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# Designing for Reflection on Shared HIV Health Information

Adrian Bussone
Centre for HCI Design
City, University of London
London, England
adrian.bussone@city.ac.uk

Simone Stumpf
Centre for HCI Design
City, University of London
London, England
simone.stumpf.1@city.ac.uk

Stephanie Wilson
Centre for HCI Design
City, University of London
London, England
s.m.wilson@city.ac.uk

## ABSTRACT

People living with chronic conditions are increasingly turning to digital technologies to track their health, coupled with reaching out to their peers to make sense of fluctuations in their health. However, there is a lack of appropriate technologies to support reflecting on shared personal health information. This paper reports on a study investigating how technology could be designed to support people living with HIV in reflecting on shared personal health information. Participants used two design provocations to reflect on changes in their health. Results showed that the design provocations encouraged reflection, with higher levels of reflection appearing to require greater use of peer information. We contribute a new understanding of how reflection on shared health information takes place and consider the next generation of digital technologies for people living with HIV.

## CCS CONCEPTS

• Human-centered computing~Empirical studies in HCI • Human-centered computing~Empirical studies in interaction design
• Human-centered computing~Empirical studies in visualization

## KEYWORDS

HIV, Personal Health Informatics, Reflection, Self-Management.

## 1 Introduction

Over 36.7 million people worldwide are living with the Human Immunodeficiency Virus (HIV)[1]. While HIV was once a terminal disease, the introduction of antiretroviral drugs (ARVs) has provided the ability to suppress the virus, enabling people to live a long life, and shifting HIV to a chronic condition [13]. With this has come an interest in HCI on the use of health-focused technology amongst people living with HIV [10, 22]. Living well with a chronic condition requires careful self-management but this is not an easy task. ARVs and HIV can have effects that make it challenging to self-manage health [13]. For example, an HIV+ female who suddenly finds herself sweating profusely, constantly thirsty, sleepless and not menstruating, is left to determine if these changes are an ARV side effect, a sign that the virus is returning, or possibly that she is experiencing early-onset menopause.

It has been argued that reflection by an individual on their health information using digital technologies is important for self-management, especially when there are fluctuations in health [18]. However, research indicates that reflecting on personal health information alone may not always result in achieving new knowledge [20]. In the absence of frequent healthcare consultations, people living with HIV and other chronic diseases are turning to each other for support in managing their conditions, often sharing personal health information with others in online forums [5, 20]. We build on this to consider how digital technology might support people living with HIV in reflecting on shared personal health information.

In order to investigate how reflection might occur with digital technology, we created two design provocations that supported shared personal health information and conducted an in-depth study in which participants interacted with the provocations. The provocations were instantiated with participants' personal health information, a question that they had about their health, and health information and responses from fictional peers. We analyzed the data using two complementary frameworks: a sensemaking framework [21] to explore the participants' process of understanding the information in the provocations, and a reflection framework [9] to explore the outcomes in terms of level of understanding achieved. The contributions of this work are:

- A detailed account of how reflection takes place with a supportive digital technology
- Design considerations for developing future digital technologies that better support reflection.

## 2 Related Work

Increasingly, people use digital technologies to gather and reflect on information about their daily lives and experiences, known as Personal Informatics [15]. As part of self-management of their health and well-being, people are now also keeping track of their health information using technologies [6, 18]. Recent work in this area has drawn attention to the need to support people in reflecting on their health information, particularly when changes occur [18].

There have been many definitions of reflection (e.g. [2, 14]), but we view reflection on personal health information as a cognitive activity that occurs when an individual explores their information, experiences, or knowledge and relates it to their previous knowledge with the intention of gaining new insights or understanding about themselves or their health. Reflection can deepen as more knowledge is integrated; thus, there are levels of reflective thought. A framework of five levels of reflection, from R0 Non-Reflective Description to R4 Critical Reflection, was proposed by Fleck and Fitzpatrick [9]. This has been used in previous research to examine the quality of reflection that individuals achieve when exploring personal health information [6]. A complementary but distinct concept is that of sensemaking. We see sensemaking as relating to the process of manipulating information while seeking understanding [21]. The stages of Pirolli and Card's framework of the sensemaking process [21] have been used to study how people manipulate information as they try to understand it, for example in chronic disease self-management [18]. Hence, levels of reflection and the sensemaking process provide two complementary perspectives onto an individual's understanding of their personal health information, by focusing on both the quality and the process.

