once or twice a year, while also reflecting monthly on their inhaler usage and daily on their symptoms.

The desire to share and converse about personal health information is also not limited to people living with HIV. Research has shown that people living with a variety of chronic conditions turn to their community to gain support and aid in understanding their personal health experience (Chee, Karahalios, & Schatz, 2009; Paays et al., 2015), e.g. people with diabetes, chronic migraines, and ALS (O'Kane et al., 2016; Frost & Massagli, 2008). While the information that they share and the questions that they ask might be different, PHI systems for chronic conditions should provide users with the ability to share personal health information, view the information of others, and reflect on it as a means of gaining new knowledge or understanding.

In summary, the design implications presented throughout this thesis, and summarized above, were all drawn from research focused on people living with HIV. However, the implications are transferable to a multitude of chronic conditions – not just those discussed here. What these design implications call for are PHI systems which are secure and covert enough to be trusted and adopted, and flexible enough to be used for tracking and reflecting over a lifetime of living with a condition.


## 7.3 Revisiting Concepts and Approach

### 7.3.1 Reflection and Sensemaking

This thesis was focused on supporting people living with HIV in reflecting on their personal health information. While there are many definitions of reflection, mine is as follows:

> **Reflection occurs when an individual examines or explores their own experiences, situations, or knowledge, processing that information and relating it to their previous knowledge with the intention of generating new knowledge or understanding about themselves.**

The outcome of reflection is contested, with some in the PI/PHI community (e.g. Choe E. K., Lee, Zhu, Riche, & Baur, 2017) believing that reflection must lead to an insight – a significant development or change in knowledge, and others (e.g. Epstein et al., 2015; Rooksby et al., 2014) believing that reflection is not defined by the magnitude of new knowledge but in the act of

reflection itself. My notion of reflection is aligned with the latter, as I believe that reflection *could* lead to new knowledge or it *could* lead to an updated understanding of the self. For example, a person who is reflecting on his or her viral loads and medication compliance may be seeking an updated understanding of their wellbeing, or that person may be seeking to develop new knowledge that explains why their viral load has or has not changed in relation to their medication compliance. As such, my position on reflective thought is also aligned with that of Fleck (2012); there are levels of reflection, and with each there are levels of understanding or knowledge. With a lower level of reflection, a person can achieve updated understanding of themselves. With a higher level, they can achieve new knowledge. What is achieved is based on what is sought and how much effort into engagement with the data takes place.

I had also described sensemaking as being the same as reflection when applied to personal information. Sensemaking is not strictly about reflection, it can be applied to the act of trying to understand and learn from *any* kind of information. When applied to personal health information (as demonstrated by Mamykina, Smaldone, & Bakken; 2015), it takes the form of reflection. The inclusion of sensemaking in Study Three, I argue, was appropriate because those individuals were trying to develop new knowledge through engagement with the information in front of them. The notion that reflection and sensemaking are the same, however, is something that I must revisit.

I believe that reflection falls across a spectrum, with low engagement leading to updated understanding on one side, and heavy engagement and novel insights on the other. I now believe that to say sensemaking is the same is incorrect, as I believe sensemaking only applies to the side of the spectrum requiring heavy engagement. This is because sensemaking is, by definition, about how individuals manage, wrangle, and manipulate data in order to make sense of it and develop insights (Pirolli & Card, 2005). Sensemaking requires individuals to engage with the information at hand in a way that requires much more effort than a brief reflective glance as a means of gaining an update. Deep engagement with data is not always required or desired, nor are the development of novel insights. Thus, I now believe that reflection and sensemaking are related, but the former pertains to an array of reflective thought while the latter only applies to some.

### 7.3.2 Process Model

The process model developed and described in Chapter 3 stands as a framework through which the activities related to PHI can be viewed. However, this model only focuses on those activities which bind the individual with the PHI system (e.g. their intention to adopt a system, how they identify and use a system, how they reflect with the system); it excludes other aspects that may influence usage and reflection, such as viewpoint into the individual's social life, the context of use, and the activities or thought patterns that lead to different decisions. Thus, the process model

does not include the more detailed nuances involved in tracking and reflecting on personal health information. Three examples of these nuances which arose in my research are provided below.

The process model begins with *Intention* – the reason with which the individual engages with PHI. In Study One, participants indicated that they fluctuated in and out of tracking over the years, rejoining when they felt it was required. My process does not include a stage for the factors that lead up to developing an intention (referred to as a Contemplation period by Prochaska, DiClemente, & Norcross, 1992). Additionally, the process model doesn't include an indication of what those triggers might be. While my research has indicated why an individual might form some intentions (e.g. forming the intention of *action* in response to seeking to understand a change in health) but others, like *monitoring*, I don't yet know.

The second point is in reference to the levels of reflection. In my description of the stage of *Reflection* (Section 3.1.6) I had written that "*Reflection* can range from a highly interactive act, where the user explores and interacts with visualizations, to a nearly unobservable one, where the user looks at a list or graph for only a brief amount of time (Li, Dey, & Forlizzi, 2010). It is not the temporal brevity that defines a reflective moment, but the mental activity in which the information found in the representation is related to the original intention (Whooley, Ploderer, & Gray, 2014)." My intention in writing these sentences was to make it clear that reflection did not require novel insights or in-depth engagement with the data, but that it could take many forms and occur on different levels (as described by Fleck, 2012). I believe that if I were to split the stage of *Reflection* up into levels, it may wrongly suggest that Critical Reflection is the ultimate aim, or that users will naturally flow from one reflective level to the next. Instead, I would add one further sentence to the two above, so that it reads:

> *Reflection* can range from a highly interactive act, where the user explores and interacts with visualizations, to a nearly unobservable one, where the user looks at a list or graph for only a brief amount of time (Li, Dey, & Forlizzi, 2010). It is not the temporal brevity that defines a reflective moment, but the mental activity in which the information found in the representation is related to the original intention (Whooley, Ploderer, & Gray, 2014). *Some intentions require deeper engagement with the data as a means of reaching higher levels of reflection, while others can be satisfied with a simple glance for gathering an update.*

Finally, the process model does not include any indication of the involvement of others, be they healthcare providers or community members, in the stages of PHI. My research indicated that Personal Health Informatics does involve social aspects, particularly when looking for support in reflection. As demonstrated in Study Two and Study Three, the ability to involve others in a person's own reflection is an important aspect of PHI, and something that the process model might need to draw attention to. As with the previous point, I feel that adding this as an additional stage or off-shoot of *Reflection* might place undue emphasis on it and imply that it must take place. Instead, I would add the following sentence to the description of the stage of *Reflection*:

*In many instances, reflection is a solo activity, but there are times when reflection might involve others who have expertise on the health information in question, whether through experience or training. In these instances, the individual will reflect on their own information alongside the input, experiences, knowledge, or information of others.*

### 7.3.3 Position and Approach

I have previously introduced my personal position and how it shaped my approach (see Section 1.5: Methodology). However, I think that this is worth expanding upon as I consider what I would change.

My personal position is one comprised of two major points, each a reaction to the literature I encountered, and continue to encounter. The first arose from reading medical literature, the second from PI/PHI literature. These points, which I detail in the following two paragraphs, are that:

- People living with HIV should be treated with respect and given personal autonomy over their lives and their medical care
- People should be provided with systems which are designed for their specific needs and desires

When I began reading the literature discussing HIV and self-management it struck me that the rhetoric of treating people living with HIV did not match the change from an acute disease to chronic one. While other conditions, such as diabetes, had countless papers being published each year pushing for patient empowerment and self-management, those relating to HIV appeared to be stuck in the late 1990's. These publications came across as patronizing: they focused on medication adherence, drug use, safe sex, and determining whether or not self-reported measures of such were factual and trustworthy (Pellowski & Kalichman, 2012). To me, this appeared as an effort focused only on reducing further transmissions of the disease than one also aimed at supporting individuals already affected in living long, healthy, and happy lives. Thus, I aligned myself with the perspective of others (e.g. Gifford and Groessl, 2002; Swendeman, Ingram, & Rotherham-Borus, 2009) who felt that the focus of non-compliance with medication was an indicator that patients are not being treated with the respect and authority they deserve and, in fact, may discourage patients from participating in collaborative care.

Personal Health Informatics is a relatively new field, and the concept of 'user-centered design' certainly predates it (see, for example, Gould & Lewis, 1985). Yet, the publications describing research on PI and PHI systems appeared to have skipped through the traditional design process, rushing to try out new and novel technologies for capturing or visualizing information (Mamykina et al., 2006). These publications were overwhelmingly describing evaluations of the systems and

as I searched for details on the basis for design choices being made and found little evidence that there was any involvement with end-users in developing those designs (Lee et al., 2010). For example, Frost et al. (2013) described a 6 month trial in which patients with bi-polar disorder used an application tracking their mood, activity, alcohol consumption, environment, etc., but never once indicated where those informational categories came from. Others, such as Lai (2007) drew their requirements from 'experts' on the condition (in the case of Lai, it was nurses) and their perspectives of what patients needed, rather than from those patients directly. I felt that this echoed the patronizing viewpoint described above, but this time from a technological standpoint – researchers were making assumptions on what was needed, and developing based on those assumptions, rather than asking end-users outright. Again, I found myself aligning with the perspective of a select few who drew argued against that approach (see Lee et al., 2010; Mamykina et al., 2006; Patel & O'Kane, 2015).

My personal position led my approach; I felt that determining how PHI systems can support people living with HIV in reflecting on their health was only truly achievable through by engaging with those end-users. This, from my perspective, required qualitative and empirical research. While others sought to connect with end-users by conducting autoethnographic research (O'Kane, Rogers, & Blandford, 2014), using pre-existing systems with fictional data to gather reactions (Choe, Lee, Zhu, Riche, & Baur, 2017), or having participants fill out questionnaires remotely (Epstein, Ping, Fogarty, & Munson, 2015), I felt that my research required end-user involvement in as direct a way as possible. Taking a qualitative and empirical approach allowed me to gather design implications in each study and instantiate them into the two prototypes in Study Three, each linking directly to the needs of the end-users.

I could have approached my research differently by using different methods to gather data. Looking back, however, I would not change my methods. I stand by those choices that I made and continue to believe that they were the most appropriate given my position and my target population. My confidence in my methods should not be taken as an indication that I have not learned and grown from my experience over the last 3.5 years. There are things I would do differently if given the chance, and these relate to myself as a researcher. In particular, I would like to address my focus, my discomfort, and my analysis.

In retrospect, I feel that while I was conducting studies I was often too focused on answering the specific research questions at hand; a result of this being that I rarely pursued different avenues of potential interest when they came up. This pertains the most to Study One, where I was aiming to understand existing practices and barriers. My questions were specific to PHI, but participants often strayed from the topic to talk about their experiences of living with HIV as a whole – particularly how it affected their relationships and their emotions. From my perspective at that time, those details had little to do with their thoughts on tracking and reflection; while I did not cut

participants off when they were talking, I did not consider these portions of the transcripts to be useful during analysis and they did not end up in the results. However, this may have resulted in excluding details on how PHI systems weave into the everyday lives of people living with HIV, and how emotions and support systems are connected to PHI. If I were to conduct these interviews again, now, I would actively engage during those instances and try to understand how they might relate to tracking and reflection.

The second point I would like to address is my discomfort with talking about HIV. Because I was so unfamiliar with HIV I did not know how to talk about it in detail with those who were living with it. By this I don't mean that I was uncomfortable talking to my participants *because* they had HIV, but that I was uncomfortable talking about HIV to my participants for fear that I would say the wrong thing. I was nervous that I would use incorrect or stigmatizing terminology. For example, one of the first questions I asked in Study One was for the date the participants were diagnosed, and I worried over how to word this – do I avoid saying HIV? Do I call it a virus, a disease, or a condition? Now, after several years of working with this population, I feel much more comfortable, but at the time I approached my interview sessions with trepidation and a feeling of walking on eggshells. In the future, I hope to overcome this challenge much more quickly and potentially may turn to healthcare providers or charity organizations for help in getting a primer.

The final point I would like to address is with regards to my analysis. Particularly with the second and third studies, I feel as though my analysis leaned too heavily on quantifying the coding rather than producing a rich narrative of what occurred. With this approach, Study Two could be transformed into a description of how individuals discussed health concerns in an online forum, rather than a discussion of the types of support being provided. Study Three could become a rich description of how reflection occurred, rather than a discussion of frequencies. I feel that by emphasizing frequencies of instances I detracted from the human aspect of the interactions, and this is something I would like to bring back in.

## 7.4 Limitations of the work

The work conducted in this thesis aimed to determine how Personal Health Informatics systems could support people living with HIV in reflecting on their health information. However, I have only explored one aspect of reflection – community-aided reflection. While the findings might indicate some aspects of what is needed to support them in other types of reflection (e.g. tracking a variety of information types, viewing representations of those various information types together), I did not explore how to support them in reflecting alone, nor in reflecting with their healthcare provider. Still, the focus on community-aided reflection was motivated by statements that participants in

the first study made, and this style of reflection has not been explored in the realm of Personal Health Informatics.

My approach to research is a qualitative one, and conducting qualitative research was required to develop an empirical understanding of how to support people living with HIV in reflection. However, recruiting participants was not easy, and my findings are based on low sample sizes. Additionally, my research was conducted only with those who spoke English, and many of the participants resided in England. As such, the demographic details of my participants are not representative of the demographic details of people living with HIV around the world. I believe the findings of each study hold true for a large portion of those living with HIV, but I cannot say for certain what other considerations need to be made for those living in different parts of the world. Easy access to healthcare, information, medication, technology, and support groups is not global, and these are aspects that are likely to have an impact on a person's ability to track and reflect on their health information.

Finally, my research never explored how a real, working PHI system would be used to track and reflect on personal health information. I implemented prototypes in the third study that simulated community-aided reflection, but did not allow participants to go through the process of PHI or respond to the fictional profiles shown. Developing and deploying a working system to be used by participants could confirm the findings of my research, identify new opportunities, and enrich our understanding of how to support reflection.

## 7.5 Future Work

This thesis has shown that there is an interest and need for reflecting on personal health information that currently available tools do not yet support, and that including the community in reflection and PHI is an approach to supporting people living with HIV in understanding their health through reflection. There are multiple opportunities for research to build upon this work, or to follow avenues that I did not.

This thesis explored supporting community-aided reflection in depth, but other styles of reflection should also be explored. Future work can build off what has been conducted and reported here to extend to supporting reflecting alone, and reflecting with a healthcare provider. Potentially there are other question types to identify, that are different from those asked of a community. Observing how personally tracked health information is reflected on alone, and how it is integrated into a consultation, explored, and discussed with a consultant would be a great next step to understanding how we might be able to better support different types of reflection.

Future work should also consider the demographics of those participating in the study, and extend on the work I have conducted by including a more global group of participants. With this, we can begin to determine how generalizable the findings are, and where there are additional opportunities for supporting reflection. In addition, researchers focused on other chronic conditions may find that some of the results reported in this thesis are transferable to their own work, and can use the findings to develop their own systems for supporting reflection.

Finally, future research should focus on progressing the work described in this thesis by developing a PHI system for people living with HIV. The implementation of such a system in the wild would not only be of a benefit to those using it, but it will also allow us to learn more about supporting reflection, and how it occurs in an uncontrolled setting. Conducting a longitudinal study of a fully-functional PHI system that supports community-aided reflection would advance our understanding of how such a system would actually be used, and what additional, or new, barriers to reflection exist.

# Chapter 8 Appendix

# Appendix 1.  Study One Ethics Form

CITY UNIVERSITY LONDON

**Senate Research Ethics Committee**

**Application for Approval of Research Involving Human Participants**

Please tick the box for which Committee you are submitting your application to

| | |
|---|---|
| ☐ | Senate Research Ethics Committee |
| ☐ | Cass Business School |
| ☒ | Computer Science |
| ☐ | School of Arts & School of Social Sciences Research Ethics Committee |
| ☐ | School of Health Sciences Research Ethics Committee |
| ☐ | Department for Learning Enhancement and Development |

For **Senate** applications: return one original and eight additional hardcopies of the completed form and any accompanying documents to Anna Ramberg, Secretary to Senate Research Ethics Committee, University Research Office, Northampton Square, London, EC1V 0HB. Please also email an electronic copy to ███████████████████ (indicating the names of those signing the hard copy).

For **Computer Science** applications: a single copy of the application form and all supporting documents should be emailed to Stephanie Wilson ████████████

For **School of Arts & School of Social Sciences** Research Ethics Committee submit a single copy of the application form and all supporting documentation to your Department's Research and Ethics Committee by email.

For **School of Health Sciences** applications: submit all forms (including the Research Registration form) electronically (in Word format in a single document) to ██████████████

For **Department for Learning Enhancement and Development** a single copy of the application form and all the supporting documentations should be emailed to Pam Parker (██████████████████

Refer to the separate guidelines while completing this form.

| **Project Title:** |
|---|
| Exploring the early process of Personal Health Informatics |

| **Short Project Title (no more than 80 characters):** |
|---|
| Exploring the early process of Personal Health Informatics |

| **Name of Principal Investigator(s) (*all* students are require to apply jointly with their supervisor and all correspondence will be with the supervisor):** |
|---|
| Dr. Simone Stumpf, Dr. George Buchanan, and Adrian Bussone |

| **Post Held (including staff/student number):** |
|---|
| Dr. Simone Stumpf: Senior Lecturer #888002590<br>Dr. George Buchanan: Reader #80015318<br>Adrian Bussone: PhD Student, HCID #130028006 |

| **Department(s)/School(s) involved at City University London:** |
|---|
| Centre for HCID, SMCSE |

| **If this is part of a degree please specify type of degree and year** |
|---|
| PhD – Year one |

| **Date of Submission of Application:** |
|---|
| 23 September 2015 (original submission)<br><br>30 October 2015 (resubmission)<br><br>11 November 2015 (resubmission) |


| **1. Information for Non-Experts** |
|---|

**Lay Title** (no more than 80 characters)

| Understanding the information and technology users identify as important for health monitoring |
|---|

**Lay Summary / Plain Language Statement** (no more than 400 words)

| This research study investigates the actions that people living with HIV (PLWH) take to find technology that will help them track their personal health information, and the information that they desire to track. It also explores the challenges that they face during these actions and the factors that affect the decisions they make. |
|---|

This research involves an interview/observation session that will last for approximately one hour. During this time, participants will be asked about the kinds information they would like to keep track of, the technology they use, and how they would go about selecting a tool to help them capture their information. I will ask them to use a computer or tablet to walk me through their actions, or their personal phone if they prefer. Interviews will be audio recorded, and photos may be captured of the screens they look at during the last activity.

