TRAVELLING AN UNFAMILIAR ROAD: IMPLICATIONS FOR THE ENTRY OF DESIGN PRACTITIONERS INTO HEALTHCARE

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Abstract

Healthcare systems worldwide are seeking to improve outcomes through digital technology. However, most health information technology projects fail to some extent, as finding an optimal balance between institutional constraints, healthcare provider practices, and patient needs often proves elusive. Many healthcare institutions have turned to design practice to address these challenges. Design practice has played a significant role in promoting a more experience-centred approach to healthcare innovation, yet much scope remains to consolidate an understanding of what constitutes 'good design' for the complex socio-technical system that is healthcare in the digital age.

Current design research engages with healthcare stakeholders, patients and carers at the forefront of an emerging field of design for health. Many of the designers entering this field do not have medical or healthcare training, and are therefore unfamiliar with the intricacies of healthcare as a context for design. However, designers' creativity and an informed, intuitive response to problem areas can offer great value to healthcare services.

I reflect on the design processes for a chronic disease self-management intervention for people with the Human Immunodeficiency Virus (HIV). Examining the processes of (i) how a cross-disciplinary team developed the intervention design and (ii) how the design practitioners grew in their understanding as they entered and worked in the domain of HIV research guided this enquiry.

I also draw on a number of design research disciplines to explore our processes for cross-disciplinary collaboration. I focus on addressing the complex and unfamiliar healthcare system as a context for design practice.

I report on a number of tools and design strategies that supported cross-disciplinary design collaboration. These are: (i) the 'Pointy versus Soft' design vernacular which serves to bridge knowledge boundaries and provide a design strategy for generative and evaluative health design work; (ii) the Collaborative Rapid Persona-building Workshop and (iii) the 'Designing in the face of stigma' design strategies for social media design with stigmatised user groups.

These outcomes are from a robust design approach developed within the medical, scientific and technological ‘cultures’ of a healthcare intervention.

This thesis presents a ‘journey’ into, through, and emerging from, the ‘unfamiliarity’ designers often experience on healthcare projects. It is hoped that these findings will enable designers unfamiliar with healthcare to (i) anticipate and recognise aspects of a healthcare design context, (ii) be equipped to engage in cross-disciplinary collaboration with healthcare system participants, and, (iii) feel confident to envision new design solutions from an empathic and intuitive design knowledge. Thus potentially contributing to a community of healthcare design practitioners.

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List of Abbreviations

AR – Action Research

COP – Communities of Practice

CCD – Cross-cultural Design

CDSM – Chronic Disease Self-management

CHI – Computer-Human Interaction

CJM – Customer Journey Map

CVD – Cardiovascular Disease

EBD – Experience-based Design

ECD – Experience Centred Design

Healthcare IT – Healthcare Information Technology

HIV – Human Immunodeficiency Virus

HM – The HealthMap Study

IDU – Infectious Diseases Unit

JMIR – Journal of Medical Internet Research

MVP – Minimum Viable Product

NHMRC – (Australian) National Health and Medical Research Council

NHS – (British) National Health Service

PD – Participatory Design

PWHIV – People living with HIV

RCT - Randomised Control Trial

SmCess – Smoking Cessation

OHC – Online Health Community

UCD – User-Centered Design

Statement of Original Authorship

The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

QUT Verified Signature

Signature:

Date: ________12 March 2016_____________

Acknowledgments

I have travelled along an astonishing road the past two years and that journey would never have begun, or been completed, without the support and sacrifice of my life-partner, my dear husband, Stephen Williams. Stephen's faith in me, and his patience as I navigated the vagaries of academic life have been unflinching. I also am very grateful to my patient and loving son, Dominic, who has missed out on so many fun times, especially this summer, as I buried myself in writing. I look forward to building some special memories with you and taking time to play and relax.

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My thanks also go to my supervisors: Jared Donovan, Julian Elliott and Karalyn McDonald.