However, providing access to information neither guarantees that reflection will occur, nor that a high level of reflection will be achieved [18], and so focus has shifted to how reflection can be better supported through information visualizations [16]. Reflection is often thought to be an individual activity [2] but others can participate in the process [14]. Individuals might improve their reflective process with support from experts or mentors [17] or by exploring another person's information [5, 17]. Recent research has investigated individuals turning to their peers via online forums to share and better understand their personal health information, for example to determine whether their personal health information was 'normal' [20], or wanting to know what caused a reaction or a specific symptom [5].

Current digital technologies for personal health information are predominantly focused on individual use, rarely supporting users in sharing and viewing the information of others [19]. A notable exception is *Patientslikeme* which allows individuals to see each other's personal health information, and visualizes this in charts [11]. However, direct comparison is made difficult as the health information is shown on different visualizations and on different web pages. In fact, little is known about how to support or promote reflection for the self-management of chronic conditions like HIV. The research reported here is the first to explore how people reflect on their personal health information alongside the information of others, and how technologies might be designed to support this process.

## 3 Method

We created two design provocations [1] providing different visualizations of shared health information and conducted an empirical investigation to explore how people reflected on their own and (fictitious) peers' personal health information. Given the challenges of recruiting participants who live with a stigmatized condition, we elected to conduct an in-depth, primarily qualitative study with a small number of participants. The research questions were:

RQ-1: What is the journey through reflection using these provocations?
RQ-2: What information helps people to reflect more deeply on their health?
RQ-3: How do people process information to reflect more deeply?
RQ-4: What design aspects might support reflection?

### 3.1 Two Design Provocations

Recent work in interaction design has turned to the use of design provocations, in which use and tensions can be explored with users in order to speculate about future technologies [1], for example, to investigate data for the quantified self [7]. Our provocations were based on work which focused on understanding the current practices and needs of people living with HIV [4, 5] and diabetes [17, 20]. Previous research on tracked and peer-shared information among people living with HIV revealed information types that it was important to include, such as the date of diagnosis, medication prescribed and the period over which it was taken, lab results at certain points in time, and the onset and duration of any reactions [4, 5]. In constructing the design provocations, we interpreted the following requirements from these previous studies: 1) allow users to share and ask questions about their information 2) represent longitudinal data, 3) represent a variety of health information types (numerical and descriptive) tracked at various points in time, 4) allow peers to share information, and 5) allow peers to provide a response.

Working from these requirements, the first author developed two design provocations with different visualization styles (Timeline and Clockplot). Developing these two styles allowed us to investigate displaying the data in a familiar way (Timeline) versus a novel and possibly more engaging way (Clockplot). Each design provocation had two different "screens": a *personal* screen with the participant's own data, and a *shared* screen with the participant's data displayed alongside personal health information from three fictitious peers and the peers' answers to their questions.

Having described the rationale behind the provocations chosen, we now describe how they differed.

*3.1.1 The Timeline Design Provocation.* Presenting data temporally is traditionally done using a linear approach that charts the data points over a period of time [3]. In order to display multiple

data types together, while still using this visualization style, a 'faceted' layout approach was taken as it is effective for facilitating comparison of information over time [3] and allowed the participants to directly compare their information against that of their peers.

With the Timeline visualization style, in the personal screen (Figure 1), personal health information is displayed chronologically from left to right along the x-axis, beginning from diagnosis and fading away after the current point in time. In the shared screen (Figure 2), the health information of three fictional peer profiles is presented within the same visualization, alongside the participant's. The participant's and the peers' information are aligned at the date of diagnosis. To identify whom the information belongs to, a small profile icon is presented adjacent to the profiles' information. The screen also displays the participant's question about their health as an annotation pointing to the relevant information. The information category (e.g. Medication, CD4, Viral Load) is labelled on the left side of the graph, and the specific information types (e.g. medication name, CD4 and Viral Load numbers) are labelled on or near the information represented.
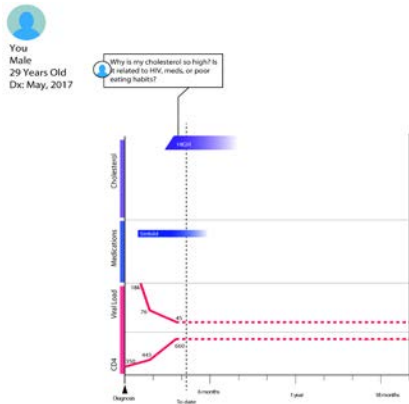


**Figure 1: Example of Timeline personal screen**

*3.1.2 The Clockplot Design Provocation.* A Clockplot presents layers of information chronologically over a radial timeline and is appropriate for representing data that occur periodically over time [3]. With this provocation, information is displayed around a profile icon representing the individual, flowing clockwise from the date of diagnosis at the 12 o'clock position (Figure 3). The clockplot presents dates that have passed since the diagnosis was made, at regular intervals.