## 2. Applicant Details

**This project involves:** (*tick as many as apply*)

| | | | |
|---|---|---|---|
| ☐ | Staff Research | ☒ | Doctoral Student |
| ☐ | Undergraduate | ☐ | M-level Project |
| ☐ | Externally funded | ☐ | External investigators |
| ☐ | Collaboration | ☐ | Other |
| Provide details of collaboration and/or other | | | |

**Address for correspondence** (including email address and telephone number)

(Principal Investigator)

| |
|---|
| Dr. Simone Stumpf, Centre for HCID, City University London, London, GB EC1V 0LT |
| Email: ███████████████ ██████████ |

**Other staff members involved**

| Title, Name & Staff Number | Post | Dept & School | Phone | Email |
|---|---|---|---|---|
| George Buchanan 80015318 | Reader | HCID, SMCSE | ████████ | █████████████████ |

**All students involved in carrying out the investigation**

| Name & Student Number | Course / Year | Dept & School | Email |
|---|---|---|---|
| Adrian Bussone 130028006 | PhD HCI – Year 1 | Centre for HCID, SMCSE | ██████████████ |

**External co-investigators**

| Title & Name | Post | Institution | Phone | Email |
|---|---|---|---|---|
| NA | | | | |

**Please describe the role(s) of all the investigators including all student(s)/external co-investigator(s) in the project, especially with regards to interaction with study participants.**

Adrian Bussone will collect and analyse the data, and be responsible for any interactions with participants, including recruitment.

Simone Stumpf and George Buchanan will assist with the study design and analysis, including publications, but will not interact with participants directly.

**If external investigators are involved, please provide details of their indemnity cover.**

N/A

**Application Details**

**2.1 Is this application being submitted to another ethics committee, or has it been previously submitted to an ethics committee?** *This includes an NHS local Research Ethics Committee or a City University London School Research Ethics Committee or any other institutional committee or collaborating partners or research site.* (See the guidelines for more information on research involving NHS staff/patients/ premises.) **YES** ☐ **NO** ☒

If yes, please provide details for the Secretary for the relevant authority/committee, as well as copies of any correspondence setting out conditions of approval.

**2.2 If any part of the investigation will be carried out under the auspices of an outside organisation, e.g. a teaching hospital, please give details and address of organisation.**

**2.3 Other approvals required – has permission to conduct research in, at or through another institution or organisation been obtained?** **YES** ☒ **NO** ☐

If yes, please provide details and include correspondence

Permission has been granted to conduct research sessions at NAZ, an HIV and sexual health organisation in London. A copy of the permission from NAZ has been included with this application. No promises have been made to this organisation.

NAZ Project London, 30 Blacks Rd, London W6 9DT  020 8741 1879

**2.4 Is any part of this research project being considered by another research ethics committee?**                                      YES ☐ NO ☒

**If yes, please give details and justification for going to separate committees, and attach correspondence and outcome**

Not applicable

**2.5 Duration of Project**

Start date:  13 November 2015          Estimated end date: 30 January 2019

| Funding Details |
| --- |

**2.6 Please provide details of the source of financial support (if any) for the proposed investigation.**

N/A

**2.6a Total amount of funding being sought:**            0.00

**2.6b Has funding been approved?**
   YES ☐ NO ☒

**If no, please provide details of when the outcome can be expected**

**2.6c Does the funding body have any requirements regarding retention, access and storage of the data?**                             YES ☐ NO ☐

**If yes, please provide details**

| International Research |
| --- |

**2.7 Is any part of the research taking place outside of England/Wales? (if not go to section 3)**                                         YES ☐ NO ☒

**If yes, please provide details of where**

Not applicable

**2.7a Have you identified and complied with all local requirements concerning ethical approval & research governance*?**                YES ☐ NO ☐

**2.7b Please provide details of the local requirements, including contact information.**

Not applicable

**2.7c Please give contact details of a local person identified to field initial complaints local so the participants can complain without having to write to or telephone the UK**

Not applicable

*Please note many countries require local ethical approval or registration of research projects, further some require specific research visas. If you do not abide by the local rules of the host country you will invalidate your ethical approval from City University London, and may run the risk of legal action within the host country.

## 3. Project Details

**3.1 Provide the background, aim and explanation for the proposed research.**

Personal informatics is a process in which a person collects data about themselves and reflects upon it with the intention of gaining a better understanding of themselves. There is very limited knowledge regarding what occurs when an individual seeks to begin collecting his or her personal information. Yet, these activities largely shape the success of the rest of the process of Personal Informatics. Without knowing the process that end-users go through, nor the barriers they face, the potential for technology to provide support cannot be explored.

The proposed research is intended to address the limited knowledge on these first stages.

The focus is drawn from concepts established and defined in Activity Theory (Engestrom, 2000; Kaptelinin & Nardi, 2006; Kuutti, 1995; Nardi, 1995). By focusing on the actions that occur, the objectives and goals which drive them, and the rules, divisions of labour, and instruments which mediate them, I aim to create a detailed and descriptive model of the overarching activities that end-users undertake. Through identifying the sequences in which these occur, and where the challenges lie, I aim to create a descriptive model of the process that takes place during the beginning. Furthermore, by identifying the relationship between the mediating factors (rules, instruments, and division of labour) and the attributes that end-users identify as important, I aim to highlight the affect of context on these stages of the personal informatics process.

In order to meet these aims, five research questions are proposed:

RQ1. What actions do these individuals conduct during the stages of *Intention* and *Identification*, and what are the goals and objectives of these actions?

RQ2. What are the challenges faced by these individuals, and in which actions do they occur?

RQ3. What is the typical sequence in which these actions occur?

RQ4. What are the instruments, rules, and divisions of labour that mediate each action?

RQ5. How do the instruments, rules, and divisions of labour relate to the attributes of information and technology that end-users identify as important?

This is a proposal for a user study, and in this proposal the target users are people living with HIV (PLWH). HIV and AIDS (an immunodeficiency syndrome that is acquired from living with HIV) are heavily stigmatised. However, this stigma has lagged behind the progress made by medicine.  Thanks to the advent of anti-retroviral therapy (ART), people living with HIV are no longer facing a *terminal* disease. Instead, if carefully managed with ART medication, PLWH are now able to live with a *chronic* disease and enjoy a normal life expectancy, much like others living with chronic illnesses such as diabetes and hypertension

(Swendeman, Ingram, & Rotheram-Borus, 2009). Despite this transfer from terminal to chronic disease, both academia and industry have failed to make progress on applications that support the tracking of personal information for PLWH. Whilst a number of applications exist within mHealth (applications which capture information documented by *patients* and are reviewed and reflected upon by *clinicians*), a review of related literature has shown a lack of research regarding the information that PLWH wish to keep track of and the technology they desire to use. Indeed, related research commonly cites information-tracking suggestions made by clinicians or other healthcare providers, rather than gathering insight from the PLWH themselves.  This only succeeds in gathering a clinical point of view, and ignores the items which end-users deem to be important. Additionally, there is a dearth of technology available to PLWH for tracking their personal health information, whilst other chronic diseases (e.g. diabetes) have a broad array to choose from. For these reasons, focusing this research study on PLWH is ideal and important in two ways. First, this research takes a first step towards exploring a real-world need and, as such, towards providing a real-world impact. Second, it allows us to explore the early process of personal health informatics amongst a population which has had limited exposure to the topic.

**3.2 Provide a summary and brief explanation of the design, methodology and plan for analysis that you propose to use.**

The five research questions will be answered through a qualitative research study that uses a combination of data collection techniques. This is a one-hour semi-structured interview / task-based observation, or both.  For each part of the study, I am seeking to recruit a maximum of twenty participants who fit the target population (adults living with HIV/AIDS). This would result in a maximum total of twenty participants.

Once a potential participant has been successfully recruited, an initial meeting will be set up and the study information sheet and informed consent form will be sent.  During the initial meeting (approximately 15 minutes long), the study session and purpose will be described, consent will be gained, and each participant will complete a brief questionnaire aimed at gathering their demographic details. Additionally, during this time, each participant will be allowed to ask any questions they have.

The Interview / Observation portion of the study will take approximately one hour, including the time spent gaining consent and completing the questionnaire. A discussion guide will be used during this session, to guide the conversation. This will not be used to take notes on during the session. To begin, participants will be asked to talk about their motivations for collecting their personal health information and current tracking practices. This will be followed by a discussion about the information they wish to capture and the context around it (e.g. how it is obtained, the frequency at which it changes, etc.). If the participant has previously taken part in the diary study, the data they captured during that time will be used to foster the discussion. From there, participants will be asked about the technology they feel comfortable with, and what they perceive to be ideal tools for supporting future collection of their personal health information. This will lead into the observation portion of the session.

At this point, participants will be asked to perform a small task while I observe. They will be asked to walk me through the steps they would take to identifying an appropriate personal informatics tool, or improving their current method. Participants will first be asked to state the device, or devices, that they would use to perform these actions. Those who indicate using their phone will be asked to do so, whilst those who indicate using a computer or tablet will be provided with the researcher's own. With each action, the researcher will enquire about the goal and perceived challenges. Additionally, the participants will be asked to explain in detail why the action is important, and what their goal was based upon. Photographs or screen recording may be used to capture their activities. This part of the study session will continue until the individual has found an ideal personal informatics tool, declares that one is not available, or has run out of time.

Following this activity the participants will be asked to indicate the typical sequence in which the actions would occur.  Finally, participants will be asked to indicate the attributes of information and technology that they perceive to be important (probes will be given, e.g. privacy, information to gather, ways to gather it, visualizations etc.) and describe why they feel these are important or necessary, particularly in relation to the instruments that are

available to them, the perceived 'rules' of the community they are in, and the availability of attributes due to division of labour.

The data gathered from the interview data, once transcribed in full, will be entered into an excel spreadsheet. All captured images (screen shots, photographs taken during the interview, photographs taken by participants, etc.) will be described in text and added to the Excel document, as well as used to provide visual examples when applicable. No notes will be taken on the Discussion Guides. A Grounded Theory analysis will be performed on all data captured in the diary study and interview session.

**3.3 Please explain your plans for dissemination, including whether participants will be provided with any information on the findings or outcomes of the project.**

The results of the proposed research will be disseminated in three ways. First, the work will be written and submitted to relevant conferences (e.g. Mobile HCI, UbiComp, etc) in order to disseminate the information via publication. Additionally, any sexual health and HIV organization within London who helps with recruitment will be given the option of receiving a summary of the results of the research so that they may advance their organization's offerings and practices. Similarly, all participants will be provided with the option of receiving a summary of the results of the research. Finally, this research will also be used in Adrian Bussone's transfer report and thesis.

**3.4 What do you consider are the ethical issues associated with conducting this research and how do you propose to address them?**

1. Confidentiality

The target demographic for this research is people living with HIV. Because of the stigma associated with this disease, and because the individuals may not have made their diagnosis public, confidentiality is of the utmost importance.

As well as taking the measures noted in Section 6 and 7 of this document, all participants will be required to indicate their preferred contact method and whether or not a message can be left on it.

2. Sensitive topics

Whilst this research does not focus on some of the more sensitive topics related to HIV, some participants may find it uncomfortable to talk about their disease in general.

To address this:

- All participants will be told and reminded that their participation is optional
- All participants will be told and reminded that they are not required to answer any questions which make them feel uncomfortable
- All participants will be told that they can end the interview session at any time
- If the interviewer senses that the individual feels uncomfortable with the topic, she will move on or potentially call the interview to an end
- All participants will be told and reminded that they are not expected to disclose sensitive information
- All participants will be told and reminded that the researcher is required to report any criminal information or information that shows the participant or others are at risk
- Participants of the diary study will be told and reminded that they should not include any identifying information in their diary (e.g. their name, names of others, etc.) and to avoid including explicit sensitive information which might compromise them if the diary is lost or stolen
- Participants using the text message version of the diary study will be told to delete each text after sending, to preserve their confidentiality

**3.5 How is the research intended to benefit the participants, third parties and/or local community?**

The results of this research study will benefit HCI researchers, developers and designers working in industry, HIV organizations and people living with HIV.

This work will benefit those in the HCI academic community who focus their work on personal informatics, and potentially those focused on health monitoring. First, this community will benefit from the identification and description of the challenges encountered by end-users, as this will indicate potential points for technology to intervene and provide support. These challenges will highlight new opportunities for researchers to focus on. Second, research within personal informatics has scarcely considered the context in which it takes place, which is why my study explores the activities that are done within - and the influences of - the broader sociotechnical context. In doing so, the results of my research may emphasize and encourage other academics to explore the larger picture of Personal Informatics: a relatively untouched topic of research. Finally, the descriptive model that results from my research will provide a starting point upon which a theory of personal informatics can be built. It should be stated that, whilst this research may be focused on people living with HIV, the findings can apply to other chronic diseases as well (Swendeman, Ingram, & Rotherham-Borus, 2009).

Developers and designers working in industry will also benefit from this research. First, with a better understanding of the steps that end-users go through to select a personal informatics tool, developers will be able to adjust their products to meet the selection criteria. Also, with a better understanding of the challenges that are faced, designers will be able to create features that help users overcome or avoid these challenges.

This research will also bring benefits to the chronic disease organizations and individuals, particularly those with HIV/AIDS. The results will be shared with interested organizations and this dissemination of knowledge may cause organizations to encourage their community to consider personal informatics as a method of managing and monitoring their own health. Potentially, these organizations will alter their programs to include information about the topic, tips for getting started, and the benefits of personal informatics. With this, people living with HIV will become more knowledgeable about their health and more empowered to manage their disease.

**3.6a Will invasive procedures (for example medical or surgical) be used?**
**YES ☐ NO ☒**

**3.6b If yes, what precautions will you take to minimise any potential harm?**

**3.7a Will intrusive procedures (for example psychological or social) be used?**

**YES ☐ NO ☒**

**3.7b If yes, what precautions will you take to minimise any potential harm?**

**3.8a In the course of the investigation might pain, discomfort (including psychological discomfort), inconvenience or danger be caused?** **YES ☐ NO ☒**

**3.8b If yes, what precautions will you take to minimise any potential harm?**

**3.9 Please describe the nature, duration and frequency of the procedures?**

## 4. Information on participants

**4.1a How many participants will be involved?**

The study will require a maximum of 20 participants.

**4.1b What is the age group and gender of the participants?**

Age and gender are not factors under investigation in this research, although participants will be over 18.

**4.1c Explain how you will determine your sample size and the selection criteria you will be using. Specify inclusion and exclusion criteria. If exclusion of participants is made on the basis of age, gender, ethnicity, race, disability, sexuality, religion or any other factor, please explain and justify why.**

The target population for this research is adults (18+) who have been diagnosed with HIV and have an interest in tracking personal information related to their disease. This includes those who have tracked in the past, those who currently track, and those who desire to begin tracking. The goal is to recruit a maximum of twenty representative individuals for each part of the study, with a total possible maximum of forty. I am not focused on creating a balance of people who currently track, want to track, or have in the past. The reason for not balancing recruitment is due to the potential lack of individuals who currently or previously have tracked their health information.

Interested individuals will need to meet a small set of specific criteria in order to be recruited to the research study. First, all participants must be capable of consenting to the study. This means that individuals who are under the age of 18 or have severe cognitive abilities cannot participate. Second, because this research study is focused on people living with HIV, each interested individual must be HIV positive. However, proof of status will not be required. Finally, due to the interviewer's limitations, the study is limited to those who can speak and read the English language, and reside within the greater London area.

We decided not to require proof of HIV status; we felt that asking potential participants to prove their status could be an intrusion on their privacy. We did consider the potential consequences of this decision. However, we determined that chances of recruiting individuals who were falsely claiming to be HIV positive were highly unlikely because we will be recruiting through sexual health and HIV organizations, and because we are not offering such incentives that would sway individuals to lie about having a disease associated with such stigma.

**4.2 How are the participants to be identified, approached and recruited, and by whom?**

In order to recruit interested individuals, I will be sending out recruitment advertisements. I am currently collaborating with NAZ, an organization that works with BAME (Black, Asian, and Minority Ethnics) individuals living with HIV, in recruiting potential participants. I will ask organizations such as NAZ to send my recruitment advertisement out to their service users through email. I will also post a link to the advertisement on Twitter, and (with permission)

post flyers in local sexual health organisations. People who are interested in learning more about the research study will be able to contact me via email, text, phone, or through a website set up specifically for recruitment. When contacted by interested individuals, I will describe the purpose and details of the study and, if interested, determine if the person fits the criteria for participating. This will be a self-selected recruitment; I will not make any direct contact with individuals requesting their participation.

**4.3 Describe the procedure that will be used when seeking and obtaining consent, including when consent will obtained. Include details of who will obtain the consent, how are you intending to arrange for a copy of the signed consent form for the participants, when will they receive it and how long the participants have between receiving information about the study and giving consent.**

Once a potential participant has been successfully recruited, they will be asked to provide a preferred method of contact and indicate whether or not it is acceptable to leave a message for them. This is important, as it will help to ensure that their participation in the research study is kept confidential. Additionally, they will be asked to indicate which part of the study they wish to participate in (diary, interview/observation, or both). Once this is completed, a date, time and location will be set up to meet. Details of the study session and informed consent forms will then be sent in order to give each individual ample opportunity to review the information, ask questions, and decide if they are interested prior to the initial meeting.

Approximately the first ten minutes of the initial in-person meeting will be spent talking about the research and study plans in detail. To facilitate this conversation I will read the Research Summary out loud and discuss it with each participant. They will be invited to ask questions at any time, and any questions that are brought up will be answered accordingly. Once all questions have been answered, we will review the Consent Form. Two consent forms have been prepared for this research study, one for participating in the Diary Study, and another for participating in the Interview/Observation. Depending upon which part of the study the participant is joining, they will receive the appropriate form. Again, any questions that the participant has will be answered at this time. If the participant declines to sign the consent form, they will be excluded from the study and their contact information will be permanently deleted. If, however, the participant chooses to take part in the study, they will be asked to sign two consent forms. In turn, I will add my signature to the forms, and one copy will be given to the participant for their records.