Jared has generously shared his time, his expertise and his own research work to support my efforts to reinvent myself as a bona fide design researcher. There were times when the world of academic design research seemed to me as strange and esoteric as the medical research domain. Jared patiently persisted with my naïve and ungainly attempts to become a serious design researcher and any competency I may display owes everything to both Jared and Margot.

Julian's invitation to join the HealthMap Study was a remarkable leap of faith and an incredible opportunity, which I confess I didn't fully comprehend at the time. Julian's desire to include design processes in the scope, the direction and the manifestation of the HealthMap Study is the foundation for this entire body of work. Julian's qualities of humanity, compassion and intellectual curiosity set the cultural tone for the HealthMap Study and supported us all in searching for a holistic solution that would really make a difference for people with Human Immunodeficiency Virus

(HIV) seeking to manage their health and wellbeing. To be a part of such a project is a privilege far beyond anywhere I ever thought my design journey would take me.

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I would also like to thank Tanya Millard for sharing her insights into chronic disease self-management and commenting on draft papers. I appreciate the time she has taken, despite her own docotoral dissertation demands, and the demands of a newborn baby!

I owe a huge debt of gratitude to Alex Tam, a wonderful Interaction Designer and colleague. Alex patiently mentored me in many skills and generously included me in his design practice. To collaborate with Alex on a design project is in itself a wonderful opportunity and I will reap the benefits of his generosity for many years to come. Beyond the development of my design skills Alex modeled the professionalism, objectivity and humility that is the hallmark of every mature designer. Given Alex's great qualities and my deepest respect for his design work I am especially fortunate to count Alex as a friend and colleague, our camaraderie and rapport was enormously encouraging to a nervous novice, and I hope that one day we can continue the collaboration... somehow, somewhere!

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1 Introduction

There is a long history of information technology deployment in healthcare, but the role of design thinking and design practice in the provision of healthcare is still emerging. This thesis reflects on the experience of designing for HealthMap, a technology-based intervention to improve cardiovascular disease risk factors for people living with Human Immunodeficiency Virus (PWHIV).

My research is as a reflective design practitioner engaged with Research Through Design and Action Research. My role in HealthMap was as a practising User Experience Designer /Interaction Designer and it is from this immersive experience that I have reflected on both my personal journey as a designer entering the domain of HIV research and the emergence of the HealthMap design. This exploration can be understood with the help of Donovan's (2011) diagram showing the relationship between Action Research and a process of design in Figure 1.1.