Each information type is displayed in a ring, with lab results presented closest to the central profile icon, followed by medication, then any reactions or other information. Numerical data is shown with numbers and, when applicable, color-coded to
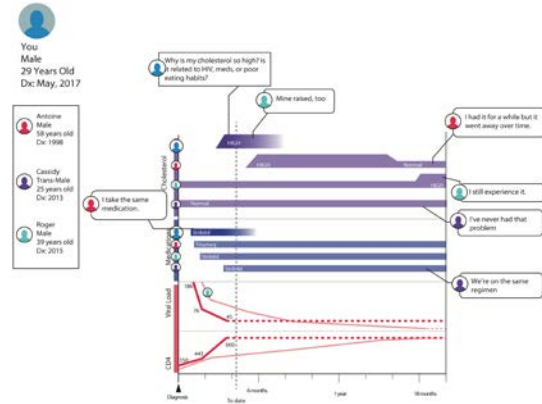


**Figure 2: Example of Timeline shared screen**

indicate the severity of the data (e.g. high viral loads are red as they are concerning, while undetectable viral loads are blue as they are not a cause for alarm). As with the Timeline, the information category (CD4, Viral Load, etc.) is labelled in a consistent location: along the 12 o'clock position. The specific information types (e.g. medication name, actual numbers, etc.) are labelled on the actual information represented.
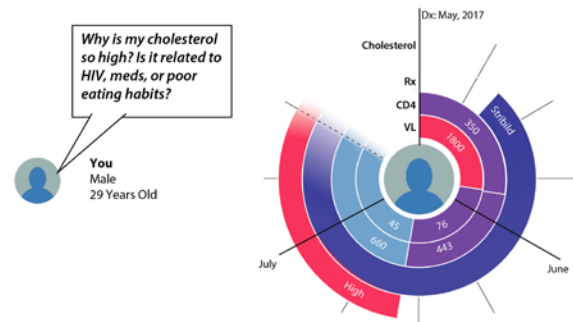


**Figure 3: Example of Clockplot personal screen**

In the shared screen (Figure 4), the participant's question is shown at the top of the screen as a word bubble emerging from the top of their profile icon. The Clockplot design provocation presents the health information of the three fictional profiles on their own Clockplots below the participant's. The comments made by the profiles are always located in the same place: above the profile icon, adjacent to the profile's information.

*3.1.3 Populating the Designs with Personal Health Information.* We created customised versions of the provocations for each participant using their health information and their question; these were elicited in advance of the main study session. We then added fictitious responses and health information from three fictitious peers. These were designed to represent a range of individuals living with HIV, including various ages, genders, times since diagnosis. All profiles shared medication, only Profile 3 shared lab results, and all three had different experiences with the
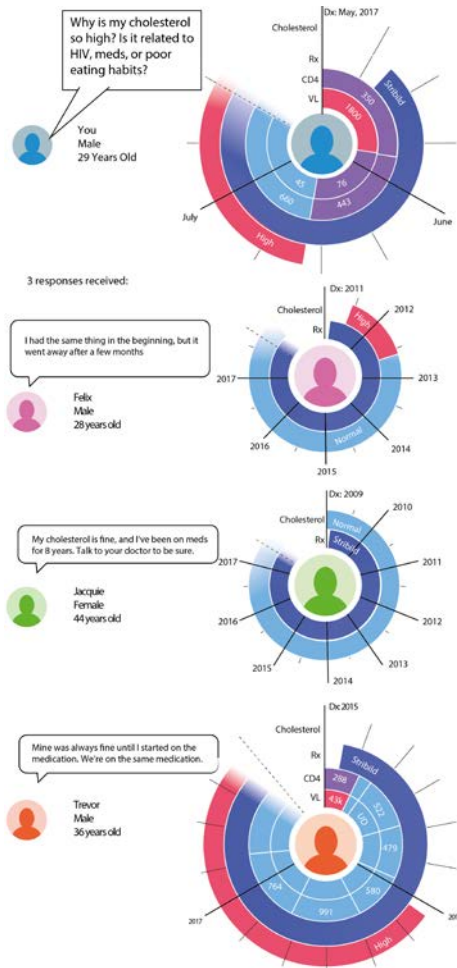
**Figure 4: Example of Clockplot shared screen**

change in health the participant had a question about (e.g. Profile 1 had experienced it but it went away, Profile 2 had never experienced it, and Profile 3 was still experiencing it).