**4.4 How will the participant's physical and mental suitability for participation be assessed? Are there any issues related to the ability of participants to give informed consent themselves or are you relying on gatekeepers on their behalf?**

The inclusion / exclusion criteria includes questions regarding the cognitive abilities of interested individuals and their ability to provide consent for themselves.

**4.5 Are there any special pressures that might make it difficult to refuse to take part in the study? Are any of the potential participants in a dependent relationship with any of the investigators (for instance student, colleague or employee) particularly those involved in recruiting for or conducting the project?**

There are no foreseeable special pressures that might make it difficult for potential participants to refuse to take part. We have also attempted to reduce any possible pressures by making this a self-selected recruitment and emphasizing that participation is entirely optional and confidential.

**4.6 Will the participant's doctor be notified?**               **YES ☐ NO ☒**

(If so, provide a sample letter to the subject's GP.)

**4.7 What procedures are in place for the appropriate referral of a study participant who discloses an emotional, psychological, health, education or other issue during the course of the research or is identified by the researcher to have such a need?**

Because we are recruiting through sexual health and HIV organizations, our participants will likely already have established contacts and connections with support systems. However, it is possible that study participants will show signs of such issues as emotional, psychological, health, education, etc. As a safeguard for such instances, the researcher will gather a collection of resources that are able to support various issues. In the event that such an instance might occur, the researcher will encourage the participant to contact the appropriate resource or seek out another option. No contact with support groups or professionals will be made on behalf of the participant. Additionally, all participants (whether showing signs of such issues or not) will be reminded to seek out support in the future, if their status changes.

**4.8 What steps will be taken to safeguard the participants from over-research? (I.e. to ensure that the participants are not being used in multiple research project.)**

Participants are given the choice to participate, and thus are free to decline to participate if they have taken part in numerous research projects recently.

**4.9 Where will the research take place?**

The in-person meetings and interviews will be conducted in private locations, either on the premises of City University London or within an HIV organization, such as NAZ. No interviews will be conducted in public spaces or in the homes of the participants.

**4.10 What health and safety issues, if any, are there to consider?**

We have identified no foreseeable health and safety issues.

**4.11 How have you addressed the health and safety concerns of the participants, researchers and any other people impacted by this study? (This includes research involving going into participants' homes.)**

As stated in 4.9, the research will take place in safe and private locations, such as the premises of City University London or private meeting rooms within HIV organizations. No sessions will be conducted in the homes of participants or the researcher.

**4.12 It is a University requirement that an at least an initial assessment of risk is undertaken for all research and if necessary a more detailed risk assessment be carried out. Has a risk assessment been undertaken?\***      **YES ☒ NO ☐**

**4.13 Are you offering any incentives or rewards for participating?**     **YES ☒ NO ☐**

**If yes please give details**

As a token of appreciation for their involvement, their travel expenses to and from the interview location will be paid. Additionally, all in-person meetings will include baked goods, coffee, tea, and water.

*Note that it is the Committee's prerogative to ask to view risk assessments.

## 5. Vulnerable groups

**5.1 Will persons from any of the following groups be participating in the study? (if not go to section 6)**

| | |
|---|---|
| Adults without capacity to consent | ☐ |
| Children under the age of 18 | ☐ |
| **Those with learning disabilities** | ☐ |
| Prisoners | ☐ |
| Vulnerable adults | ☒ |
| Young offenders (16-21 years) | ☐ |
| Those who would be considered to have a particular dependent relationship with the investigator (e.g. those in care homes, students, employees, colleagues) | ☐ |

**5.2 Will you be recruiting or have direct contact with any children under the age of 18?**

**YES ☐ NO ☒ 5.2a**

**If yes, please give details of the child protection procedures you propose to adopt should there be any evidence of or suspicion of harm (physical, emotional or sexual) to a young person. Include a referral protocol identifying what to do and who should be contacted.**

| |
|---|
| Not applicable |

**5.2b Please give details of how you propose to ensure the well-being of the young person, particularly with respect to ensuring that they do not feel pressured to take part in the research and that they are free to withdraw from the study without any prejudice to themselves at anytime.**

| |
|---|
| Not applicable |

**5.3 Will you be recruiting or have direct contact with vulnerable adults? YES ☒ NO ☐**

**5.3a If yes, please give details of the protection procedures you propose to adopt should there be any evidence of or suspicion of harm (physical, emotional or sexual) to a vulnerable adult. Include a referral protocol identifying what to do and who should be contacted.**

| |
|---|
| Because we are recruiting through sexual health and HIV organizations, our participants will likely already have established contacts and connections with support systems. However, it |

is possible that study participants will show signs of such issues as emotional, psychological, health, education, etc. As a safeguard for such instances, the researcher will gather a collection of resources that are able to support various issues. In the event that such an instance might occur, the researcher will encourage the participant to contact the appropriate resource or seek out another option. No contact with support groups or professionals will be made on behalf of the participant. Additionally, all participants (whether showing signs of such issues or not) will be reminded to seek out support in the future, if their status changes.

**5.3b Please give details of how you propose to ensure the well-being of the vulnerable adult, particularly with respect to ensuring that they do not feel pressured to take part in the research and that they are free to withdraw from the study without any prejudice to themselves at anytime. You should indicate how you intend to ascertain that person's views and wishes.**

We will make it clear, at several points throughout the study, that participation is completely voluntary and that they will not be penalized in any way for choosing to not participate or withdraw. It is also made clear that they do not need to provide any reasons for withdrawing or not taking part. This study is independent of sexual health and HIV organizations, and their decisions will in no way impact their ability to receive support from the organization, or the quality of support they receive. The target population may include vulnerable individuals, but we will not be recruiting any individuals who are not competently able to give consent. Additionally, we stress that participants are not obligated in any way to discuss sensitive or uncomfortable topics.

**5.3c Please give details of any City staff or students who will have contact with vulnerable adults and/or will have contact with young people (under the age of 18) and details of current (within the last 3 years) City University London Disclosure and Barring check.**

| Name | Dept & School | Student/Staff Number | Date of DBS | Type of disclosure |
|------|---------------|----------------------|-------------|--------------------|
| Adrian Bussone | Centre for HCID, SMCSE | 130028006 | N/A | N/A |

**5.3d Please give details of any non-City staff or students who will have contact with vulnerable adults and/or will have contact with young people (under the age of 18) and details of current (within the last 3 years) Disclosure and Barring check.**

| Name | Institution | Address of organisation that requested the disclosure | Date of DBS | Type of disclosure |
|------|-------------|-------------------------------------------------------|-------------|--------------------|
|  |  |  |  |  |

**5.4 Will you be recruiting any participants who fall under the Mental Capacity Act 2005?**
**YES ☐ NO ☒**

**If so you MUST get approval from an NHS NRES approved committee (**see separate guidelines for more information).

**6. Data Collection**

**6.1a Please indicate which of the following you will be using to collect your data**

*Please tick all that apply*

| | |
|---|---|
| Questionnaire | ☒ |
| Interviews | ☒ |
| Participant observation | ☒ |
| Focus groups | ☐ |
| Audio/digital-recording interviewees or events | ☒ |
| Video recording | ☐ |
| Physiological measurements | ☐ |
| Quantitative research (please provide details) | ☐ |
| Other | ☐ |

**6.1b What steps, if any, will be taken to safeguard the confidentiality of the participants (including companies)?**

Communication methods were one of the major considerations for maintaining ethics and confidentiality, and there are three main points here. First, as mentioned in the recruitment discussion, I will not be directly contacting any individuals to request their participation. Instead, it will be up to each individual to contact me if they are interested. Second, all individuals who contact me will be asked to indicate their preferred method of contact (e.g. phone call, email, text message). If their preferred method is a phone call, they will also be asked to indicate whether or not it is acceptable to leave a message. Additionally, none of the messages I leave (whether on a voice mail, text, or email) will reference HIV or AIDS. This is done to ensure that the participant's diagnosis remains confidential in the event the message is intercepted or observed by a third party. Fourth, I will not make use of any mailing lists or group emails/texts when sending information to participants or interested individuals. I will only use one-to-one contact. Finally, all communications will be conducted through City University London's provided methods or a private telephone connection.

Also, all signed consent forms will be kept in a locked filing cabinet, preventing others from seeing the names that are on the forms. All individuals who are successfully recruited into the study will be assigned a unique identification number. The link between the individual's name and their unique identification number will be contained on only one piece of paper, which will be kept in a locked drawer in an area separate from the signed consent forms. All audio data will be stored in a locked folder on my personal computer until it is transcribed in full. Once it has been transcribed, the audio files will be moved to a locked folder on an external hard drive. Finally, all transcripts, photographs, and diaries will be examined for identifiable data. If found, the identifiable data will be permanently removed. Examples of what is considered 'identifiable data' follow:

- Names of participants, friends, family, acquaintances
- Names of workplace or locations frequently visited

| • Images containing faces, tattoos, birthmarks, scars |
|---|

**6.1c If you are using interviews or focus groups, please provide a topic guide**

| The discussion guide to be used during the interview sessions is attached. However, the following bullet points summarize the topics to be covered:<br><br>• Questions around the motivations and goals of collecting personal health information<br>• Current collection practices<br>• Discussion about the information they would like to collect<br>• Discussion about the technology they have available and feel comfortable using<br>• Discussion about the kind of technology they think would help them keep track of their health information |
|---|

| **7. Confidentiality and Data Handling** |
|---|

**7.1a Will the research involve:**

| | |
|---|---|
| • **complete anonymity of participants** (i.e. researchers will not meet, or know the identity of participants, as participants, as participants are a part of a random sample and are required to return responses with no form of personal identification)**?** | ☐ |
| • **anonymised sample or data** (i.e. an *irreversible* process whereby identifiers are removed from data and replaced by a code, with no record retained of how the code relates to the identifiers. It is then impossible to identify the individual to whom the sample of information relates)**?** | ☐ |
| • **de-identified samples or data** (i.e. a *reversible* process whereby identifiers are replaced by a code, to which the researcher retains the key, in a secure location)? | ☒ |
| • **subjects being referred to by pseudonym in any publication arising from the research?** | ☐ |
| • **any other method of protecting the privacy of participants?** (e.g. use of direct quotes with specific permission only; use of real name with specific, written permission only) | ☐ |
| **Please give details of 'any other method of protecting the privacy of participants' is used** | |
| | |

**7.1b Which of the following methods of assuring confidentiality of data will be implemented?**

*Please tick all that apply*

| | |
|---|---|
| • data to be kept in a locked filing cabinet | ☐ |
| • data and identifiers to be kept in separate, locked filing cabinets | ☒ |

| | |
|---|---|
| • access to computer files to be available by password only | ☒ |
| • storage at City University London | ☒ |
| • stored at other site | ☐ |
| **If stored at another site, please give details** | |

**7.1c Who will have access to the data?**

Access by named researcher(s) only                **YES ☒ NO ☐**

Access by people other than named researcher(s)      **YES ☐ NO ☒**

*If people other than the named researcher(s), please explain by whom and for what purpose*

| |
|---|
| |

**7.2a Is the data intended for reuse or to be shared as part of longitudinal research?**
                                               **YES ☐ NO ☒**

**7.2b Is the data intended for reuse or to be shared as part of a different/wider research project now, or in the future?**       **YES ☐ NO ☒**

**7.2c Does the funding body (e.g. ESRC) require that the data be stored and made available for reuse/sharing?**       **YES ☐ NO ☒**

**7.2d If you have responded yes to any of the questions above, explain how you are intending to obtain explicit consent for the reuse and/or sharing of the data.**

| |
|---|
| |

**7.3 Retention and Destruction of Data**

**7.3a Does the funding body or your professional organisation/affiliation place obligations or recommendations on the retention and destruction of research data?**
                                               **YES ☒ NO☐**

*If yes, what are your affiliations/funding and what are the requirements? (If no, please refer to University guidelines on retention.)*

| |
|---|
| We will follow City University London's guidelines. |

**7.3b How long are you intending to keep the data?**

*Note that the University guidelines on retention state a minimum of 10 years.*

| |
|---|
| As per the University's guidelines, all data will be retained for ten years. |

**7.3c How are you intending to destroy the data after this period?**

At the end of the ten years, all electronic data will be permanently deleted and all paper data will be shredded and disposed of.

## 8. Curriculum Vitae

CV OF APPLICANTS (**Please duplicate this page for each applicant, including external persons and students involved.**)

| | |
|---|---|
| NAME: | Adrian Bussone |
| CURRENT POST (from) | City University London |
| Title of Post: | PhD Student |
| Department: | Centre for HCID |
| Is your post funded for the duration of this proposal? | Yes |
| Funding source (if not City University London) | City University London |

Please give a summary of your training/experience that is relevant to this research project

Training:

Completed Research Methods and Professional Issues module, with distinction, as part of MSc in Human Centred Systems at City University London

Completed Human Subject Research training course through the NIH, in the United States of America as part of job-related work

Experience:

Previous research involving human participants at City University London as part of MSc dissertation

Over 500 hours facilitating and conducting IRB-approved research involving human participants and the use of medical systems

| | |
|---|---|
| NAME: | Simone Stumpf |
| CURRENT POST (from) | 2009 |
| Title of Post: | Senior Lecturer |
| Department: | CS |

| Is your post funded for the duration of this proposal? | Yes |
|---|---|
| Funding source (if not City University London) | |

| Please give a summary of your training/experience that is relevant to this research project |
|---|
| Dr Stumpf received a PhD in Computer Science in 2001 and a BSc in Computer Science with Cognitive Science in 1996, both from University College London. She worked at Oregon State University as a Research Manager (where she received IRB Ethics training) and University College London as a Research Fellow where she conducted numerous user studies, including a large-scale user acceptance study at a German airport. Dr. Stumpf also has industrial experience as a User Experience Architect and supervises the City Interaction Lab. Dr Stumpf is the Deputy Chair of the CSREC. |

| NAME: | George Buchanan |
|---|---|
| CURRENT POST (from) | |
| Title of Post: | Reader |
| Department: | Computer Science |
| Is your post funded for the duration of this proposal? | Yes |
| Funding source (if not City University London) | |

| Please give a summary of your training/experience that is relevant to this research project |
|---|
| I am the the Director of the Centre for Human-Computer Interaction Design. My research interests surround information interaction: from web search, through browsing digital libraries, to accessing information on a mobile phone. I am an investigator of CHI+MED, which seeks to improve the safety of medical devices. Current collaborations include two projects with University College London and Swansea University, and an ongoing involvement with the New Zealand Digital Library Project at the University of Waikato. |

**8.1 Supervisor's statement on the student's skills and ability to carry out the proposed research, as well as the merits of the research topic (up to 500 words)**

Adrian Bussone's work is advancing our understanding of the process and technology in Personal Health Informatics, which has the potential to empower people in the management of chronic diseases. She has built up a strong relationship with an organisation working with people living with HIV who are very keen to support her work.

Although she is in her first year of her PhD, she has extensive knowledge of working with users from her previous employment, her MSc in Human-Centred Systems and as part of her research assistant position at City University London working on the EU-funded

EMBalance project. As part of this work she has also gained experience of the special circumstances that working in the in healthcare area place on conducting user studies.

| | |
|---|---|
| **Supervisor's Signature** | █████████ |
| **Print Name** | Simone Stumpf |
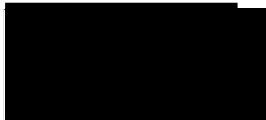
## 9. Participant Information Sheet and 10. Consent Form

**Please use the templates provided below for the Participant Information Sheet and Consent Form. They should be used for all research projects and by both staff and students. Note that there are occasions when you will need to include additional information, or make slight changes to the standard text – more information can be found under the application guidelines.**

## 11. Additional Information

| |
|---|
| |

## 12. Declarations by Investigator(s)

• I certify that to the best of my knowledge the information given above, together with any accompanying information, is complete and correct.
• I have read the University's guidelines on human research ethics, and accept the responsibility for the conduct of the procedures set out in the attached application.
• I have attempted to identify all risks related to the research that may arise in conducting the project.
• I understand that **no** research work involving human participants or data can commence until **full** ethical approval has been given

| | Print Name | Signature |
|---|---|---|
| **Principal Investigator(s)** (student and supervisor if student project) | Simone Stumpf | ███████████ |
| | ADRIAN BUSSONE | ████████ |
| **Associate Dean for Research (or equivalent) or authorised signatory** | | |

| Date | |
|---|---|

**Researcher's checklist for compliance with the Data Protection Act, 1998**

This checklist is for use alongside the *Guidance notes on Research and the Data Protection Act 1998.* Please refer to the notes for a full explanation of the requirements.

