
Personal health data trails in the context of stigmatizing long-term condition

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Abstract

In this position paper, we consider *personal data trails* in the context of critically exploring technology design for supporting the self-management of stigmatizing long-term conditions like Human Immunodeficiency Virus (HIV). Drawing on developing discourses in Critical Digital Health and Personal Health Informatics, we frame pertinent research questions for critically exploring the design of trusted systems and



PATIENT-GENERATED DATA SHARING WITH CLINICIANS



PERSONAL DATA SHARING WITHIN PEER COMMUNITY



SHARING BEYOND THE PEER COMMUNITY AND CLINIC

Figure 1 INTUIT three critical sharing contexts.

mechanisms for securely managing and navigating emergent and near-future personal data trails in health and beyond.

Author Keywords

Personal Health Informatics; HIV; Long-term condition; Digital health; Privacy; Trust; Informed consent.

CSS Concepts

• **Human-centered computing~Human computer interaction (HCI)**; *Haptic devices*; User studies; Please use the 2012 Classifiers and see this link to embed them in the text:

https://dl.acm.org/ccs/ccs_flat.cfm

Introduction

In our research, we explore the notion of *personal data trails* within the context of routinely managing health and wellbeing. Specifically we consider the sharing of personal data with healthcare professionals (HCPs) and peers to support the self-management of potentially stigmatizing long-term conditions (LTCs) like Human Immunodeficiency Virus (HIV). Our work focuses on exploring users' Trust, Identity, Privacy and Security (TIPS) concerns, and the extent to which users may feel informed about the management of personal data trails generated as part of their healthcare routine.

For the workshop, we provide contexts to connect personal data trails to critical digital health [10]. In this paper, we frame personal health data trails in relation to our interdisciplinary programme of UK-funded Design (IXD) research entitled 'INTUIT: Interaction Design for Trusted Sharing of Personal Health Data to Live Well with HIV' (www.intuitproject.org). We identify two main research objectives that are relevant to this workshop.

In doing so, we demonstrate how the INTUIT project and its identified contexts of personal data sharing (Figure 1) provide a useful frame for critically exploring the speculative design of tools for safely navigating past, present, and emergent data trails.

Framing Personal Health Data Trails

Personal Health Informatics

Personal Health Informatics (PHI) is a discourse on the use of self-tracking tools for gaining knowledge about one's personal health and routines from tracked digital information [9]. We see PHI as an interesting context for thinking about personal data trails and how these might be generated from self-tracking devices that have enabled their users to collect personal data for the purpose of self-management and self-care (e.g. Figure 2). These new tools support self-tracking practices by providing individuals with new means for making sense of and sharing data about lived experiences [14].

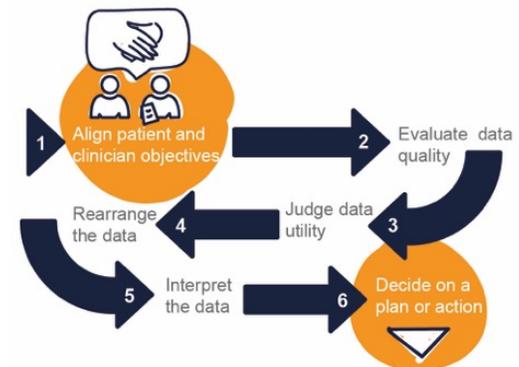


Figure 2 Sketch, "the six-stage workflow for using patient-generated data. Stages take place chronologically, within each several barriers commonly arise" via [17].



Figure 3 Sketch, examples of self-tracking mobile apps used for the purpose of health and wellbeing.

In the clinical context, there is potential value in patients sharing Patient-Generated Data (PGData) with HCPs about symptoms or medication adherence to support LTC self-management (e.g. Figures 3 and 4) [4][2][3]. However, there is evidence of barriers to the trusted sharing of such data for this purpose [17], especially considering privacy and identity concerns or the reuse and proliferation of personal health data trails at scale [6][10][18].

We suggest that current PHI technologies providing the means to generate personal health data trails do not arguably address the psychosocial needs and privacy concerns of users who live with LTCs like HIV. The communication of health and lifestyle data is often linked to the fear or experience of forms of stigma, raising complex trust, identity, privacy and security (TIPS) concerns for data sharing [15]. As part of INTUIT, we aim to design, develop, and evaluate innovative prototype secure systems and services for communicating and representing PGData collected by people living with HIV that address their TIPS concerns.

OBJECTIVE #1:
 Designing trusted PHI tools that address the psychosocial needs and privacy concerns of people living with potentially stigmatizing LTCs like HIV.