## 3.2 Participants

The study was approved by the Computer Science Ethics Committee of City, University of London. Recruitment advertisements were sent out through social media, HIV-specific online forums, and sexual health organizations. Before joining the study, all participants were provided with a Study Information Sheet explaining the study in full, and were asked to sign an Informed Consent form. All participants had experienced a change in their health within the last 6 months and were wondering what caused it (e.g. "why is my cholesterol so high?"), and all participant questions were of similar complexity. 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. The sensitive data (the participants' health information) was kept stored in a password-protected folder on the first author's personal computer and the details were not shared with others (Fig. 1-4 are examples, not actual participant information).

Six participants were recruited, with an average age of 34 (Table 1). Five identified as male and one (P04) as female. Two participants described themselves as Asian, two as Mixed, one Black African and one Caucasian. Four participants described themselves as homosexual, one as heterosexual, and one as asexual. The majority were diagnosed relatively recently.

**Table 1: Breakdown of participant demographics**

| ID | Age | Gender | Ethnicity | Sexual Orientation | Year of Diagnosis |
|----|-----|--------|-----------|--------------------|--------------------|
| P01 | 24 | Man (Cis) | Asian | Homosexual | 2016 |
| P02 | 28 | Man (Cis) | Asian | Homosexual | 2017 |
| P03 | 47 | Man (Cis) | Caucasian | Asexual | 2015 |
| P04 | 46 | Woman (Cis) | Black African | Heterosexual | 2008 |
| P05 | 34 | Man (Cis) | Mixed | Homosexual | 2015 |
| P06 | 25 | Man (Cis) | Mixed | Homosexual | 2016 |

## 3.3 Procedure

The study began with a pre-study questionnaire which gathered participants' demographic details, a question they had about a change in their health, and personal health details with which to populate the provocations. This was followed by a 15-minute pre-session phone call to review the information collected in the questionnaire and gather any additional details that may be required to create the design provocations.

The main session, lasting approximately 45 minutes, was held either in-person or remotely via Skype. Participants were asked to explore the design provocations as they considered the question they had about their health. All participants explored both design provocations: 3 explored Timeline first and 3 explored Clockplot first. They were first shown the personal screen, as a means of familiarization, then shown the shared screen. Importantly, all participants were reminded throughout the study that the profiles they saw were fictional and that their health information had not been shared with others.

Participants were asked to voice their thoughts while referring to what they saw on the screen and what they were reflecting on, and to use the mouse to indicate what they were looking at. Once both design provocations had been reviewed, the main session concluded with a brief interview for participants to provide feedback.

## 3.4 Data Collection and Analysis

Participants' comments and a video of the computer screen were captured using a screen recorder. The audio was transcribed in full and anonymized by the first author. The transcript was segmented into units of analysis by chunking it into sentences in which a piece of information or feature was mentioned. If multiple pieces of information or features were described in the same sentence, they were kept together in one unit. The video recordings were watched to supplement the transcripts, for example, to identify instances where a participant was circling information or a feature with the cursor.

Four sets of codes were defined: one for levels of reflection, one for coding the health information that participants referred to when reflecting, one for the *Sensemaking Process* they employed as they manipulated information during reflection, and one for the features of the designs they used during reflection. One researcher applied these codes to the transcripts using a protocol analysis process [8]. Since these codes did not rely on interpretation of meaning, they were considered reliable without conducting any inter-coder agreement checks.

*3.4.1 Levels of Reflection Code Set.* We analyzed the levels of reflection that occurred when interacting with the provocations based on codes defined by [9], adding one code to this existing set, R2.5 Comparative Reflection. This was done to separate the instances where individuals merely stated that similarities were present (R2 Dialogical Reflection) and instances where they displayed deeper thought about those similarities (Table 2).

**Table 2: Levels of Reflection (LoR) code set**

| Code | Applied when describing… | Example |
|---|---|---|
| R0 Non-Reflective Description | Personal information without further elaboration. | "This is when I was diagnosed" |
| R1 Reflective Description | Personal information with contextual detail not included in visualization. | "This is showing the period where I experienced hair loss." |
| R2.0 Dialogical Reflection | Similarities between pieces of personal and profile information. | "This is Roger, we are on the same regimen" |
| R2.5 Comparative Reflection | Relationships between personal and profile information, evidence of interpreting or questioning. | "Roger still experiences it, so I'm not an outlier" |
| R3 Transformative Reflection | Challenging assumptions, suggesting hypotheses or reasons. | "Does that mean there is a link between these medications and weight gain?" |

*3.4.2 Information Type Code Set.* We coded for use of information types (Table 3) to see how participants used information when reflecting. The codes were based on [5], however, we split out instances when participants referred to their own health information, or that of a profile.