You may choose to keep this form with your research project documentation so that you can prove that you have taken into account the requirements of the Data Protection Act.

| | *REQUIREMENT* | ✓ | |
|---|---|---|---|
| | *Meeting the conditions for the research exemptions:* | | |
| 1 | The information is being used *exclusively* for research purposes. | ✓ | Mandatory |
| 2 | You are not using the information to support measures or decisions relating to *any* identifiable living individual. | ✓ | Mandatory |
| 3 | You are not using the data in a way that will cause, or is likely to cause, substantial damage or substantial distress to any data subject. | ✓ | Mandatory |
| 4 | You will not make the result of your research, or any resulting statistics, available in a form that identifies the data subject. | ✓ | Mandatory |
| | *Meeting the conditions of the First Data Protection Principle:* | | |
| 1 | You have fulfilled one of the conditions for using personal data, e.g. you have obtained consent from the data subject. Indicate which condition you have fulfilled here:<br><br>Obtaining consent from each participant | ✓ | Mandatory |
| 2 | If you will be using sensitive personal data you have fulfilled one of the conditions for using sensitive personal data, e.g. you have obtained explicit consent from the data subject. Indicate which condition you have fulfilled here:<br><br>All participants will be informed of the data to be captured and consent to it. | ✓ | Mandatory if using sensitive data |
| 3 | You have informed data subjects of:<br><br>  i.     What you are doing with the data;<br>  ii.    Who will hold the data, usually City University London;<br>  iii.   Who will have access to or receive copies of the data. | ✓ | Mandatory unless B4 applies |
| 4 | You are excused from fulfilling B3 only if all of the following conditions apply:<br><br>  i.     The data has been obtained from a third party;<br>  ii.    Provision of the information would involve disproportionate effort;<br>  iii.   You record the reasons for believing that disproportionate effort applies, please also give brief details here:<br>_____<br><br>N.B. Please see the guidelines above when assessing disproportionate effort. | | Required only when claiming disproportionate effort |

| | | | |
|---|---|---|---|
| | *Meeting the conditions of the Third Data Protection Principle:* | | |
| 1 | You have designed the project to collect as much information as you need for your research but not more information than you need. | ✓ | Mandatory |
| | *Meeting the conditions of the Fourth Data Protection Principle:* | | |
| 1 | You will take reasonable measures to ensure that the information you collect is accurate. | ✓ | Mandatory |
| 2 | Where necessary you have put processes in place to keep the information up to date. | ✓ | Mandatory |
| | *Meeting the conditions of the Sixth Data Protection Principle:* | | |
| | *You have made arrangements to comply with the rights of the data subject.  In particular you have made arrangements to:*<br><br>   i.   Inform the data subject that you are going to use their personal data.<br>   ii.   Stop using an individual's data if it is likely to cause unwarranted substantial damage or substantial distress to the data subject or another.<br>   iii.   Ensure that no decision, which significantly affects a data subject, is based solely on the automatic processing of their data.<br>   iv.   Stop, rectify, erase or destroy the personal data of an individual, if necessary.<br>Please give brief details of the measures you intend to take here:<br><br>We will be providing an information sheet and consent form to all recruited individuals to inform them of how their personal data will be used. Additionally, the contact information and personal data of any individuals who do not complete the study will be permanently deleted. | ✓ | Mandatory |

**Appendix 2. Recruitment Advertisement (Study 1)**



Figure 62: Recruitment flyer showing recruitment advertisement information

# Appendix 3.   Inclusion and Exclusion Checklist (Study 1)

Thank you for your interest in this research! I'd like to start by providing you a very brief summary of the purpose of the research and what it involves. Then, if you are interested in participating, I'll ask you a few questions to make sure you're a good fit. This research study is focused on getting a better understanding of the kind of information that people living with HIV want to keep track of, and the kind of technology or tools that they find to be most useful to track this information. This is an exploratory study, so I'm really focusing on what each individual person wants, thinks, and needs. You don't need any specialized knowledge about technology, tracking information, data, or anything like that.

Interview / Observation:

This would also take place in a private location in London. The interview and observation part of the study starts the same way as the diary study, with a description of the session, consent, and a questionnaire. The session will last approximately one hour. During this hour, we will talk about your thoughts about collecting information, and then I'd ask you to walk me through how you might approach finding something that would help you collect the information we talked about. You could do this on my computer, tablet, or on your phone if that's what you would typically use. I will be audio recording this session, and I might take a few photographs, but it's important for you to know that this will all be entirely confidential, and any identifiable information will be removed. Do you have any questions? Are you interested in participating? (If yes, go through questions)

| | |
|---|---|
| What is your age?  *(exclude if <18)* | _____ years old |
| Do you consider yourself to speak and read the English language fluently? *(exclude if 'no')* | YES   or   NO |
| Have you been diagnosed as HIV positive? *(exclude if 'no')* | YES    or    NO |
| Do you live in or near London? *(exclude if 'no')* | YES    or    NO |
| Are you able to consent to participating in this research yourself, or do you have a condition which requires someone else to provide consent for you? *(exclude if they cannot provide consent for themselves)* | ____ I can consent myself <br> ____ I require someone else to provide consent for me |
| Are you willing and able to travel into London in order to participate in this research study? Your travel will be compensated. *(exclude if 'no')* | YES    or    NO |

Include individual in study?   YES  or  NO

If Yes, get full name and schedule date, time, and location for study session

Name: _____  Session location:_____

Date: _____/____/_____    Time: _____

Preferred contact method: _____

Is it okay to leave a message?   YES  or  NO

# Appendix 4.  Study Information Sheet

Responsible Institution: City University London

Title of Study: Exploring the early process of Personal Health Informatics

We would like to invite you to take part in a research study. There are two parts to this research study, and you are invited to participate in one part or both, if you would like. Before you decide whether you would like to take part, it is important that you understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully and discuss it with others if you wish. Feel free to ask if there is anything that is not clear of if you would like more information.

## What is the purpose of the study?

The purpose of the study is to understand what health-related information people living with HIV would like to keep track of, and how technology can support this. This is an exploratory study, and we are trying to find out what information people living with HIV feel to be important, beyond the typical things like CD4 counts and viral loads. Additionally, we are also trying to find out what kinds of technology or tools people living with HIV think would be useful for capturing and keeping track of this information, as well as how they would like to capture it.

## Why have I been invited?

You have been invited to participate in this study because you expressed interest in participating and because you are an adult living in or around London who has been diagnosed with HIV. A maximum of forty other individuals like you will be involved in this study.

## Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be asked to sign a consent form. You will be free to withdraw at *any* time and without giving a reason. You will not be penalized in any way for not taking part or withdrawing.

## What will happen if I take part? What do I have to do?

If you choose to take part in this study, you will be asked to participate in an interview session. That would take place at a private, quiet location, such as a local sexual health clinic or the Interaction Lab at City University London, or over Skype.

For the **Interview Session**, the in-person meeting will be approximately one hour. It will begin with an overview of what will occur during that time, completing the consent form, and completing a brief questionnaire. The purpose of this questionnaire is to gather demographic details of the participants of the study. You will be asked to indicate your ethnicity, country of origin, gender, sexual orientation, language, age, year of diagnosis, and the technology that you own.

Then, you will be asked to talk about your motivations for tracking your health information, discuss the information you want to collect, and talk about the different kinds of technology you use. If you have previously completed the diary study, we may review some of the information captured during this time. Towards the end of the session, you'll be asked to use a computer, tablet, or your personal phone to look for something that you think would help you collect your personal health information. This session will be audio recorded, and some photographs of the screen may be captured. The audio and visual data will be de-identified (e.g. any names of people or businesses will be replaced, any identifiable information contained in photographs such as faces or tattoos will be blurred out or pixelated) and used for analysis.

## Compensation:

Your participation in this research project is greatly appreciated. As thanks, your travel to and from the two in-person meetings will be reimbursed, and you will be provided with ample baked goods and refreshments.

## What are the possible disadvantages and risks of taking part?

This study is completely confidential, and we have identified no reasonably foreseeable risks of harm, safety, or side effects to you as a result of taking part in this study.

## What are the benefits of taking part?

There are no direct benefits to you for taking part in this study. However, as a participant you will help us understand more about the informational needs of people living with HIV, which may help the design of supportive technology in the future.

## What will happen when the study stops?

When the research study stops, all collected information will be stored on a personal external hard drive which is password protected. It is City University London's policy to retain all research records for ten years. After ten years have passed, all documents related to the participants will be destroyed. Participation in the project is voluntary, and you can choose not to participate in part or all of the project. You can withdraw at

any stage of the project without being penalized or disadvantaged in any way. If you choose to withdraw from the research study, your data will be excluded from the research and destroyed.

### Will my taking part in the study be kept confidential?

Your participation will be kept confidential. We will ensure your anonymity in the following way:

- You will be assigned a unique identification number which will be used for all data and records, rather than your personal name
- All audio recordings will be stored on a password protected folder either on the interviewer's personal computer or external hard drive. The password will only be known by the researcher (Adrian Bussone).
- Transcripts made of the audio recordings and images captured will all be completely anonymized. Only anonymized data will be shared with other researchers interested in the work. No information containing identifiable features, comments, or names will be shared with other individuals.
- All signed consent forms will be kept in a sealed envelop, stored in a locked cabinet and destroyed after one year.
- Only direct communication will be made, and only through modes of communication that you have approved.

### What about sensitive or criminal information?

The researcher is obligated to report any information about criminal activities that put you or others at risk, such as unprotected sex, sharing needles, etc. However, the researcher is not obligated to report any *sensitive* and *legal* information (such as mental health problems, safe sexual activity, recreational drug use, gender identification or sexual attractions); this information will remain confidential.

### What will happen to the results of the research study?

The results of the study will be documented in a written report. Possible future publications might arise from the research, but will not include your personal details or identifiable features/comments – your anonymity will be maintained. If you wish to receive a copy of the summary of results, please send a request email to adrian.bussone.1@city.ac.uk

### What will happen if I don't want to carry on with the study?

You are free to discontinue the study at any time, without explanation or penalty to you.

### What if there is a problem?

If you have any problems, concerns, or questions about this study, you should speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complains procedure.

To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: *Understanding the information and technology users identify as important for health monitoring*, conducted by Adrian Bussone

You could also write to the Secretary at: Anna Ramberg, Secretary to Senate Research Ethics Committee, Research Office, E214, City University London, Northampton Square, London EC1V 0HB

Or email the Secretary at: ███████████████████

City University London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

### Who has reviewed this study?

This study has been approved by City University London's Computer Science Research Ethics Committee

### Further information and contact details:

Researcher:       Adrian Bussone, PhD student, ███████████████████████
Supervisor:        Dr. Simone Stumpf, ████████████████████
**Thank you for taking the time to read this information sheet.**

# Appendix 5.   Consent Form for Interview / Observation

**CONSENT FORM**

**Study Title: Understanding the information and technology users identify as important for health monitoring**
**Study Task: Interview / Observation**
**Researcher:  Adrian Bussone**
**Responsible Institution: City University London**

| | | |
|---|---|---|
| 1. | I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records.<br><br>I understand that this interview will involve:<br><br>• completing a questionnaire asking me my age, gender, ethnicity, language, sexual orientation, and time since being diagnosed<br>• being interviewed by the researcher<br>• allowing the interview to be audiotaped and photographed<br>• using a computer, tablet, or phone to show how I would look for something to help me track my personal information | **Please initial** |
| 2. | This information will be held and processed for the purpose of the completion of Adrian Bussone's PhD thesis and future research publications.<br><br>I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.<br><br>I understand that a unique identification number will be assigned to me, all collected data will be de-identified\*, and all raw data will be kept secure in a locked cabinet in order to protect my identity from being made public.<br><br>I consent to the use of de-identified\* images in publications.<br><br>\*De-Identification: Any names of people, specific locations such as workplaces, or other information which could lead to identifying you as a participant will be replaced with generic terms (e.g. "Bob" will be replaced with "Person"). Any identifiable information included in images captured, such as faces or tattoos, will be edited out of the image using pixilation, cropping, or blurring. | **Please initial** |
| 3. | I understand that the researcher is required to report any criminal offences (such as unsafe sex, sharing needles, or selling drugs), but that all sensitive information about legal activities will be kept confidential (such as mental health problems, sexual activities, recreational drug use, etc.). | **Please initial** |
| 4. | I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can | |

| | withdraw at any stage of the project without being penalized or disadvantaged in any way. | **Please initial** |
|---|---|---|
| 5. | I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998. | **Please initial** |
| 6. | I agree to take part in the above study. | **Please initial** |

_____        _____        _____

Name of Participant        Signature        Date

_____        _____        _____

Name of Researcher        Signature        Date

# Appendix 6.   Key to Participant Unique IDs (Example)

| Participant Name | Date of Consent | Assigned ID# | Diary | Interview |
|---|---|---|---|---|
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# Appendix 7. Participant Questionnaire

Participant ID: P_____                Date: _____-_____-_____

*Please fill out this brief questionnaire before we get started.*

1. What is your ethnicity?

    White:
    
    [ ] British
    [ ] Irish
    [ ] Other
    Mixed:
    [ ] White and Black Caribbean
    [ ] White and Black African
    [ ] White and Asian
    [ ] Other
    Asian or Asian British:
    [ ] Indian
    [ ] Pakistani
    [ ] Bangladeshi
    [ ] Other
    Black or Black British:
    [ ] Caribbean
    [ ] African
    [ ] Other
    Latin:
    [ ] Latin
    Chinese or other ethnic group:
    [ ] Chinese
    [ ] Other
    Or…
    [ ] Other: _____
    [ ] Prefer not to say


2. What country were you born in?    _____


3. How would you describe your gender?

    [ ] Male
    [ ] Female
    [ ] Trans Male
    [ ] Trans Female
    [ ] Gender queer / Non Binary
    [ ] Other (please specify): _____
    [ ] Prefer not to say

4. Which of the following best describes your sexual orientation?

    [ ] Heterosexual / Straight (Attracted to the opposite gender)
    [ ] Lesbian / Gay (Attracted to the same gender)
    [ ] Bisexual  (Attracted to both genders)
    [ ] Other (please specify): _____
    [ ] Prefer not to say

5. Is English your first language?

    [ ] Yes
    [ ] No
    If no, what is your first language? _____

6. What is your age?

    _____ years

7. In what year were you diagnosed?

    _____

8. Please indicate the different kinds of technology you own:

    [ ] Mobile Phone        [ ] Smart Phone
    [ ] Smart Watch        [ ] Digital Camera
    [ ] Fitness Tracker      [ ] Tablet / iPad
    [ ] Desktop Computer  [ ] Laptop
    [ ] Gaming Console     [ ] e-Book Reader
    [ ] Other: _____

# Appendix 8.   Discussion Guide

Participant ID: P____

Date:   ____-_____-_____

Intro (~10min)

Welcome, thank for participation
Describe study session and introduce materials [Study description form]
Gain consent [Consent form]
Assign unique identification number
Provide questionnaire to gather demographic details [Questionniare]
Begin recording

Start Session Intro (~5 min):

During this part of the study we will talk about your interest in collecting your personal information. When I talk about 'collecting' or 'tracking' your personal information, I'm talking about the kind of information that you think would be important to keep track of in order to better understand your health, your lifestyle, and other things like that. So, it could be things like CD4 levels or what you ate, how much you exercised, etc. And you might want to keep track of it for many different reasons, like to understand your health better, keep track of symptoms, etc. I'm interested in understanding how you might approach tracking your personal information; specifically the things that you think about and the things that you do in order to find a tool that might help you collect it.

We'll start by talking about your motivation and your interest in collecting this information. If you have completed the diary study, we'll look over the diary you filled out and the things you captured (in the diary and digitally). If not, we'll talk about what information you think you would like to capture. And finally I'll ask you to walk me through how you would go about selecting something to help you collect this information. I might ask you to do this on my laptop, tablet, or on your phone – whatever you think you would typically use.

Feel free to ask me questions at any time, or let me know if you need a break!

Before we start, I just want to emphasize that you don't have to talk about anything that makes you uncomfortable. And all of this is confidential.

| Initial questions (~10 min): |
| --- |
| *Ask questions around motivation, current practices, intention, and access.* |
| **What initially motivated you to gather information related to your health?** *(Points to motivations, potentially rules/division of labour)* |
| **What do you hope to gain from collecting your information? (What are your goals, what do you plan to do with it, how do you plan on using it? Why would it be helpful?)** |
| **Do you currently collect any information related to your health?**<br><br>       Why/ Why not?<br><br>What information do you collect? How do you currently collect it? Are you satisfied with that method? |

| Focus on Information (~15 min): |
| --- |
| *(Flow from Information to frequency to tech available to desired tool)*<br>Let's start by talking about the information you think you would like to capture. |
| *For each piece of information, ask:*<br><br>Why this? Why do you think this is important? What would it tell you?<br><br>Where does this information come from?<br><br>How frequently does it change / How often do you think you would want to record it? (Daily, hourly, monthly…) |
| *After going through all of the desired information…* |
| Is there anything else you would be interested in capturing, that you think is related, even indirectly? |
| Is there any other information that you would like to track but don't feel like you have access to? |
| And how frequently do you think you would like to, or need to, record all of this different information? |
| *Turn to the questionnaire on tech they have available…* |
| Okay, so you noted that you have access to these different types of devices… I just want to ask you a couple of quick questions about that. |

| |
|---|
| Are there any others that you have? (like wii fit or wearables or xbox…) |
| Which ones do you use most frequently? |
| How often? |
| Which do you feel most comfortable using? |
| Do you feel comfortable using technology in general? Going on-line? |
| Okay, so let's go back to the information you want to capture. What are your thoughts on how you would record that information to use later? (e.g. typing it into something, taking pictures of it, having it measured) |
| Why do you think you prefer that method? |
| What about privacy and security of the information? Do you have any concerns about that? (not just other people accessing it…) |
| Do you think it would effect how you would want to record the information? Where you record it? (do it at home vs on the bus, e.g.) |
| Do you think it effects the kind of technology you would use to record it? Like using an app vs a website vs something else? |
| Okay, now I'd like you to think about how you would look for a tool that would help you collect this information. |
| Okay, let's think about how you would like to capture, or record the information. Would you want some sort of technology to use for this? |
| *(e.g. app, spreadsheet, website, wearable)* |
| Why do you want that? |
| Where do you want your data to be kept? On the technology, or..? |
| What would you use to look for it (internet on phone, computer, laptop?) |
| Okay, would you mind showing me on [your phone, my computer, my tablet] how you would go about it? I might take a few photos of the screen while you do it. At this point I'd like you to walk me through the steps, telling what you are doing and why, as well as what you're thinking. Just to remind you, I'd like you to think out loud, telling me what your thoughts are and what you're doing. |
| *In this section, ask:* |
| What's the first thing you'd do? Why this? |
| What is the goal of this / What are you looking for? |
| Why is that important? |
| Is this what you would use (website, forum, app store)? Why this? |
| Why that search term? |
| Are you finding what you are looking for? (Why not? / What's missing?) |
| *This part of the study ends when the participant either finds something useful, doesn't find something useful, or runs out of time* |

| Wrap up: |
|---|
| Okay, great! I want to ask you some questions about what you just did. |
| First, did you have any problems during that, such as not being able to find something, or not knowing where to look? |
| *(Interviewer can also point out some observed problems)* |
| Can you tell me more about that? |
| At the point where we stopped, had you found something that you think would be suitable for your needs? |
| IF YES: What makes this suitable? Is there anything else you would have wanted? Do you feel like you settled in any way? |
| IF NO: Why was this unsuitable? What else do you want or need? What would you do next? |
| How does the technology you typically use affect what you are looking for in a personal informatics tool? |
| Before we wrap up, I'd like you to tell me your thoughts on what we just did. Do you have any questions for me? Things you think I should know or think about? |

**Thank participant. End recording. Provide compensation.**

# Appendix 9.  Copy of Permission Letter from NAZ

NAZ
SEXUAL HEALTH FOR EVERYONE

27th October 2015

RE: Adrian Bussone,
PhD student, Centre for Human Computer Interaction Design, City University
London

To whom it may concern,

NAZ is a sexual health charity supporting minority communities experience better sexual health through its programmes and services. Adrian Bussone approached NAZ in September 2015 with a view to recruit participants through our organisation and to use our premises to conduct her interview. Her request has been accepted and will be subject to compliance with NAZ's data protection protocols and client confidentiality.