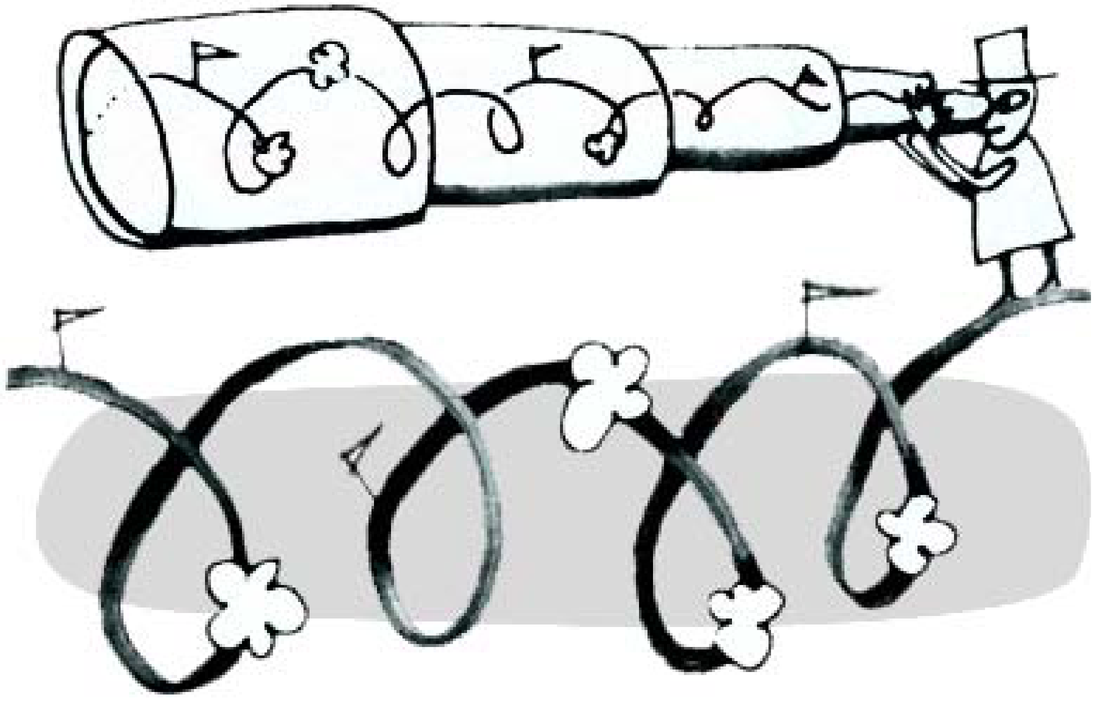

Figure 1.1 Relation between Action Research and a process of design (Donovan, 2011:65)

In this diagram the loops of the lower spiral represent the stages of a design process where the clouds indicate design activities that move design forward and the flags mark the emerging understandings that inform the next phase of engagement.

The person in the upper half of the diagram is reflecting on the design process and the results gained through 'telescoping' the events: seeing patterns and connections with the benefit of critical thinking. The aim is to extract research insights not apparent while engaged in design action (Donovan, 2011:65-66).

The outcomes of this critical reflection have been to identify and offer framing concepts and effective tools that were valuable in the HealthMap design project in order to contribute to a knowledge base of good practice for healthcare design. This follows Schön's belief that *...practice knowledge* [can be] *made explicit and formulated as to be useful in other situations too*. (as cited in Wright and McCarthy, 2010:92)

1.1 Motivations

The overarching goal of this thesis is to contribute knowledge that can help to build a community of practice for design practitioners and design researchers in the healthcare domain. Although examples of User-Centred Design (UCD) processes successfully employed on health design projects exist, there are still many particularities about the field of healthcare that are yet to be identified, articulated and widely shared in the Interaction Design practice community. Some examples of specific needs are: i) the need to address the unfamiliarity of design practitioners with the strong, value-driven, cultural context of healthcare, ii) the need to offer tools for exploring and traversing the boundaries between medically-centred healthcare knowledge and UCD – with a view to compiling a knowledge base that is meaningful to a multi-disciplinary community of practice for healthcare design and iii) the need to understand more fully the value of design framing and design methodologies in contributing to healthcare innovation, especially the role of intuition and empathic design (Brereton, 2009; Chen et al., 2014; Ross, 2014; Sanders et al., 2010; Segalowitz and Brereton, 2009; Stolterman, 2008; Wenger et al., 2002; Wright and McCarthy, 2008).

Identifying the characteristics, opportunities and obstacles of healthcare design has been the focus of recent work in Service Design and User-Centred Design, and this thesis takes a similar exploratory, case-study approach (Bowen, Dearden, Wright, Wolstenholme, and Cobb, 2010; Bowen, McSeveny, Lockley, Woltenholme, Cobb and Dearden., 2013; Dearden, Wright, Bowen, Rahman, Cobb and Wolstenhome, 2010; Jones, 2013).

There is also an underlying attitude in Interaction Design practice to approach problems from new perspectives. In addition to the knowledge gaps described above this thesis aims to articulate how a design approach can seek to navigate the socio-technical complexity often encountered in healthcare technology projects.

1.2 Research Goals

The research questions discussed in this paper emerged from an initial aim to explore the role of design in a chronic disease management healthcare context, and to address an overarching goal 'What can be learned from the HealthMap design project that offers insight to designers who are unfamiliar with the healthcare domain?'

This exploration was informed by twelve months immersion in HealthMap design and project strategy work, followed by a reflective enquiry into the HealthMap design data, design activities and design artefacts. My enquiry was into the emergence of the HealthMap design, its design journey, and the touchpoints that indicated success or difficulty.