**Table 3: Information Type code set**

| Super-code | Code | Applied to… |
|---|---|---|
| | | |

| Participant Health Information | Reactions | Change in health that the participant is concerned with |
|---|---|---|
| | Diagnosis | Date that the participant was diagnosed with HIV |
| | Medication | Name of the medication(s) taken, as well as the start/end/duration of that medication being taken |
| | Lab Results | CD4/viral load of the participant |
| Peer Health Information | Reactions | Experience of fictitious profile |
| | Diagnosis | Date that the fictitious profile was diagnosed with HIV |
| | Medication | Name of the medication(s) taken, as well as the start/end/duration of that medication being taken |
| | Lab Results | CD4/viral load of the fictitious profile |

*3.4.3 Sensemaking Process Code Set.* We were interested in how participants processed information while they were reflecting. To this end, we employed the sensemaking process framework from [21] and adapted our descriptions and definitions from it (Table 4).

*3.4.4 Feature Code Set.* The Feature code set (Table 5) was used to identify the design features participants referred to while interacting with the provocations. We separated features on the personal screen and shared screen.

## 4   Results

We report the results in four sections, each answering one of the research questions. We first focus on levels of reflection and participants' journeys through reflection, we then consider the information that participants used during reflection and the sensemaking process they engaged in, before turning to how the designs supported reflection.

## 4.1 The journey through reflection (RQ1)

We first examined the total instances of each level of reflection, per participant (Figure 5). On average, there were slightly fewer instances of levels of reflection codes for Clockplot (mean=10.50) than for Timeline (mean=12.67), but this might have been due to the unfamiliarity of this visualization style. We did not notice a

**Table 4: Sensemaking process code set**

| Code | Applied when… | Example |
|---|---|---|
| Shoebox | Information/features deemed relevant enough to mention | "I see a lot of comments, the data of other people" |
| Evidence File | Considering smaller, more specific pieces of information | "I'm just looking at Trevor's cholesterol" |
| Schema | A pattern noticed as to how pieces of information are related | "Felix had it and we have been on medication for a similar amount of time" |
| Hypotheses | A tentative idea about the answer to the participant's original question | "Maybe the medication causes it, since Felix and I both have it and are at similar stages" |

**Table 5: Feature code set**

| Super-code | Code | Applied to… |
|---|---|---|
| Shared screen | Profile Details | The details of a fictional profile |
| | Temporally arranged data | The Timeline or Clockplot visualization of the information |
| | Comment | Profile's comment |
| Personal screen | Question | Reading out, or looking at their question |
| | Temporally arranged data | The Timeline or Clockplot visualization of the information |

pattern related to the order in which the provocations were shown to the participants (recall that we alternated the order). From here on, we combine the analysis from the two provocations, unless there is a strong pattern to highlight.

A breakdown of the LoR codes per participant (Figure 5) indicates that while every participant made some statements about their own experience (R0 Non-reflective Description), there were surprisingly few statements which demonstrated R1 Reflective Description.

All participants engaged in higher levels of reflection, R2.0 Dialogical and R2.5 Comparative Reflection. In these levels, participants stated similarities between their own information and experiences and those of the fictional profiles, or they described, questioned, and interpreted relationships between the fictional profiles' information and experiences and their own. Here, the visualization type mattered: instances of R2 Dialogic Reflection with the Timeline were almost double the instances with the Clockplot. This was likely due to how the profile information and

comments were visualized in the Timeline style which allowed easier comparison between the participants' and profiles' data.
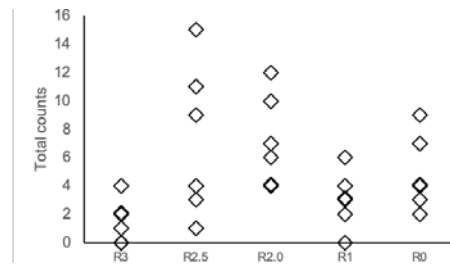


**Figure 5: Counts of every LoR code for each participant. (each diamond represents the count for a participant, overlapping data points nudged for visual differentiation)**

There were only a few instances where individuals achieved some insight about their experiences, coded as R3 Transformative Reflection, but we believe the results indicate that even limited engagement can lead to deepening reflection. To investigate this, we turned our attention to understanding the depth of reflection over a session through participants' reflection journeys (Figure 6). Higher levels of reflection (darker blue) were never achieved in the personal screen. All participants moved up and down through the levels of reflection while they explored the designs, and there appeared to be an upward trend towards higher levels of reflection as the session progressed.
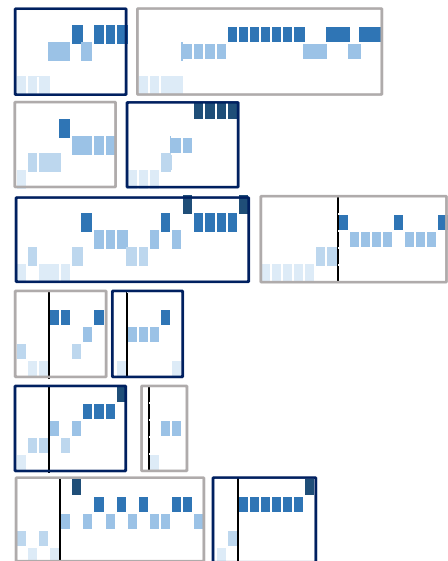