We are keen to see the results of her research and wish her every success for the future.

Yours Faithfully
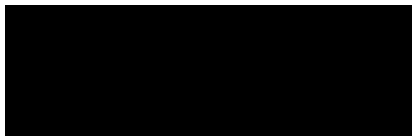
Marion Wadibia
Chief Executive Officer, NAZ

NAZ, 30 BLACKS ROAD, HAMMERSMITH, LONDON, W6 9DT
T: 020 8741 1879  F: 020 8834 0231  E: naz@naz.org.uk  www.naz.org.uk

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# Appendix 10. Ethics Form (Study Two)

Computer Science Research Ethics Committee (CSREC)

Staff and research students in the Department of Computer Science undertaking research that involves human participation must apply for ethical review and approval before the research can commence. If the research is low-risk, an application can be submitted for a proportionate review using this form. Applicants are advised to read the information in the SMCSE Framework for Delegated Authority for Research Ethics prior to submitting an application.

There are two parts:

*Part A: Ethics Checklist.* The checklist determines whether the research is low-risk. If it is, Part B of the form should also be completed. If not, the checklist provides guidance as to where approval should be sought, but the checklist itself does not need to be submitted.

*Part B: Ethics Proportionate Review Form.* This part is the application for ethical approval of low-risk research and should only be completed if the answer to all questions (1 – 18) is NO.

Completed forms should be returned to the Chair of CSREC by email (s.m.wilson@city.ac.uk).

Part A: Ethics Checklist

| If your answer to any of the following questions (1 – 3) is YES, you must apply to an appropriate external ethics committee for approval: | | *Delete as appropriate* |
|---|---|---|
| 1. | Does your research require approval from the National Research Ethics Service (NRES)? (E.g. because you are recruiting current NHS patients or staff? If you are unsure, please check at http://www.hra.nhs.uk/research-community/before-you-apply/determine-which-review-body-approvals-are-required/) | No |
| 2. | Will you recruit any participants who fall under the auspices of the Mental Capacity Act? (Such research needs to be approved by an external ethics committee such as NRES or the Social Care Research Ethics Committee http://www.scie.org.uk/research/ethics-committee/) | No |
| 3. | Will you recruit any participants who are currently under the auspices of the Criminal Justice System, for example, but not limited to, people on remand, prisoners and those on probation? (Such research needs to be authorised by the ethics approval system of the National Offender Management Service.) | No |

| If your answer to any of the following questions (4 – 11) is YES, you must apply to the Senate Research Ethics Committee for approval (unless you are applying to an external ethics committee): | | *Delete as appropriate* |
|---|---|---|
| 4. | Does your research involve participants who are unable to give informed consent, for example, but not limited to, people who may have a degree of learning disability or mental health problem, that means they are unable to make an informed decision on their own behalf? | No |
| 5. | Is there a risk that your research might lead to disclosures from participants concerning their involvement in illegal activities? | No |
| 6. | Is there a risk that obscene and or illegal material may need to be accessed for your research study (including online content and other material)? | No |
| 7. | Does your research involve participants disclosing information about sensitive subjects? | No |
| 8. | Does your research involve the researcher travelling to another country outside of the UK, where the Foreign & Commonwealth Office has issued a travel warning? (http://www.fco.gov.uk/en/) | No |
| 9. | Does your research involve invasive or intrusive procedures? For example, these may include, but are not limited to, electrical stimulation, heat, cold or bruising. | No |
| 10. | Does your research involve animals? | No |

| 11. | Does your research involve the administration of drugs, placebos or other substances to study participants? | No |
|---|---|---|

| If your answer to any of the following questions (12 – 18) is YES, you must submit a full application to the Computer Science Research Ethics Committee (CSREC) for approval (unless you are applying to an external ethics committee or the Senate Research Ethics Committee). Your application may be referred to the Senate Research Ethics Committee. | *Delete as appropriate* |
|---|---|
| 12. | Does your research involve participants who are under the age of 18? | No |
| 13. | Does your research involve adults who are vulnerable because of their social, psychological or medical circumstances (vulnerable adults)? This includes adults with cognitive and / or learning disabilities, adults with physical disabilities and older people. | No |
| 14. | Does your research involve participants who are recruited because they are staff or students of City University London? For example, students studying on a particular course or module. (If yes, approval is also required from the Head of Department or Programme Director.) | No |
| 15. | Does your research involve intentional deception of participants? | No |
| 16. | Does your research involve participants taking part without their informed consent? | No |
| 17. | Does your research pose a risk to participants greater than that in normal working life? | No |
| 18. | Does your research pose a risk to you, the researcher(s), greater than that in normal working life? | No |

| You must make a proportionate review application to the CSREC if your research involves human participation and you are not submitting any other ethics application (i.e. your answer to all questions 1 – 18 is "NO"). |
|---|

Part B: Ethics Proportionate Review Form

If you answered NO to all questions 1 – 18, you may use this part of the form to submit an application for a proportionate ethics review of your research. The form must be accompanied by all relevant information sheets, consent forms and interview/questionnaire schedules.

Note that all research participants should be fully informed about: the purpose of the research; the procedures affecting them or affecting any information collected about them, including information about what they will be asked to do, what data will be collected, how the data will be used, to whom it will be disclosed, and how long it will be kept; the fact that they can withdraw at any time without penalty.

| Background Information | |
|---|---|
| Name: | Adrian Bussone |
| Supervisor (if student): | Dr. Simone Stumpf |

| Your Research Project | |
|---|---|
| Title: | Exploring the use of online community forums for shared reflection |
| Start date: | 17 July, 2016 |
| End date: | 30 January, 2019 |
| Within the Personal Health Informatics community, the reflection that takes place for an individual to reach an insight has always been considered strictly an individualistic act - one that involves only the individual and their personal information. However, the results of my first research study indicated that people living with HIV also turn to their *community* to aid in reflection, particularly online. This style of reflection has not yet been explored within PHI, leaving a gap in the community's knowledge on the commonality of shared reflection in online communities and the way in which it occurs. As such, this study is proposed to answer the following two research questions: <br><br> **RQ1: Do individuals use online community forums to reflect on their personal health information?** | |

**RQ2: If shared reflection does occur in online forums, what takes place?**

To address these questions, a research study involving both qualitative and quantitative data will be conducted. This study will analyse threads made on an online public HIV community forum run by POZ (https://www.poz.com). POZ is a public website whose forums are open to everyone, including Google search engines, and do not require registration for access. All users are made aware of this in a privacy warning on each forum page.

A web scraper will be used to collect 25 of the most recent threads in each topic category (ten topic categories in total) on the POZ community forums. The scraper will gather thread titles, the IDs of the users who comment, and the comments made within the threads. These data will be stored in a password-protected folder on the researcher's personal computer.

The scraped data will first be anonymized, with all user names replaced (e.g. "CleverMoniker" would be replaced with "User1") and potentially identifiable data removed (e.g. specific locations, names, etc.). The process of anonymization will be permanent; no copies of non-anonymised data will be kept.

Once anonymised, the data will be analysed using both thematic analysis and descriptive statistics. To answer RQ 1, each thread will be reviewed to determine if it is an example of shared reflection on personal information. Those threads that fit the criteria will then be analysed using thematic analysis to determine the original poster's intentions for posting, information presented, and style of presenting information (to answer RQ 2). All comments in the thread will also be analysed using thematic analysis to determine styles of response and data presentation.

To further protect the users of the POZ community forum, the website will not be named in any publications or presentations.

| Attachments (these must be provided if applicable): | *Delete as appropriate* |
|---|---|
| Participant information sheet(s) | **Not applicable** |
| Consent form(s) | **Not applicable** |
| Questionnaire(s) | **Not applicable** |
| Topic guide(s) for interviews and focus groups | **Not applicable** |
| Permission from external organisations (e.g. for recruitment of participants) | **Not applicable** |

# Appendix 11. Topic Primer for Coder 2

Sometimes a user will have more than one question at the same time, and there can be any combination of question types together.

Some questions are not counted as community-aided reflection. These are questions that a) do not focus on health concerns, b) do not focus on the health concern that they have experienced, or b) do not aim to understand the health concern, but instead how to cure it/fix it

Ex non-CAR: Will I get other side effects?

Sometimes they ask two questions but both questions can be coded as the same one

Sometimes they ask one question and you can't figure out which code it is so I put it in both

CD4: This is one of the immune system counts (typically the one focused on the most), CD4s are the cells that kill the virus.

When it goes up, that's good! There's also a general range that people like to hit. When it goes down (or when it is low) that's bad – that means the virus can take over.

T-Cells: like CD4, but a different name

CD8: This is also something about the immune system. CD8s are typically high in people with HIV, but no one really knows why. Regardless, people with HIV don't want a high CD8. But, the tests that HIV+ people get done ever so often also indicate the ratio of CD4s to CD8s, so that they can see that CD8s are going down while CD4s are going up (= YAY, treatment is working!)  The 'normal' range for the ratio is between 0.9 and 6.0

VL: Viral Load. This is the amount of the virus in the blood. It can be in the millions when they are first diagnosed (DX), but then after they take ARVs (meds!) it can go waaaaaaayyyyy down to being undetectable (UD). The target for being UD changes: it literally means that the amount of a person's virus in their body is lower than what the blood testing system can detect. So that means that being UD used to mean having, say 200VL or lower, but not it is like 90 or lower.

For more details on understanding tests, CD4s, etc., visit: https://www.poz.com/basics/hiv-basics/understanding-lab-work-blood-tests

# Appendix 12. Coding Guidance for Coder 2

**Did that cause this?**

Code when:

- Users indicate health concern and potential causes for it, and asks for input
- User posts some information of concern and links it to a potential cause, and asks if anyone has a similar experience (they are looking to determine if it is a cause based on the experiences of others)

**Include:** Is X or Y a reason for this?  Did anyone else taking X experience Y?

**Exclude:** What caused this? Why did this happen?


**What caused this?**

Code when:

- Users indicate a health concern and do not indicate potential causes for it, asking for input on what may have been the reason

**Include:** Why would this happen? Why was # so high? Why might # have dropped so low?

**Exclude:** If a user indicates a health concern, does not indicate potential causes for it, and asks if anyone else experienced it


**What's going to happen?**

Code when:

- Users want to know what changes will happen *in the future* regarding the health information they are concerned with
- User posts some information of concern and expresses fear or doubt over future, and asks if anyone has similar experience (they are looking to determine their future based on the experiences of others)

**Include:** Will X go away? When will X go away? Will I ever reach UD? I'm nervous about Y, has anyone else experienced this?

**Exclude:** Has anyone found anything that helps X go away? Why is my VL so high at this point?

**Note:** This code is not about evaluating progress to date, but about anticipating the future


**Is this normal progress? / Is this normal at this point in time?**

Code when:

- User is trying to determine if something is at a normal range in relation to when they think they contracted HIV
- User is trying to determine if something is changing at a good rate in relation to the time they have been on antiretrovirals (meds)

**Include:** Shouldn't my viral load be much lower if I was recently infected? Do these CD4s/VLs show a good improvement?

**Exclude:** Why is my VL so high? Why is my CD4 so low? Why hasn't this changed?

**Note:** This code is not about anticipating the future, but evaluating progress to date


**Is this normal, or a cause for concern?**

Code when:

- User indicates health concern and seeks input to determine whether or not they should be worried / whether or not it might be a cause for concern.
- User indicates a health concern and asks if it is normal / if others have experienced (with no indications about progress, potential causes, etc).

**Include:** What do you think, should I be worried?  Is this normal or a bad sign?  I'm worried about X, any thoughts?  Does X mean that Y might have gone in a bad direction?

### Some more subtle differences:

If a user indicates a health concern, links it to a potential cause, and asks if others have similar experiences: *Did this cause that?*

If a user indicates a health concern, expresses fear or doubt over future, and asks if others have similar experiences: *What's going to happen?*

If a user indicates a health concern regarding lab results, shows concern over progress, and asks if others have similar experiences: *Is this normal progress? / Is this normal at this point in time?*

Otherwise:

If a user indicates a health concern, and asks if others have similar experiences: *Is this normal or cause for concern?*

### Also:

If a user posts a question that seeks to determine if something specific was the cause or if something unknown was the cause, code as both *What Caused This and Did That Cause This*

Example: Did x cause this? What else could it be?

# Appendix 13. Ethics Form (Study 3)

**City Research Ethics Committees**

**Application for Approval of Research Involving Human Participants**

Please tick the box for which Committee you are submitting your application to

| | |
|---|---|
| ☐ | Senate Research Ethics Committee |
| ☐ | Cass Business School |
| ☒ | Department of Computer Science |
| ☐ | Department of Sociology |
| ☐ | School of Health Sciences Research Ethics Committee |
| ☐ | Department for Learning Enhancement and Development |

For **Senate** applications: a single copy of the application form and all supporting documents should be emailed to █████████████████████

For **Computer Science** applications: a single copy of the application form and all supporting documents should be emailed to █████████████████

For the Department of Sociology, submit all forms in Word format in a single document electronically. For projects falling under Sociology, Media Studies, Criminology, Food Policy and Q-Step, please send to ██████████████████; and for projects falling under CCI, to █████████████████

For **School of Health Sciences** applications: submit all forms (including the Research Registration form) electronically (in Word format in a single document) to █████████████

For **Department for Learning Enhancement and Development:** a single copy of the application form and all the supporting documentation should be emailed to ██████████████

Refer to the separate guidelines while completing this form.

| **Project Title:** |
|---|
| Exploring reflection on health with visualizations of community input |
| **Short Project Title (no more than 80 characters):** |
| Exploring reflection on health with visualizations of community input |
| **Name of Principal Investigator(s) (if this is a student project, please note that the Principal Investigator is the supervisor and all correspondence will be with the supervisor):** |
| Simone Stumpf, Stephanie Wilson, and Adrian Bussone |
| **Post Held (including staff/student number):** |
| Simone Stumpf: Senior Lecturer #888002590 |
| Stephanie Wilson: Reader #90007082 |
| Adrian Bussone: PhD Student, HCID #130028006 |
| **Department(s)/School(s) involved at City:** |
| Centre for HCID, SMCSE |
| **If this is part of a degree please specify type of degree:** |
| This is for Adrian Bussone's PhD – Year three |
| **Date of Submission of Application:** |
| 11th September, 2017 |

Tick this box if you do not grant City permission to use your application form for training purposes ☒

| **1. Applicant Details** |
|---|

**This project involves:** (*tick as many as apply*)

| | | | |
|---|---|---|---|
| ☐ | Staff Research | ☒ | Doctoral Student |
| ☐ | Undergraduate | ☐ | M-level Project |
| ☐ | Externally funded | ☐ | External investigators |
| ☐ | Other | | |

| Provide details of external investigators and/or other | |
|---|---|

**Contact details for the Principal Investigator** (including email address and telephone number)

| Simone Stumpf, Centre for HCID, City University London, London, GB EC1V 0LT |
|---|
| Email: ███████████████████████████████████ |

**Other staff members involved**

| Title, Name & Staff Number | Post | Dept & School | Phone | Email |
|---|---|---|---|---|
| Stephanie Wilson 90007082 | Reader | HCID, SMCSE | ███████ | ███████████ |

**All students involved in carrying out the investigation**

| Name & Student Number | Course / Year | Dept & School | Email |
|---|---|---|---|
| Adrian Bussone 130028006 | PhD HCI – Year 3 | Centre for HCID, SMCSE | ████████████ |

**External co-investigators**

| Title & Name | Post | Institution | Phone | Email |
|---|---|---|---|---|
| | | | | |

**Please describe the role(s) of all the investigators, including all student(s)/external co-investigator(s) in the project, especially with regards to interaction with study participants.**

| Adrian Bussone will collect and analyse the data, and be responsible for any interactions with participants, including recruitment.<br><br>Simone Stumpf and Stephanie Wilson will assist with the study design and analysis, including publications, but will not interact with participants directly nor view any non-anonymised data. |
|---|

**If external investigators are involved, please provide details of their indemnity cover.**

| N/A |
|---|

---

**Application Details**

**1.1 Is this application or any part of this research project being submitted to another ethics committee, or has it previously been submitted to an ethics committee?** *This includes an NHS local Research Ethics Committee or a City local Research Ethics Committee or any other institutional committee or collaborating partners or research site.* (See the guidelines for more information on research involving NHS patients.)  **YES ☐ NO ☒**

**If yes, please give details and justification for going to separate committees, details of the Secretary of the relevant authority/committee, and, if appropriate, attach correspondence and details of the outcome of the application, including any conditions of approval or reasons for rejection.**

| |
|---|

**1.2 If any part of the investigation is being carried out under the auspices of an outside organisation, involves collaboration between institutions or individual external researchers, or institutions/organisations where interviews/fieldwork will take place please give details and address of organisation(s).**

| |
|---|

**1.3 Has permission to conduct research in, at or through another institution or organisation been obtained?**                                  **YES ☐ NO ☒**

If yes, please provide details and attach the supporting correspondence.

| |
|---|

**1.4 Duration of Project**

Start date: 28 September 2017                    Estimated end date: 30 January 2019

**Funding Details**

**1.5 Is the project reliant on funding?** If no, please go to the next section.        **YES ☐ NO ☒**

**If yes, please provide details of the source of financial support (e.g. funding body, charity etc.) for the proposed investigation.**

| 1.5a Has funding been applied for? | YES ☐ NO ☐ |
|---|---|
| 1.5b Has funding been approved? | YES ☐ NO ☐ |

**If no, please provide details of when the outcome can be expected**

<br>

| **International Research** |
|---|

**1.6 Is any part of the research taking place outside of England/Wales? (if no go to section 2)**

<div align="center">YES ☐ NO ☒</div>

**If yes, please provide details of where.**

> Not applicable, but for clarity:
>
> With the exception of participants who choose to meet in person (if local to London), this research study will be conducted via the internet (online questionnaires and interviews) over a virtual connection for remote participation.
>
> There will be no overseas travel or travel outside of England for the study, but overseas individuals who meet the criteria can participate remotely.