Personal data trails and stigmatizing LTCs
 Through effective treatment, HIV has been transformed into a LTC with normal life expectancy for the majority of people who receive clinical care [11]. The focus of HIV healthcare has consequently shifted towards supporting self-management and enhancing people's

quality of life as they age [8]. In this context, new tools associated with IoT, mobile and wearable technologies have a role to play. However HIV remains highly stigmatized [5]. There are many barriers and challenges to designing for the trusted capture and sharing of personal data; users' concerns are amplified by experiences of HIV-related stigma and its psychosocial impacts [16][13][12][15] (e.g. Figure 5).

INTUIT aims to deliver foundational understanding about TIPS concerns for sharing personal data in order to self-manage LTCs that may be associated with experience of stigma. By focusing on HIV, the team aspires to design and critically evaluate digital tools and services to support trusted data sharing for the purpose of self-management and wellbeing.

OBJECTIVE #2:
 Understanding the applied ethical issues and practical challenges of sharing PGData and develop ethical frameworks for socially responsible design innovation in the digital healthcare context.

Our interdisciplinary programme engages design, medicine, public health, computer science, psychology, ethics, and the literary arts. We work in close collaboration with experts in the lived experience of HIV, plus other intended end users of the considered technologies, including healthcare providers, communities, and private organizations (see Figure 1).

Design-led methods including speculative design help us approach design with PGData from more critical, creative and future-oriented perspectives – for



Figure 4 Sketch, examples of data generated shared by the patient during a consultation.



Figure 5 Sketch, an example of HIV-related mobile app via [15]

example, how data might be collected and shared, and the legacy traces left by such self-tracking practices. In the second phase of our research programme, we take inspiration from Speculative Enactments [7] to explore consequential actions in data sharing and applied ethical dilemmas related to consent and care.

The theme of the workshop resonates with the project team's collective aspiration of addressing applied ethical issues associated with TIPS, and delivering transferrable insights that can be of value for understanding barriers to PGData sharing in other health contexts, such as living with long-term mental health conditions.

Three Research Contexts for Situating Trusted Interactions with Personal Health Data

We envision personal health data trails generated in three critical sharing contexts (Figure 1), which we outline below to provide some background and to situate it. We also identify key questions informed by our three research contexts, which we will describe further at the workshop should the paper be accepted.

Patient-clinician communication

The long-term management of patients with stable HIV is typically supported by 20-30 minutes annual face-to-face consultations with a clinician. In this consultation room context, we aim to identify the personal data people wish to capture and share about their own condition and experiences, and what concerns (relating to confidentiality and consent) they have about communicating these data to HCPs. We are keen to investigate existing personal data trails and speculate on future kinds of data that could be generated by new

PHI tools that may support or in some cases disrupt patient-clinician communication. Additionally, we are interested in what informed consent might mean in relation to the sharing of personal health data within the current fragmented care services [1].

What might personal health data trails look like in the future? How might patients' information be safely managed and navigated for the purpose of trusted sharing?



Figure 6 Sketch, considering TIPS when sharing personal health data with peers online.

Peer Sharing within the HIV Community

People living with HIV monitor and self-manage their health and wellbeing by tracking personal data and sharing it with peers via online platforms (e.g. forums

such as *PatientsLikeMe*). A wide range of PGData is shared with the community e.g. medication taken and date of diagnosis. Responses from the online peer community provide informational and emotional support, largely drawing on individuals' own lived experiences. In this context, we investigate what types of data are shared and how users factor in TIPS issues when making decisions about their health (Figure 6). We consider personal data trails that raise challenges for anonymizing and managing traces of data shared over time within a particular community.

How can users safely navigate and share personal information online with others?

Sharing beyond the HIV Community and Clinic
The sharing of PGData with people and organizations outside of the HIV community (including private organizations) is assumed to be particularly challenging for people with HIV in light of the multiple concerns around stigma and confidentiality. In this context, we ask how people living with stigmatizing LTCs like HIV critically engage with TIPS issues around sharing their personal data with online others, and how they manage their identity across multiple online communities.

How can design address TIPS issues related to personal health data trails when shared with others and aggregated at scale?

Conclusion

Our position paper considers the concept of personal data trails in relation to the critical digital health

studies. We introduce a design-led, interdisciplinary research programme that is critically exploring how individuals use data sharing tools to manage living and ageing well with LTCs, focusing on the specific clinical and social context of HIV. We framed personal data trails in relation to PHI and identified two design objectives from our research that we find relevant for the workshop and the *situating of trusted data interactions* in people's lives. If accepted, we would support our workshop presentation with material artifacts and provocations that have been designed to support the pursuit of empirical studies within the programme.

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