**Figure 6: LoR journey for each participant. Levels indicated in opacity with lightest R0 and darkest R3. Timeline results outlined with grey. Thin vertical line indicates switch from personal to shared screen.**

As participants switched design provocations, they returned to lower levels of reflection while they familiarized themselves with the visualization. R3 Transformative Reflection instances appeared

relatively late in these journeys, after the participant had engaged in R2 Dialogical and R2.5 Comparative Reflection.

## 4.2 Information Used in Reflecting (RQ2)

In line with the findings of [5], all participants hoped to understand what caused a change in their health (e.g. 'What caused my sudden hair loss?' or 'What caused me to become so lethargic?'). Across all instances of reflection, Participant Health Information was coded a total of 84 times, and Peer Health Information was coded a total of 101. Figure 7 shows that higher levels of reflection seem to be associated with drawing on information shared by peers, highlighting the importance of making other data and perspectives available. Thus, being able to directly compare and reflect on shared personal information may lead to important insights and deepen reflection.

We then focused on whether certain information is particularly useful in reflection at each level. Within lower levels of reflection, such as R0 Non-reflective Description (Figure 8, R0) and R1 Reflective Description (Figure 8, R1), participants touched upon all information types at similar frequencies. For example: *"So, I can see the diagnosis of my condition, and the two different types of medication I've taken over time. (*P02)".
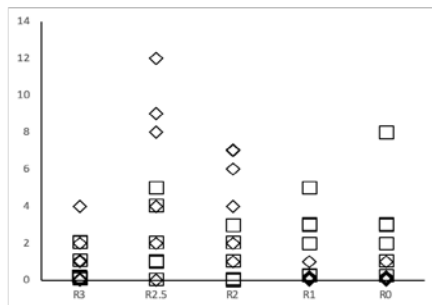


**Figure 7: Count of Participant (squares) and Peer (diamonds) Health Information coded for each participant co-occurring with an LoR code (each symbol represents the count for a participant)**

The predominant information types used in higher levels of reflection such as R2 Dialogical Reflection, R2.5 Comparative Reflection and R3 Transformative Reflection (Figure 8, R2-R3) were Reactions and Medication. We noted that in these higher levels of reflection, the participants' attention shifted to their peers' personal health information, and that they frequently drew relationships between the items of information, for example: *"Perhaps Cassidy's medication [is extraneous] because […] 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."*

When R3 Transformative Reflection was reached by participants, they frequently used information that was not included in the coded information types, for example: *"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)". This indicates that transformative reflection might be encouraged with a richer set of information (e.g. age, gender, weight, etc.) as suggested by [5].
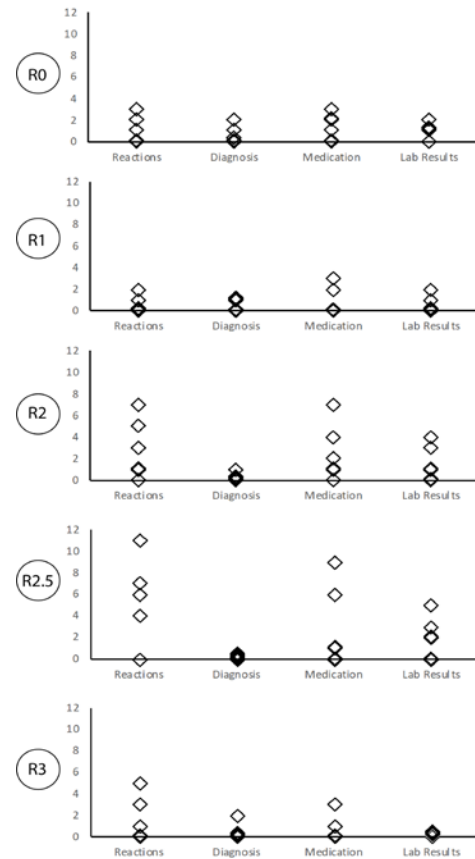


**Figure 8: Count of Information Types co-occurring with Reflection Codes for each participant (each diamond represents the count for a participant)**