**1.7 Have you identified and complied with all local requirements concerning ethical approval & research governance*?** YES ☐ NO ☐

**1.7a Please provide details of the local requirements, including contact information.**

**1.7b Please give contact details of a local person identified to field initial complaints locally so the participants can complain without having to write to or telephone the UK.**

*Please note that many countries require local ethical approval or registration of research projects, further some require specific research visas. If you do not abide by the local rules of the host country, you will invalidate your ethical approval from City, and may run the risk of legal action within the host country.

| **2. Project Details** |
|---|

**2.1 Provide the background (including the current state of the art in this field), aim(s) and objectives of the proposed research,**

> The results of the first and second research study conducted as part of this PhD provided evidence of people living with HIV who turn to their community for help in understanding changes in their health. This activity is frequently observed in online-forums: individuals living with the same chronic condition share details about their health and experiences in order to help others reflect on changes in their own health. This study aims to explore how a more visual format designed to support this activity will affect reflection.
>
> The research study, which is focused on people living with HIV, will answer two questions:
>
> RQ1. Which features of such a tool will be used at the different stages of the reflection process?
>
> RQ2. What level of sensemaking will an HIV+ person achieve when using such a tool to reflect on personal health information?
>
> This is a proposal for a user study, and in this proposal the target users are people living with HIV (PLWH). Thanks to the advent of anti-retroviral therapy (ART), people living with HIV are no longer facing a *terminal* disease. Instead, if carefully managed with ART medication, PLWH are now able to live with a *chronic* disease and enjoy a normal life expectancy, much like others living with chronic illnesses such as diabetes and hypertension (Swendeman, Ingram, & Rotheram-Borus, 2009). Despite this transfer from terminal to chronic disease, both academia and industry have failed to make progress on developing tools to support PLWH in understanding their health. HIV and the medication can cause changes in the bodies and minds of those infected, and these changes can be confusing. As such, PLWH frequently turn to online forums to share their health information with the community as a means of trying to understand what has occurred. In response, members of the community share their own health information and experiences, and these details help individuals reflect on their health and make sense of the changes. However, online forums are not designed with the intention of supporting this activity.
>
> For these reasons, focusing this research study on PLWH is ideal and important as it takes a first step towards exploring means of supporting a real-world need and, as such, towards providing a real-world impact.

**2.2 Please explain how this project will further existing knowledge.**

Currently, online forums are the only digital format for communities to share their health experiences. The results of this research can be used to advance the design of online forums, or develop new technology to support the sharing of information online. The project will also contribute the novel designs of two visualization tools with features for supporting reflection.

## 2.3 Provide a summary and brief explanation of the design, methodology and plan for analysis that you propose to use.

**Overview:** In order to answer the research questions, recruited individuals will be observed viewing two visual prototypes and reflecting on their health experiences. The prototypes are visual simulations of the exchange of health information and experiences in a community. Each prototype will contain the health information provided by the participant, and simulated health information and comments from fictional characters. The collected data will be analysed to address the two research questions.

**Recruitment and Consent:** We are seeking to recruit a minimum of ten participants (maximum of sixteen) who fit the target population (HIV+ adults who have wondered about the cause of a change in their health in the last six months). A recruitment ad (Attachment 4) will be used to recruit self-selecting participants. Once a potential participant has contacted Adrian Bussone they will be sent the study information sheet (Attachment 5) and consent form (Attachment 6) via email to read, review, and respond with any questions they might have. After consent has been gained, an initial meeting (pre-session) will be set up and the participant will be sent a link to the online pre-interview questionnaire (Attachment 7) to complete before the Pre-Session meeting. The purpose of the pre-interview questionnaire is to gather their demographic details and details about their health (what change they noticed, what they wondered, their lab results and medication prescribed). These health details will be used by Adrian Bussone to personalise the visual prototypes such that they show the participant's health information.

**Pre-Session:** The point of the Pre-Session is to ensure the participants understand the study, what to expect, and to review the information provided in the completed pre-interview questionnaire. The pre-session will be held over Skype, Google Hangouts, or similar audio connection - not in person. During this time, the researcher will discuss the point of the study, what will occur, and again answer any questions the participant might have. The researcher will then ask the participant to ensure their internet connection is suitable for screen-sharing by briefly switching to camera-mode over Skype or Google Hangouts. In the interest of professionalism and appreciation of the participant's time, if the internet connection is deemed to be less than adequate for the needs of the study, the individual will be thanked for their time and their participation in the study will end.

Once it has been determined that their connection is strong enough for the one-on-one session, the researcher will review the completed pre-interview questionnaire with the participant in order to make sure the information is complete and suitable for creating the personalized prototypes. If additional information is gathered during this time, the researcher will add it to the spreadsheet containing the questionnaire responses. The researcher will remind the participant that the visualizations that will be reviewed in the one-on-one session will contain fictional characters simulating community members responding to their information.

**Preparatory Work:** The preparatory work will take place between the Pre-Session and the One-on-one Session and will not involve the participant. During this time, the researcher will use the health information provided by the participant to personalize the visual prototypes to show the participant's information, question about their health, and fictional responses from three characters. These three characters will "share" similar health information to the participant, and will "provide comments" in response to the participant's question. These comments, as shown in the attached examples, will only consist of sharing their own experience or suggesting the participant talk to their doctor. There will be no other suggestions or medical information provided.

**One-on-one Session:** The one-on-one session will be held remotely using a screen-sharing tool such as Skype or Google Hangouts, or in person in a private location (such as City University) if the participant chooses. This session will last approximately 45 minutes and will be audio and screen recorded using Camtasia. A discussion guide (Attachment 8) will be used by the researcher during the session, to keep the session on track and guide the participant.

In the first few minutes of the one-on-one session (part 1 in the discussion guide), participants will be thanked for their participation, reminded of the purpose of the study and of what will occur. To prevent the researcher from accidentally capturing any sensitive information / data on the participant's computer, participants will be asked to close all other windows, browser tabs and other documents before recording begins. They will also be asked to confirm that their Desktop does not contain any information that they are unwilling to be part of the recording. Participants will also be reminded that the responses they see in the prototypes are not from real individuals, but representative profiles.

Once the participant has been reminded of the study purposes and procedure, the data collection will begin (part 2 in discussion guide). The researcher will share her screen view with the participant to show the visual prototypes. Because this is a within-subject study, the order in which the visual prototypes are seen will be alternated with each participant. The participant will first be shown a view

of the prototype showing only their health information (Attachment 2A or 3A), as a means of familiarizing them with the visualization. They will be asked to talk through what they see, referencing the different features, and tell the researcher when they feel they are comfortable with the visualization style and ready to move on.

Then, the participant will be shown a second view of the prototype (Attachment 2B or 3B), this one containing the simulated responses. They will be asked to use what they see to reflect on their health and find an answer to their question. They will be asked to refer to what they see in on the screen while they think out loud, and to use the mouse to indicate what they are looking at. The researcher will occasionally prompt the participant in order to determine what they are thinking, looking at, or where they are in the sensemaking process. This will end once the participant declares they are finished, or that they feel they have found an answer to their question. The participant will then be asked to complete the online sensemaking questionnaire for the prototype they just saw (Attachment 9).

The above process, from presenting the first view of a prototype to completion of the sensemaking questionnaire, will be repeated for the second prototype. Participants will be asked to focus on the prototype they see, not comparing it to the first version. Again, this will last until the individual feels they are finished or have found an answer to their question.

Once both prototypes are reviewed and reflection questionnaires completed, the researcher will ask some final questions about what they have seen (part 4 in discussion guide) – if it surprised them, what was helpful, what they would change, etc. Participants will be given an opportunity to provide feedback and ask the researcher questions as well. Finally, the participant will be thanked for their time, the session and recording will end, and the incentive will be sent via PayPal as thanks.

**Analysis:** There are two research questions, and the plan for analysing the data to answer both are below:

RQ1. Which features of such a tool will be used at the different stages of the reflection process?

The recordings from the one-on-one sessions will be transcribed to show the participant's comments as they reflect and the features of the prototype they were looking at while reflecting (using the mouse movements and comments). These transcripts will be reviewed and thematically analysed using codes defining different stages in the process of reflection / sensemaking (Pirolli and Card, 2005) and codes defining the different features. Combining these will allow us to see which features are referred to at the different stages of reflecting. The responses to the open-ended questions will also be used to explain the results.

RQ2. What level of sensemaking will an HIV+ person achieve when using such a tool to reflect on personal health information?

The results from the sensemaking questionnaires will be entered into a spreadsheet and analysed according to the method described by the authors who developed the validated questionnaire (Kholod et al., 2017): determining the level of sensemaking achieved based on the sum of the responses to the visual analogue scale.

**2.4 Please explain how/if participants will be provided with the findings or outcomes of the project.**

All participants will be provided with the option of receiving a summary of the results of the research. This information is included in the Information Sheet, where participants are told that they can contact the researcher if they are interested in receiving the results.

**2.5 What do you consider are the ethical issues associated with conducting this research and how do you propose to address them?**

**1. Confidentiality**

The target demographic for this research is people living with HIV. Because of the stigma associated with this disease, and because the individuals may not have made their diagnosis public, confidentiality is of the utmost importance. Communication methods are one of the major considerations for maintaining ethics and confidentiality, and this pertains to both recruitment and the study itself.

**Regarding recruitment:** Directly contacting any individuals to request their participation will not be done. Instead, it is up to each individual to initiate contact if they are interested. The phone number provided on the recruitment flyer is a dedicated research phone that is only used by Adrian Bussone, and kept in a locked drawer. Interested individuals responding to the recruitment flyer are invited to email Adrian's university email, text this number, or send a WhatsApp to this number. WhatsApp was chosen as it is a free, universally available, and end-to-end encrypted text messaging service.

**Following recruitment:**

All contact with participants will be one-to-one, there will be no use of mailing lists or group messages when contacting participants. All communications will be conducted through City University London's provided methods, the private dedicated research phone connections, or private connections on Skype or Google Hangouts.

2. Sensitive topics

Whilst this research does not focus on some of the more sensitive topics related to HIV, some participants may find it uncomfortable to talk about their disease in general.

To address this:

- All participants will be told and reminded that their participation is optional
- All participants will be told and reminded that they are not required to answer any questions which make them feel uncomfortable or provide any information that makes them uncomfortable
- All participants will be told that they can stop participation at any time
- All participants will be told and reminded that they are not expected to disclose sensitive information
- Participants will be told and reminded that they should not include any identifying information in the pre-interview questionnaire (e.g. their name)

3. Health and Wellbeing

In order to ensure that the information reviewed in the study is not taken as medical advice there will be several repeated reminders in place. These reminders will ensure that participants understand that the comments and responses from the other profiles are fictitious and should not be taken as medical advice, and that they should speak with a medical professional about any concerns they have with their health.

**2.6 How is the research intended to benefit the participants, third parties and/or the local community? Please consider both direct and long term benefits.**

There are no direct benefits to those who participate in the research. It is possible that participants may feel a greater sense of self-confidence or importance as part of taking part in a study that could lead to the development or shaping of new technology. Also, there may be longer term benefits that result from the implementation of new designs developed from the results of the research.

**2.7 Will invasive procedures (for example medical or surgical) be used?**
**YES ☐ NO ☒**

**2.7a If yes, what precautions will you take to minimise any potential harm?**

**2.8 Will intrusive procedures (for example psychological or social) be used?**
**YES ☐ NO ☒**

**2.8a If yes, what precautions will you take to minimise any potential harm?**

**2.9 In the course of the investigation might pain, discomfort (including psychological discomfort), inconvenience or danger be caused?**      **YES ☐ NO ☒**

**2.9a If yes, what precautions will you take to minimise any potential harm?**

## 3. Information about Participants

**3.1 How many participants will be involved?**

This study will require a minimum of 10 participants and a maximum of 16.

**3.1a What is the age group and gender of the participants?**

This research is not focused on recruiting a representative sample due to the likely difficulty in recruitment. Participants will not be selected based on age or gender, as these are not factors under investigation in this research, although all participants will be aged 18 or older. However, it is likely that we will recruit a greater number of males who have sex with men than heterosexual males or females, which is in line with the profile of people living with HIV.

**3.1b Explain how the sample size has been determined. If statistical sampling is relevant to this application, please include details of how the sample size was calculated.**

This is a qualitative research study with convenience sampling. As such, high numbers of participants are not required and statistical sampling size is not relevant.

**3.1c Please specify inclusion and exclusion criteria. If exclusion of participants is made on the basis of age, gender, ethnicity, race, disability, sexuality, religion or any other factor, please justify this.**

Interested individuals will need to meet a set of specific criteria in order to be recruited to the research study. Participants must be capable of consenting to the study, meaning that those who are under the

age of 18 will not be able to participate. They must also be HIV positive, although proof of status will not be required. They must have wondered about what caused a change in their health in the last 6 months, and be willing to share their health information with the researcher for the purpose of the study. Finally, they must be willing to use a computer with a strong internet connection to view the visual prototypes, and (if meeting remotely) to meet the researcher for the study sessions.

**3.2 How are the participants to be identified, approached and recruited, and by whom?**

Recruitment advertisements (Attachment 4) will be sent out through social media (Twitter, Facebook, Gumtree, Craigslist). Those HIV-specific forums (e.g. POZ, Reddit, and Google Hangout groups) who accept postings for research recruitment will be contacted. Sexual health and HIV clinics will also be asked to send the recruitment details on as well, or post the flyer in their buildings.

This will require self-selected recruitment. No individuals will be contacted to request participation – instead, interested individuals will approach the main researcher, Bussone, and express their interest in participation. Bussone will respond directly to these interested individuals with the study information sheet (Attachment 5) and consent form (Attachment 6) to complete recruitment.

**3.3 Describe the procedure that will be used when seeking and obtaining consent, including when consent will be obtained. Include details of (a) who will obtain the consent, (b) how you are intending to arrange for a copy of the signed consent form to be given to the participants, (c) when they will receive the participant information sheet, and (d) how long the participants have between receiving information about the study and giving consent.**

Once interested individuals have contacted the main researcher, Bussone, they will be asked to provide an email address which they are comfortable with receiving the details of the study. Bussone will then mail the study information sheet (Attachment 5) and Consent form (Attachment 6) for them to review. They will be invited to respond with any questions or concerns before signing and returning the consent form. Once the completed consent form has been received, Bussone will sign and return a copy for the participant to complete. Participants will have at least 24 hours between receiving the information materials and signing the consent form.

To ensure that participants fully understand the study and their participation, the information materials will be reviewed verbally during the start of the Pre-Session.

**3.4 How will the participant's physical and mental suitability for participation be assessed? Are there any issues related to the ability of participants to give informed consent themselves or are you relying on gatekeepers on their behalf?**

People living with HIV are, overall, largely healthy individuals with fluctuations in their health similar to those that non-HIV+ experience throughout their lives. It is unlikely that any interested individuals have a diminished capacity to give informed consent. Because this study is available to be done remotely, physical impairments will not prevent participation. Interested individuals will be provided with the study information materials and allowed to judge whether they want to be involved in the project themselves.

**3.5 Are there any special pressures that may make it difficult for participants to refuse to take part in the study? Are any of the potential participants in a dependent relationship with any of the investigators (for instance student, colleague or employee) particularly those involved in recruiting for or conducting the project?**

There are no dependent relationships with the research team and no pressures for involvement. Participants will be reminded that their decision to take part will not affect them in any way, including the care that they receive.

**3.6 Will the participant's doctor be notified?**                     **YES ☐ NO ☒**

(If so, provide a sample letter to the subject's GP.)

**3.7 What procedures are in place for the appropriate referral of a study participant who discloses an emotional, psychological, health, education or other issue during the course of the research or is identified by the researcher to have such a need?**

All participants will be recommended, and reminded, to seek medical advice regarding any questions or concerns they have about their health.

Any participant disclosing or displaying a more serious need will be provided with the contact details of health clinics, emotional support numbers, or educational materials local to them. No contact with support groups or professionals will be made on behalf of the participant. Additionally, all participants (whether showing signs of such issues or not) will be reminded to seek out support in the future, if their status changes.

**3.8 Is there any risk (emotional, psychological, health or other issues) to the researcher(s)?**

Risks are minimal.  It is unlikely, but participants may disclose distressing information to the researchers, e.g. about the events leading to their infection or their time spent dealing with their diagnosis. The researcher will have regular meetings with the rest of the research team where any distressing issues can be discussed.

All remote sessions over Skype or Hangouts will be held in private locations with the researcher in a private room in the University. In-person interviews will be held in a private room in the University (e.g. Interaction Lab).

**3.9 What steps will be taken to safeguard the participants from over-research (i.e. to ensure that the participants are not being used in multiple research projects including those of other researchers)? Please consider all research projects whatever their field, not just those performed by you.**

Participants are self-selecting and given the choice to participate, and thus are free to decline to participate if they have taken part in numerous research projects recently.

**3.10 Where will the research take place?**

Remote sessions:

All remote sessions will take place over Skype or Google Hangouts, with the researcher in a private room at City, University of London. Participants will be asked to find a similarly suitable private place to speak.

In person sessions:

All in-person sessions will be conducted in a private location on the premises of City, University of London.

**3.11 What health and safety issues, if any, are there to consider?**

We have identified no foreseeable health and safety issues.

**3.12 How have you addressed the health and safety concerns of the participants, researchers and any other people impacted by this study? (This includes research involving going into participants' homes.)**

As stated in 3.10, the research will take place in safe and private locations. No sessions will be conducted in the homes of participants or the researcher.

**3.13 It is a requirement that at least an initial assessment of risk be undertaken for all research and if necessary a more detailed risk assessment be carried out. Has a risk assessment been undertaken?\*** YES ☒ NO ☐

Please contact the Health & Safety Office (safetyoffice@city.ac.uk) for advice on risk assessments and/or how to complete it.

**3.14 Are you offering any incentives or rewards for participating? YES ☒ NO ☐**

**If yes please give details**

As a token of appreciation for involvement and compensation for their time, all participants will receive an incentive of £15 (or equivalent in their local currency) via PayPal following the completion of the study. Additionally, all in-person meetings will include baked goods, coffee, tea, and water.