## 4.3 How is information processed? (RQ3)

We first investigated the participants' sensemaking process as they considered information in the provocations (Figure 9). The most frequent code was Evidence File (102 instances overall), where smaller, more specific pieces of information were considered. The next most frequent was Schema (56 instances), in which participants identified a pattern when considering the information contained in the provocations. These results suggest that people used the designs in a systematic and detailed way to support reflection. Shoebox and Hypothesis, the lowest and the highest levels of the sensemaking process, only occurred 19 and 8 times respectively, across all participants. This mirrors the pattern we saw in levels of reflection, where R1 Reflective Description and R3 Transformative Reflection occurred less frequently than other levels of reflection (see Figure 5 for comparison). Investigating further, we looked for co-occurrences of sensemaking process and levels of reflection codes.
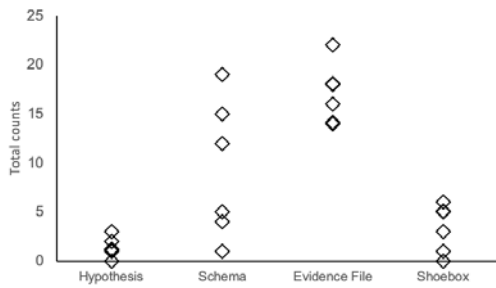
**Figure 9: Each participant's total sensemaking codes (each diamond represents the count for a participant)**

To carry out this analysis, we looked for the number of "matches" between the sensemaking and the levels of reflection code sets per participant. To account for differences between participants, we normalized each co-occurrence by the sum of the all sensemaking process and LoR instances for each participant. The result was expressed as a percentage. For example, P1 had 1 instance of Hypothesis which co-occurred with R2.5 Comparative Reflection. There were 72 instances of both codes in this this transcript (40 instances of sensemaking process and 32 instances of LoR codes); hence this co-occurrence accounts for 1.39% of all codes for this participant. Figure 10 shows these percentages visually, one bar for each participant. It shows that Schema was predominantly associated with R2 Dialogical, R2.5 Comparative, and R3 Transformative Reflection, whereas Evidence File was more associated with R0 Non-reflective description, R1 Reflective description, and R2 Dialogical and R2.5 Comparative. This suggests that successful information manipulation leads to higher levels of reflection. On the other hand, glancing at or considering specific information in isolation, indicated by Shoebox and Evidence File, only gets an individual partway up the ladder of reflection. Hence, designs and visualizations must allow patterns and relationships to be easily identified so that higher levels of reflection can occur.

## 4.4 What features might support reflection? (RQ4)

In order to investigate how to support reflection on peer contributions, we turned our attention to the use of the design features in the different levels of reflection ().

During R0 Non-reflective description and R1 Reflective levels, participants concentrated mainly on the temporal display of the data. For example: *"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)". In higher levels of reflection, such as R2 Dialogical, R2.5 Comparative Reflection and R3 Transformative Reflection, the Comments and Profile Details took on more prominence: *"Yeah, her levels have changed, we're on the same medication. Trisha. Okay. (*P04)".
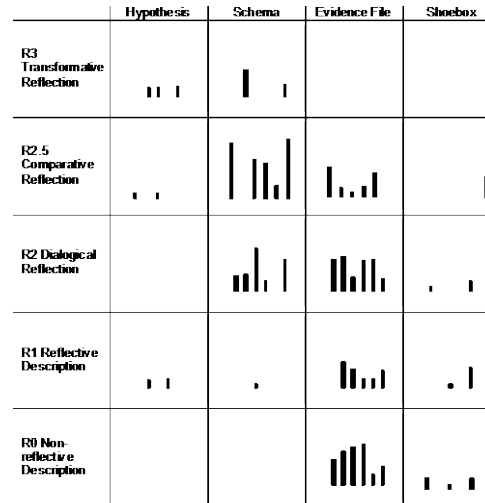


**Figure 10: Co-occurrence matrix for sensemaking and LoR codes; each bar shows % co-occurrence for participant (each bar represents data for a participant)**
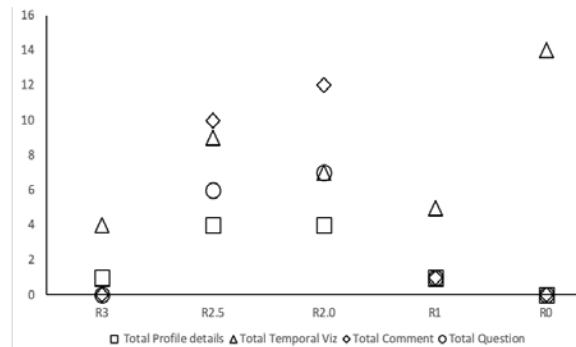


**Figure 11: Total counts of each Feature code co-occurring with LoR codes (each symbol represents data for a participant)**

Participants also drew on Profile Details and the temporally arranged data to develop meaning: "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 […] 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. (P03)". Participants repeatedly stated that they found value in being able to view their information alongside the information of others: "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)".

Feedback during the interviews was overwhelmingly positive. While the Clockplot was thought to be aesthetically appealing, participants preferred the Timeline because it was more familiar and easier to process. However, even the Timeline screens need to be carefully designed so as not to become overwhelming. To reduce

information overload, participants wanted to explore the data more interactively by showing or hiding different data types at different times. This would also allow a richer set of information than currently provided in these provocations.

Furthermore, participants thought it would be helpful to compare their information with people who were very similar to themselves: *"Let me filter out other people who are not as similar to my profile. [...] It's like finding someone to date - you filter out people with common interests (*P01)". This indicates that providing the ability to add and compare peer health information alongside some contextual background data could bring about higher levels of reflection for people living with HIV.

## 5   Discussion

We have explored how reflection occurs when using digital technologies that support shared personal health information, working with people living with HIV. The results show the participants' journeys with reflection: low level reflection when exploring what was shown in the visualizations and recalling previous experiences, then building upon this and reflecting more deeply as the information available enabled them to recall their experiences in more detail. From there, connections and similarities were described between personal and peer information, ultimately leading several participants to engage critically with their personal health information and changes in health. The results further reveal that reflecting with peers' personal health information was especially helpful in providing insights and supporting higher levels of reflection, as was additional information that went beyond specific medical details.

The work reported here is not without its limitations. We did not find any large differences between the two provocations, but this may be due to our sample size. Exploring this in further detail, with a larger number of participants, is an opportunity for future research. We chose to focus on a rich qualitative analysis with a relatively small number of participants to understand patterns in the use of the design provocations. Working with additional participants, and indeed alternative visualizations, may reveal further patterns. The design provocations were not interactive and it would be fruitful to explore the impact of interactivity on participants' behavior. Furthermore, it would be useful to understand how such design provocations could be used "in the wild" rather than within the constraints of a lab study.

Supporting reflection is currently not a prime concern in digital technologies for people with HIV but we hope that in future this becomes more important to researchers and designers. To this end, we have captured some design considerations. Firstly, this research suggests that it is important to track multiple types of information: numerical and textual, specifically related to the condition and related to general health and well-being. In addition to commonly captured and tracked information, such as medication, a richer set of information (reactions, other conditions, age, weight, etc.) would be useful to people wanting to reflect on their health. This data should be visualized to be easy to process and find patterns,

possibly through interactive exploration that allows data to be filtered and flexibly explored, allowing overviews and details. Comparing their own information with their peers' was important to participants and enabled higher levels of reflection, but is not a feature that is adequately supported in current technology. All participants asked when this technology would be available, demonstrating the need for this kind of support.

Finally, the desire to share, reflect on and communicate about personal health information is not limited to people living with HIV. It has been shown that people living with a variety of chronic conditions, e.g. people with diabetes, chronic migraines, and ALS [20, 11] turn to their peers to gain support and help in understanding their personal health experiences. HIV is now considered a chronic condition [12], and chronic conditions come with individualized triggers, symptoms, and treatments [20]. Despite the differences, the characteristics, complexity, and challenges of chronic conditions have much in common [13, 20]. Thus, specific details (e.g. the types of health information of interest) may vary, but the findings reported here could be generalized to other chronic conditions. For example, it has been shown that individuals with bi-polar disorder may be better able to monitor their condition by tracking the weather, alcohol consumption, activity levels [12], and people living with diabetes can gain a better self-understanding of their condition when they are able to track nutritional intake, health decisions, and/or activity levels e.g. [17].

## 6   Conclusion

Previous work has demonstrated that individuals explore the health information of others to inform their personal care [11] or understand if their experiences are normal [5, 20], but none has investigated how reflection might occur with a technology intended to support it. We conducted an empirical study using two design provocations to investigate how people with HIV reflect using shared personal health information. We found that:

- Even limited use of shared personal health information can lead to higher levels of reflection;
- Reactions, Medication and Lab Results are important to reflection but the type of information provided in digital technologies should be extended to cover age, weight, etc.
- Processing information in isolation is associated with lower levels of reflection while higher levels of reflection require integrating information to develop patterns;
- Technology needs to be designed so that shared information can be explored interactively.

While the focus of this work involved people living with HIV, we argue that many of our findings could transfer to other chronic conditions, but may also prove useful to investigate health in general. Combined with the current trend for data capture through wearable and mobile devices, our research is an important step to better support reflection in digital technologies.

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