**3.15 Does the research involve any of the following:**

| | |
|---|---|
| Children under the age of 5 years | YES ☐ NO ☒ |
| Clinical trials / intervention testing? | YES ☐ NO ☒ |
| Over 500 participants? | YES ☐ NO ☒ |
| **Are you specifically recruiting pregnant women** | YES ☐ NO ☒ |
| Excluding information collected via questionnaires (either paper based or online), is any part of the research taking place outside of the UK? | YES ☐ NO ☒ |

If you have answered 'yes' to any of the above questions you will need to check that the City's insurance will cover your research. You should do this by submitting this application to insurance@city.ac.uk before applying for ethics approval.

\*Note that it is the Committee's prerogative to ask to view risk assessments.

| 4. Vulnerable Groups |
|---|

**4.1 Will persons from any of the following groups be participating in the study? (If not go to section 5.)**

| | |
|---|---|
| Adults without capacity to consent | ☐ |
| Children under the age of 18 | ☐ |
| **Those with learning disabilities** | ☐ |
| Prisoners | ☐ |
| Vulnerable adults | ☒ |

| Young offenders (16-21 years) | ☐ |
|---|---|
| Those who would be considered to have a particular dependent relationship with the investigator (e.g. those in care homes, students, employees, colleagues) | ☐ |

**4.2 Will you be recruiting or have direct contact with any children under the age of 18?**

**YES ☐ NO ☒**

**4.2a If yes, please give details of the child protection procedures you propose to adopt should there be any evidence of or suspicion of harm (physical, emotional or sexual) to a young person. Include a referral protocol identifying what to do and who should be contacted.**

| N/A |
|---|

**4.2b Please give details of how you propose to ensure the well-being of the young person, particularly with respect to ensuring that they do not feel pressured to take part in the research and that they are free to withdraw from the study without any prejudice to themselves at any time.**

| N/A |
|---|

**4.3 Will you be recruiting or have direct contact with vulnerable adults? YES ☒ NO ☐**

**4.3a If yes, please give details of the protection procedures you propose to adopt should there be any evidence of or suspicion of harm (physical, emotional or sexual) to a vulnerable adult. Include a referral protocol, identifying what to do and who should be contacted.**

People living with HIV might be classified as 'vulnerable' because of their medical status, but are typically as physically and mentally fit as those not living with the disease. For this reason, we do not believe that a DBS check is required.

However, it is possible that study participants will show signs of such issues as emotional, psychological, health, education, etc. As a safeguard for such instances, the researcher will gather a collection of resources that are able to support various issues. In the event that such an instance might occur, the researcher will encourage the participant to contact the appropriate resource or seek out another option. No contact with support groups or professionals will be made on behalf of the participant. Additionally, all participants (whether showing signs of such issues or not) will be reminded to seek out support in the future, if their status changes.

**4.3b Please give details of how you propose to ensure the well-being of vulnerable adults, particularly with respect to ensuring that they do not feel pressured to take part in the research and that they are free to withdraw from the study without any prejudice to themselves at anytime. You should indicate how you intend to ascertain that person's views and wishes.**

We will make it clear, at several points throughout the study, that participation is completely voluntary and that they will not be penalized in any way for choosing to not participate or withdraw. It is also made clear that they do not need to provide any reasons for withdrawing or not taking part. This study is independent of sexual health and HIV organizations, and their decisions will in no way impact their ability to receive support from the organization, or the quality of support they receive. The target population may include vulnerable individuals, but we will not be recruiting any individuals who are not competently able to give consent. Additionally, we stress that participants are not obligated in any way to discuss sensitive or uncomfortable topics.

**4.3c Please give details of any City staff or students who will have contact with vulnerable adults and/or will have contact with young people (under the age of 18) and details of current (within the last 3 years) City Disclosure and Barring check.**

| Name | Dept & School | Student/Staff Number | Date of DBS | Type of disclosure |
|---|---|---|---|---|
| Adrian Bussone | Centre for HCID, SMCSE | 130028006 | N/A | N/A |

**4.3d Please give details of any non-City staff or students who will have contact with vulnerable adults and/or will have contact with young people (under the age of 18) and details of current (within the last 3 years) Disclosure and Barring check.**

| Name | Institution | Address of organisation that requested the disclosure | Date of DBS | Type of disclosure |
|---|---|---|---|---|
|  |  |  |  |  |

**4.4 Will you be recruiting any participants who fall under the Mental Capacity Act 2005?**

**YES ☐ NO ☒**

**If so you MUST get approval from an HRA approved committee** (see separate guidelines for more information).

**5. Data Collection**

**5.1 Please indicate which of the following you will be using to collect your data**

*Please tick all that apply*

| | |
|---|---|
| Questionnaire | ☒ |
| Interviews | ☒ |
| Participant observation | ☒ |
| Focus groups | ☐ |
| Audio/digital-recording interviewees or events | ☒ |
| Video recording | ☒ |
| Physiological measurements | ☐ |
| Digital/computer data | ☒ |
| Other | ☐ |
| **Please give details if you have ticked other** | |

**5.1b What steps, if any, will be taken to safeguard the confidentiality of the participants (including companies)?**

First, as mentioned in the recruitment discussion, there will be no contact to individuals directly requesting their participation.

Only on-to-one contact will be made when sending information to participants - there will be no mailing lists or group emails/texts.

All communications will be conducted through City University London's provided methods or a private telephone connection, Skype, or Google Hangouts.

Also, all signed consent forms will be kept in a locked filing cabinet, preventing others from seeing the names that are on the forms. All individuals who are successfully recruited into the study will be assigned a unique identification number. The link between the individual's name and their unique identification number will be contained on only one piece of paper, which will be kept in a locked drawer in an area separate from the signed consent forms. All audio and video data will be stored in a locked folder on my personal computer until it is transcribed in full. Once it has been transcribed, the raw files will be moved to a locked folder on an external hard drive. Finally, all transcripts will be examined for identifiable data. If found, the identifiable data will be permanently removed. Examples of what is considered 'identifiable data' follow:

- Names of participants, friends, family, acquaintances
- Names of workplace or locations frequently visited

**If you are using interviews or focus groups, please attach a topic guide. If you are using questionnaire, please attach the questionnaire.**

**6. Confidentiality and Data Handling**

**6.1 Will the research involve:**

| | |
|---|---|
| • **complete anonymity of participants** (i.e. researchers will not meet, or know the identity of participants, as participants are a part of a random sample and are required to return responses with no form of personal identification)**?** | ☐ |
| • **anonymised sample or data** (i.e. an *irreversible* process whereby identifiers are removed from data and replaced by a code, with no record retained of how the code relates to the identifiers. It is then impossible to identify the individual to whom the sample of information relates)**?** | ☐ |
| • **de-identified samples or data** (i.e. a *reversible* process whereby identifiers are replaced by a code, to which the researcher retains the key, in a secure location)? | ☒ |
| • **subjects being referred to by pseudonym in any publication arising from the research?** | ☐ |

| • **any other method of protecting the privacy of participants?** (e.g. use of direct quotes with specific permission only; use of real name with specific, written permission only) | ☐ |
|---|---|
| **Please give details of 'any other method of protecting the privacy of participants' is used** | |
| | |

**6.1a Which of the following methods of assuring confidentiality of data will be implemented?**

*Please tick all the options that apply*

| • data to be kept in a locked filing cabinet | ☐ |
|---|---|
| • data and identifiers to be kept in separate, locked filing cabinets | ☒ |
| • access to computer files to be available by password only | ☒ |
| • storage at City | ☒ |
| • stored on an encrypted device (e.g. laptop, hard drive, USB) | ☒ |
| • stored at other site | ☐ |
| **If stored at another site, please give details.** | |

**6.1b Will the data be accessed by people other than the named researcher?**     YES ☐  NO ☒

*If yes, please explain by whom and for what purpose.*

The raw data will only be accessed by the main researcher, Adrian Bussone. The rest of the research team (Stumpf and Wilson) will have access to the anonymised data when in the presence of Bussone. Access by people other than the named researchers will not be allowed.

**6.2 Is the data intended for reuse or to be shared as part of longitudinal research, or a different/wider research project now, or in the future?**     YES ☐ NO ☒

**If yes, please provide details.**

| |
|---|

**6.2a If the project is funded, does the funding body (e.g. ESRC) require that the data be stored and made available for reuse/sharing?**     YES ☐ NO ☒

**6.2b If you have responded yes to any of the questions above, explain how you are intending to obtain explicit consent for the reuse and/or sharing of the data.**

| |
|---|

---

**6.3 Retention and Destruction of Data**

**6.3a Does the funding body or your professional organisation/affiliation place obligations or recommendations on the retention and destruction of research data?**     YES ☒ NO

*If yes, what are your affiliations/funding and what are the requirements? (If no, please specify City guidelines on retention.)*

City requires that we retain the data for 10 years, which we will comply with.

**6.3b How long are you intending to keep the data?**

*Note that the institutional guidelines on retention state a minimum of 10 years.*

As per the University's guidelines, all data will be retained for ten years.

**6.3c How are you intending to destroy the data after this period?**

*Please find guidance here.*

At the end of the ten years, all electronic data will be permanently deleted and all paper data will be shredded and disposed of.

---

**7. Curriculum Vitae**

CV OF APPLICANTS (**Please duplicate this page for each applicant, including external persons and students involved.**)

| NAME: | Adrian Bussone |
|---|---|
| Title of Post: | PhD Researcher at City |
| Department: | Centre for HCID |

| Is your post funded for the duration of this proposal? | Yes |
|---|---|
| Funding source (if not City) | City, University of London |
| Please give a summary of your training/experience that is relevant to this research project | |

Training:

Completed Research Methods and Professional Issues module, with distinction, as part of MSc in Human Centred Systems at City University London

Completed Human Subject Research training course through the NIH, in the United States of America as part of job-related work

Experience:

Previous research involving human participants at City University London as part of MSc dissertation

Over 500 hours facilitating and conducting IRB-approved research involving human participants and the use of medical systems

Previous work researching HIV+ communities, including interviews with HIV+ adults

| NAME: | Simone Stumpf |
|---|---|
| Title of Post: | Senior Lecturer |
| Department: | CS |
| Is your post funded for the duration of this proposal? | Yes |
| Funding source (if not City University London) | |
| Please give a summary of your training/experience that is relevant to this research project | |

Dr Stumpf received a PhD in Computer Science in 2001 and a BSc in Computer Science with Cognitive Science in 1996, both from University College London. She worked at Oregon State University as a Research Manager (where she received IRB Ethics training) and University College London as a Research Fellow where she conducted numerous user studies, including a large-scale user acceptance study at a German airport. Dr. Stumpf also has industrial experience as a User Experience Architect and supervises the City Interaction Lab. Dr Stumpf is the Deputy Chair of the CSREC.

| NAME: | Stephanie Wilson |
|---|---|
| Title of Post: | Reader |
| Department: | Computer Science |
| Is your post funded for the duration of this proposal? | Yes |
| Funding source (if not City) | |
| Please give a summary of your training/experience that is relevant to this research project | |

I have a background in Computer Science and have worked in the area of HCI and usability for over 20 years. For the last 6 years, I have worked as PI and CI on a series of projects investigating technology for people with aphasia. These have included the EPSRC-funded GReAT project that developed a gesture therapy tool for people with aphasia and the Stroke Association-funded EVA Park project that developed a virtual world for people with aphasia. Both of these projects involved activities similar to the ones planned in this application.

**8.1 Supervisor's statement on the student's skills and ability to carry out the proposed research, as well as the merits of the research topic (up to 500 words)**

Adrian Bussone's work is advancing our understanding of how to support self-understanding of health through community involvement, which has the potential to empower people in the management of chronic diseases.

She is in her third year of her PhD, and she has extensive knowledge of working with users from her previous studies, previous employment, her MSc in Human-Centred Systems and as part of her research assistant position at City University London working on the EU-funded EMBalance project. As part of this work she has also gained experience of the special circumstances that working in the healthcare area place on conducting studies with individuals.

**I confirm that I have discussed the project with the student to my satisfaction.**

| Supervisor's Signature |  |
|---|---|
| **Print Name** | Simone Stumpf |

## 8. Additional documents

You are expected to provide copies of relevant documents including all letters to be sent to participants and other individuals (such as GPs) and organisations involved in the research. Please follow the guidelines and templates which can be found at http://www.city.ac.uk/research/research-and-enterprise/research-ethics
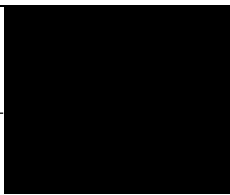
| **Document Checklist** | | |
|---|---|---|
| **Please place an 'X' in all appropriate spaces for all documents you are submitting** | | |
| | **Attached** | **Not applicable** |
| Copy of study advertisement | **X** | |
| Participant information sheet | X | |
| Participant consent form | **X** | |
| Questionnaire(s) | **X** | |
| Topic guide(s) | **X** | |
| Confirmation letter from external organisations | | **X** |
| Confirmation that insurance is in place | | **X** |
| Product information | | **X** |
| GP Letter | | **X** |
| Other (please provide details): *Examples of the prototypes to be used in the study and Flowchart of study procedure* | **X** | |

## 9. Additional Information

| |
|---|
| |

## 10. Declarations by Investigator(s)

- I certify that to the best of my knowledge the information given above, together with any accompanying information, is complete and correct.

- I have read City's guidelines on human research ethics, and accept the responsibility for the conduct of the procedures set out in the attached application.

- I have attempted to identify all risks related to the research that may arise in conducting the project.

- I understand that **no** research work involving human participants or data can commence until **full** ethical approval has been given

| | Print Name | Signature |
|---|---|---|
| **Principal Investigator(s)** (student and supervisor if student project) | Simone Stumpf | |
| | Adrian Bussone | |
| **Associate Dean for Research (or equivalent) or authorised signatory** | | |
| **Date** | 11th September, 2017 | |

**Appendix 14. Recruitment Advertisement**

## Interested in technology that helps people understand their health with the help of their community?

If you are over 18, HIV+ and have wondered what has caused a change in your health in the last six months, consider taking part in an easy research project!
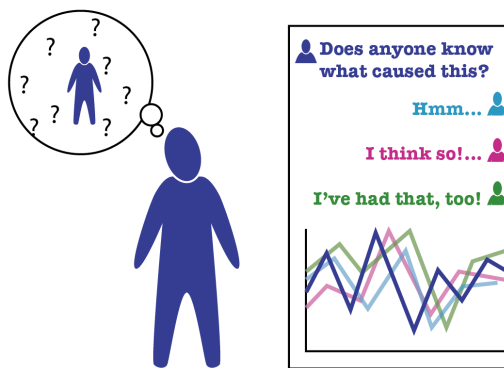
The study is focused on technology that helps people understand their health with the help of others. Your participation will help lead to developing this technology!

To participate, you'd be asked to share details about your health with the researcher who will use them to create personalised visualizations with simulated responses from the community. Then, you'll be asked to discuss the visualizations with the researcher, talking about how they help - or hinder - making sense of your health.

This study can be done over Skype or Google Hangouts - You can do this study in person (if in London) or from the comfort of your couch! *Your participation will be anonymous, community responses are simulated - no information will actually be shared with others.*

**As thanks for participation, you'll receive £15 via PayPal!**
**(or equivalent in your local currency)**

**Interested? Want to learn more?**
Email, Text, or WhatsApp!
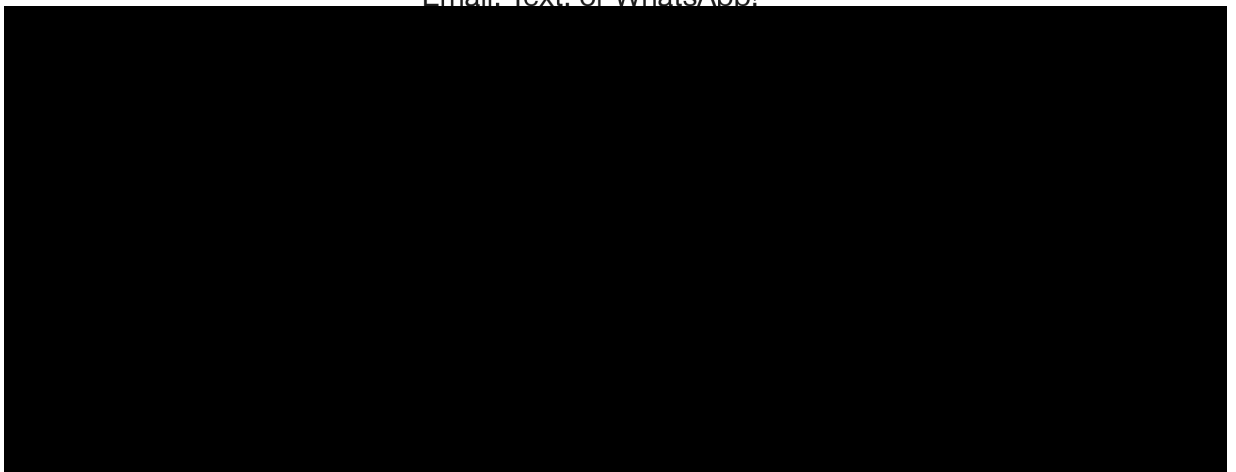
# Appendix 15. Study information sheet



**Responsible Institution: City, University of London**

**Title of Study: Exploring reflection on health with visualizations of community input**

We would like to invite you to take part in a research study. You are invited to participate in this study because you recently, or currently, had a question about what caused a change in your health.

Before you decide whether you would like to take part, it is important that you understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully and discuss it with others if you wish. Feel free to ask if there is anything that is not clear of if you would like more information.

### What is the purpose of the study?

This research is part of Adrian Bussone's PhD thesis, focused on helping people living with HIV understand their health. When facing confusion over what caused a change in health, people often turn to online forums where they share details of their health and, in turn, receive the experiences of others in their community. This activity helps people understand their own health.

The purpose of this study is to explore how this activity might take place when using a more visual format. We want to understand how different visual formats support people in self-understanding. The visualizations will include the health information you provided, as well as simulated responses from the community.

### Why have I been invited?

You have been invited to participate in this study because you expressed interest in participating and because you meet all of the inclusion criteria:

- You are an adult (18+) living with HIV
- You have a question about what has caused a change in your health in the last 6 months
- You are willing to share details about your health to be used for creating personalized visualizations (including lab results and your medication)
- You are willing to meet in-person or over a strong internet connection to view the visualizations

A minimum of ten other individuals similar to you will be recruited for participation in this study.

### Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be asked to sign a consent form. You will be free to withdraw at any time and without giving a reason. You will not be penalized in any way for not taking part or withdrawing.

### What will happen if I take part? What do I have to do?

If you choose to take part in this study, you will be asked to meet with the researcher twice: once for a brief phone conversation (or Skype, etc), and once over Skype or Google Hangouts for approximately 45 minutes. If you are located near London, you may choose to have this second meeting in person.

You will be asked to fill out a short online questionnaire before your first meeting. The purpose of this questionnaire is to gather detail about who you are (your ethnicity, gender, etc), and details about your health which will be used to personalize the visualizations. The questionnaire will be sent to you via a link, and you

will be asked to complete it within 3 days. The answers you provide in the questionnaire will be reviewed during the first meeting with the researcher, which will last approximately 10 minutes, and will take place less than two days after your questionnaire has been completed. If you are not located near London, you will also be asked to conduct a brief test to ensure that your internet connection is suitable for the test.

The second meeting will take place a few days later, after the researcher has personalized the visualizations according to the health details you provided and the question you have about what caused a change in your health. During this time, the researcher will ask you to think out loud as you explore each visualization and reflect on the change in your health. You will also be asked to complete two brief online questionnaires during this time.

A screen recorder and audio recorder will be used for later analysis. The screen recorder will be used to capture what you are looking at on the screen, while the audio recorder will capture what you are saying. If, for some reason, the screen recorder fails, you will be asked to describe both what you are looking at and what you are thinking.

**Compensation:**

Your participation in this research project is greatly appreciated. As thanks for your time and participation, you will be sent £15 (or equivalent in your local currency) via PayPal upon completing the study.

**What are the possible disadvantages and risks of taking part?**

This study is completely confidential, and we have identified no reasonably foreseeable risks of harm, safety, or side effects to you as a result of taking part in this study.

**What are the benefits of taking part?**

There are no direct benefits to you for taking part in this study. However, as a participant you will help us understand more about how technology can help people living with HIV understand changes in their health.

**What will happen when the study stops?**

When the research study stops, all collected information will be stored on a personal external hard drive which is password protected. It is City, University of London's policy to retain all research records for ten years. After ten years have passed, all documents related to the participants will be destroyed. Participation in the project is voluntary, and you can choose not to participate in part or all of the project. You can withdraw at any stage of the project without being penalized or disadvantaged in any way. If you choose to withdraw from the research study, your data will be excluded from the research and destroyed.

**Will my taking part in the study be kept confidential?**

Your participation will be kept confidential. We will ensure your anonymity in the following way:

- You will be assigned a unique identification number which will be used for all data and records, rather than your personal name
- All recordings will be stored on a password protected folder either on the interviewer's personal computer or external hard drive. The password will only be known by the researcher (Adrian Bussone).
- Transcripts made of the audio recordings and images captured from the screen recording will all be completely anonymized. Only anonymized data will be shared with other researchers interested in the work. No information containing identifiable features, comments, or names will be shared with other individuals.
- All signed consent forms will be kept in a sealed envelope, stored in a locked cabinet and destroyed after one year.
- Only direct communication will be made, and only through modes of communication that you have approved.

Please avoid including any identifiable information (your name, address, etc) in the questionnaires you fill out.

**What about sensitive information?**

You are not expected to disclose any sensitive information, or discuss anything that makes you feel uncomfortable.

**What will happen to the results of the research study?**

The results of this study will be used as part of Adrian Bussone's PhD Thesis. The results of the study will be documented in a written report. Possible future publications might arise from the research, but will not include your personal details or identifiable features/comments – your anonymity will be maintained. If you wish to receive a copy of the summary of results, please send a request email to adrian.bussone.1@city.ac.uk

**What will happen if I don't want to carry on with the study?**

You are free to discontinue the study at any time, without explanation or penalty to you.

**What if there is a problem?**

If you have any problems, concerns, or questions about this study, you should speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complains procedure.

To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: Exploring reflection on health with visualizations of community input, conducted by Adrian Bussone

You could also write to the Secretary at:

Anna Ramberg, Secretary to Senate Research Ethics Committee, Research Office, E214, City, University of London, Northampton Square, London EC1V 0HB

Or email the Secretary at: Anna.Ramberg.1@city.ac.uk

City, University of London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

**Who has reviewed this study?**

This study has been approved by City University London's Computer Science Research Ethics Committee

**Further information and contact details:**

Researcher:     Adrian Bussone, PhD student

Supervisor:     Dr. Simone Stumpf

**Thank you for taking the time to read this information sheet.**

## Appendix 16. Consent form

Responsible Institution: City, University of London

Title of Study: Exploring reflection on health with visualizations of community input

| | | |
|---|---|---|
| 1. | I confirm that I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records.<br><br>I understand this will involve:<br><br>• Completing a questionnaire asking me my age, gender, ethnicity, sexual orientation, time since being diagnosed, my question about the change in my health, and details about my health (e.g. medication taken, lab results)<br>• Being asked to reflect on my health while exploring the visualizations, with the researcher<br>• Allowing the meetings with the researcher to be audiotaped and the screen to be videotaped<br>• Completing questionnaires about how the visualizations helped make sense of my health<br>• Using a computer to view with the visualizations and (if meeting remotely) meet the researcher for the study session (via Skype or Google Hangouts) | ———<br>Initials |
| 2. | This information will be held and processed for the purpose of the completion of Adrian Bussone's PhD thesis and future research publications.<br><br>I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.<br><br>I understand that a unique identification number will be assigned to me, all collected data will be de-identified*, and all raw data will be kept secure in a locked cabinet in order to protect my identity from being made public.<br><br>*De-Identification: Any names of people, specific locations, or other information which could lead to identifying you as a participant will be replaced with generic terms (e.g. "Bob" will be replaced with "Person"). | ———<br>Initials |
| 3. | I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalized or disadvantaged in any way. | ———<br>Intials |
| 4. | I agree to City, University of London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on City complying with its duties and obligations under the Data Protection Act 1998. | ———<br>Intials |
| 5. | I agree to the use of anonymised quotes and visualizations in publications, including Adrian Bussone's thesis | ———<br>Intials |
| 6. | I agree to take part in the above study. | ———<br>Intials |

_____   _____   _____

Name of Participant              Signature                              Date

_____   _____   _____

Name of Researcher              Signature                              Date

*When completed, 1 copy for participant; 1 copy for researcher file.*

# Appendix 17. Pre-Study Questionnaire

*Please fill out this brief questionnaire and before your call with the researcher.*

*NOTE: Please do not include any information that could be used to identify you, such as your name*

9. What is your ethnicity?

   White:
   - [ ] British
   - [ ] Irish
   - [ ] Other

   Mixed:
   - [ ] White and Black Caribbean
   - [ ] White and Black African
   - [ ] White and Asian
   - [ ] Other

   Asian or Asian British:
   - [ ] Indian
   - [ ] Pakistani
   - [ ] Bangladeshi
   - [ ] Other

   Black or Black British:
   - [ ] Caribbean
   - [ ] African
   - [ ] Other

   Latin:
   - [ ] Latin

   Chinese or other ethnic group:
   - [ ] Chinese
   - [ ] Other

   Or…
   - [ ] Other: _____
   - [ ] Prefer not to say

10. How would you describe your gender?

    - [ ] Male
    - [ ] Female
    - [ ] Trans Male
    - [ ] Trans Female
    - [ ] Gender queer / Non Binary
    - [ ] Other (please specify): _____
    - [ ] Prefer not to say

11. Which of the following best describes your sexual orientation?

    - [ ] Heterosexual / Straight (Attracted to the opposite gender)
    - [ ] Lesbian / Gay (Attracted to the same gender)
    - [ ] Bisexual  (Attracted to both genders)
    - [ ] Other (please specify): _____
    - [ ] Prefer not to say

12. What is your age? _____ years

*Your responses to the following questions will be used to create the prototypes, which we will explore during the study. The more detailed you are, the more detailed the prototypes will be. Please don't include anything that makes you feel uncomfortable with sharing. If you are unsure about how to answer something, fill in as much as you can. You can discuss it further with the researcher during the audio call.*

13. You are invited to participate in this study because you recently, or currently, had a question about *what caused a change in your health*. Please write your question here:

> [blank box]

 (for example: Did my medication give me high cholesterol? What caused me to lose weight?)

14. When did you notice your health concern beginning?

 _____ (Please be as specific about the date as possible

15. Has it fluctuated at all? If so, try to explain how, and when:

> [blank box]

16. When were you diagnosed? (Please try to be as specific as possible) _____

17. What medication are you currently taking (specifically antiretrovirals), if any?

Medication Name: _____  Date started: _____ (approximately)

(Add more) (Add past medication)

18. Please list the dates and results of your lab results (CD4 or t-cells, viral load, or percentage):

> [blank box]

19. What other information, if relevant to your question, would you like included in your prototype?

> [blank box]

*Thank you! These answers will be used to personalize the visualizations that we will use during the main session.*

# Appendix 18. Discussion Guide

Welcome, thank for participation

Describe study session and introduce materials

Remind participant that the responses they see are fictional, just simulations

Remind participant that this is not a medical study and that they will not receive any medical care, but that this study is about how technology can help communities share health information more effectively

Ask participant to close other applications, browser tabs, or windows before recording begins.

Begin recording

2. Reflection with first prototype

| First prototype, no responses |
| --- |
| Prototype: A  or  B |
| *The focus of the study is to use the prototypes I show you to reflect on your health and try to find an answer to your question.*<br><br>*(Repeat question to participant)* |
| *I'm going to show you a prototype that has the health information you provided me shown in a visualization, along with your question. I'll show you the responses in just a moment, but I just want you to familiarize yourself with what it looks like*<br><br>Show prototype<br><br>*Tell me about what you are thinking, and what you're seeing.*<br><br>*Does everything make sense?* |

| First prototype, with responses |
| --- |
| *Now I'm going to show you the same thing but with three responses to your question. I'd like you to explore this and use what you see here to reflect on your question.*<br><br>*I'll be showing you the same information in a different style in a moment, so try to focus on how the presentation affects your thoughts, not just what the responders are saying.*<br><br>**Again, while you reflect on your question, please let me know what you are looking at so I can understand how it helps you reflect. I can see your mouse movements, so please use your mouse to indicate.** |
| Show participant prototype with responses |
| Prompts:<br><br>*Feel free to just describe what you see as you think about your question.*<br><br>*What are you looking at now? What are you thinking?*<br><br>*Do you feel like there are some bits of information that are more relavent to you or your question? Or are there some you've discarded?  Which ones?*<br><br>*How are you using what you see to find an answer to your question?*<br><br>*Is there anything here that helps you find an answer to your question? What?*<br><br>*Do you think you've come up with an answer to your question?  Out of the things you've seen here, what has led to that?* |
| Stop when participant feels they have found an answer to their question |

| Sensemaking Questionnaire |
|---|
| *Great, thank you! I'll show you the next version in just a moment, but I want you to complete this quick questionnaire based on what you've just seen.* |
| Provide participant with reflection questionnaire |

### 3.  Reflection with second prototype

| Second prototype, no responses |
|---|
| Prototype: A  or  B |
| *Okay, so I know that you just spent some time reflecting on your question, but because the focus of the study is to see how the prototypes help reflection I'm going to ask you to do it one more time.* |
| *I'm going to show you a different prototype that has the health information you provided me shown in a visualization, along with your question. I'll show you the responses in just a moment, but I just want you to familiarize yourself with what it looks like.*<br><br>Show prototype<br><br>*Tell me about what you are thinking, what you are seeing.*<br><br>*Does everything make sense?* |

| Second prototype, with responses |
|---|
| *Now I'm going to show you the same thing but with three responses to your question. I'd like you to explore this and use what you see here to reflect on your question.*<br><br>*Try to focus on how the presentation affects your thoughts, not just what the responders are saying.*<br><br>***Again, while you reflect on your question, please let me know what you are looking at so I can understand how it helps you reflect. I can see your mouse movements, so please use your mouse to indicate.*** |
| Show participant prototype with responses |
| Prompts:<br><br>*Feel free to just describe what you see as you think about your question.*<br><br>*What are you looking at now? What are you thinking?*<br><br>*Do you feel like there are some bits of information that are more relevant to you or your question? Or are there some you've discarded?  Which ones?*<br><br>*How are you using what you see to find an answer to your question?*<br><br>*Is there anything here that helps you find an answer to your question? What?*<br><br>*Do you think you've come up with an answer to your question?  Out of the things you've seen here, what has led to that?* |
| Stop when participant feels they have found an answer to their question |

| Reflection Questionnaire |
|---|
| *Great, thank you! I'm going to ask you a few more questions in a minute, but I want you to complete this quick questionnaire based on what you've just seen.* |
| Provide participant with reflection questionnaire |

### 4. Final Questions

| Final questions |
| --- |
| *Okay, so I just wanted to ask you some final questions about the prototypes you saw.* |
| *First, I wanted to ask about your experience using the prototypes to reflect on your question about your health…* |
| *Do you feel like seeing the health information of other, similar people, helped you reflect better? Deeper?* |
| *Do you think the comments helped?* |
| *How so?* |
| *Is there anything that you expected to see but didn't? What?* |
| *What did you find helpful? Why?* |
| *What did you find unhelpful? Why?* |
| *What would you change? Why?* |
| *Do you think these helped you understand more about your question or your health? Can you describe how?* |
| *Do you have any questions for me? Anything else you want to say?* |
| *Okay, thank you so much for your time. I really appreciate it. I'm going to send over the Amazon voucher now.* |
| **Remind participant that the responses they saw in the prototypes were fictional simulations**<br><br>**Tell participant to speak to their doctor or local clinic if they have any questions or concerns about their health**<br><br>**Thank, send incentive, end session, stop recording.** |

# Appendix 19. Sensemaking Questionnaire

**To what extent do you think you were able to…**

**1.1.   Construct an understanding from the available information?**

|___|___|___|___|___|___|___|___|___|___|___|

To a small extent                                                                To a large extent

**1.2.  Gain insight from the available information?**

|___|___|___|___|___|___|___|___|___|___|___|

To a small extent                                                                To a large extent

**1.3.  Make sense of the available information?**

|___|___|___|___|___|___|___|___|___|___|___|

To a small extent                                                                To a large extent

**1.4.  Draw a link between the available information and things you were aware of already?**

|___|___|___|___|___|___|___|___|___|___|___|

To a small extent                                                                To a large extent

**1.5.  Draw a link between information you encountered and your prior knowledge?**

|___|___|___|___|___|___|___|___|___|___|___|

To a small extent                                                                To a large extent

**1.6.  Develop a coherent view of the information?**

|___|___|___|___|___|___|___|___|___|___|___|

To a small extent                                                                To a large extent

**1.7.  Find structure in the information?**

|___|___|___|___|___|___|___|___|___|___|___|

To a small extent                                                                To a large extent

**1.8.  Find a way to (mentally or otherwise) organize the information?**

|___|___|___|___|___|___|___|___|___|___|___|

To a small extent                                                                To a large extent

**1.9.  Understand connections between things?**

|___|___|___|___|___|___|___|___|___|___|___|

To a small extent                                                                To a large extent

**1.10. Discover where the gaps are in how you understand a situation?**

|___|___|___|___|___|___|___|___|___|___|___|

To a small extent                                                    To a large extent

**1.11. Bridge gaps in your understanding of a situation?**

|___|___|___|___|___|___|___|___|___|___|
To a small extent                                                    To a large extent

**1.12. Reduce any confusion?**

|___|___|___|___|___|___|___|___|___|___|
To a small extent                                                    To a large extent

**1.13. Reduce any uncertainty?**

|___|___|___|___|___|___|___|___|___|___|
To a small extent                                                    To a large extent

**1.14. Reduce any ambiguity?**

|___|___|___|___|___|___|___|___|___|___|
To a small extent                                                    To a large extent

**Participant ID:_____**

**Prototype:        _____**

**Order: _____**

# Appendix 20. Full Results of Sensemaking Questionnaire

| Participant ID | P01 | | P02 | | P03 | | P04 | | P06 | |
|---|---|---|---|---|---|---|---|---|---|---|
| View | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 |
| Prototype | CP | T | T | CP | CP | T | T | CP | T | CP |
| To what extent were you able to… | | | | | | | | | | |
| Construct an understanding from the available information? | 5 | 9 | 5 | 8 | 10 | 11 | 10 | 11 | 7 | 7 |
| Gain insight from the available information? | 7 | 9 | 5 | 8 | 10 | 11 | 11 | 11 | 7 | 7 |
| Make sense of the available information? | 8 | 11 | 4 | 9 | 11 | 11 | 11 | 11 | 7 | 7 |
| Draw a link between the available information and the things you were aware of already? | 8 | 8 | 2 | 8 | 10 | 11 | 11 | 11 | 8 | 7 |
| Draw a link between information you encountered and your prior knowledge? | 3 | 8 | 2 | 9 | 7 | 9 | 11 | 11 | 8 | 7 |
| Develop a coherent view of the information? | 9 | 10 | 4 | 9 | 10 | 11 | 11 | 11 | 7 | 7 |
| Find structure in the information? | 8 | 10 | 5 | 9 | 11 | 11 | 11 | 11 | 7 | 7 |
| Find a way to (mentally or otherwise) organize the information? | 7 | 10 | 5 | 8 | 11 | 11 | 11 | 11 | 5 | 8 |
| Understand connections between things? | 9 | 9 | 2 | 9 | 11 | 11 | 11 | 11 | 5 | 8 |
| Discover where the gaps are in how you understand a situation? | 10 | 8 | 2 | 7 | 10 | 10 | 11 | 11 | 8 | 7 |
| Bridge gaps in your understanding of a situation? | 5 | 9 | 3 | 8 | 8 | 10 | 11 | 11 | 6 | 7 |
| Reduce any confusion? | 10 | 10 | 3 | 8 | 8 | 3 | 11 | 11 | 5 | 8 |
| Reduce any uncertainty? | 10 | 9 | 2 | 7 | 6 | 9 | 11 | 11 | 5 | 8 |
| Reduce any ambiguity? | 6 | 9 | 4 | 7 | 9 | 10 | 11 | 11 | 5 | 6 |
| Average score per question | 7.5 | 9.2 | 3.4 | 8.1 | 9.4 | 9.9 | 10.9 | 11 | 6.4 | 7.2 |
| SUM | 105 | 129 | 48 | 114 | 132 | 139 | 153 | 154 | 90 | 101 |

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