The resulting Research Questions (RQ) for this thesis are RQ1) How can we begin to map the healthcare cultural landscape? RQ2) What contributes to the effective use of design personas in a healthcare design project? RQ3) How can we envisage social media features for the highly stigmatised HIV positive population?

How this enquiry was conducted is described in Section 4: Methodology. The three resulting research papers are presented in Section 5: Results.

1.2.1 Investigation

The reflective enquiry led to two lines of investigation, 'project' and 'personal'. The project inquiry identified key touchpoints in the design project, and selected two workshops as particularly significant. The first workshop was an idea-generating workshop utilising two objects with opposing attributes as design provocations. This workshop proved a rich design activity for the HealthMap team with a number of outcomes. One outcome was a strategic framing concept for describing the healthcare landscape when designing for chronic disease self-management (CDSM). This is presented in Paper 1: *Pointy versus Soft: towards a design language for Chronic Disease Self–Management in Healthcare.*

The second workshop was a collaborative persona-building workshop. On reflection the workshop served as a dialogical process for testing and validating my empathically-driven design understanding, including my tacit knowledge of stigma.

Analysing the processes that comprised the persona-building workshop and identifying the outcomes from the workshop are the focus for Paper 2: *A collaborative rapid persona-building workshop: creating design personas with health researchers*.

The personal inquiry was into the development of empathic design understanding, which evolved into a rudimentary tacit knowledge of HIV and accompanying stigmas. The developing empathic understanding of stigma engendered a shared assumption with the HealthMap researchers against the suitability of mainstream social media features for people with HIV. I decided to test the validity of this assumption by re-examining the HealthMap qualitative data and comparing the findings with relevant literature. The results are presented in Paper 3: *Dipping a toe in the water': addressing the effects of stigma and avoidance when designing social media features for people with HIV*.

1.3 Thesis overview

This thesis begins in Section 2 by describing the HealthMap project. It introduces the HealthMap intervention aims, its stakeholders, design team and the HealthMap design processes and outcomes. This articulates the context for the reflexive enquiry. That is, it presents the contextual factors from which the research concepts and design practice enquiries emerged.

Section 3 discusses the literature relating to the basis for a reflective practice approach to HealthMap and its suitability as a case study in User-Centred Design. It also introduces literature relevant to recent health technology design research, literature on the need for understanding around designing for stigma and for clarity in the practice of design personas in a healthcare domain.

Section 4 discusses the methodology for reflecting on the personal empathic domain knowledge and the inquiry into the HealthMap project design work. This section shows how the data was approached, the analytical methods and how the research questions emerged and were framed.

Section 5 contains the three submitted papers:

1) *Pointy versus Soft: towards a design language for chronic disease self-management in healthcare.* This paper contributes the framing concept of healthcare as a 'landscape' for design in which the persistent, 'hard' features of systemic functionality and safety can be understood as 'pointy' and the affective, human-centred needs as pervasive 'soft' terrain features. It identifies particular healthcare characteristics as

constant pointy and soft landmarks requiring strategic design approaches. In this thesis ‘Pointy versus soft’ will be applied as a design strategy to describe and conceptualise the healthcare context for design work.

Pointy Versus Soft was submitted as a short paper to two conferences: OzCHI 2013 and to PervasiveHealth 2014. While not accepted as a short paper, reviewer comments recommended further elucidation of underlying data to support a long paper format. The paper was extensively revised and extended, then submitted to the Journal of Medical Internet Research (JMIR) in March 2015.

2) *A Collaborative Rapid Persona-building Workshop: Creating Design Personas with Health Researchers,* describes the HealthMap Collaborative Persona-building Workshop as a process for health researchers to participate in design and was published in the International Journal of Sociotechnology and Knowledge Development: Double Issue on Sociotechnology and Pervasive Health (IJSKD) 6(2):17–35.

3) *Dipping a toe in the water’: addressing the effects of stigma and avoidance when designing social media features for people with HIV.* This paper contributes two design strategies: a) ‘Designing in the face of stigma: a design tension’ and b) ‘Finding meaningful support in the face of stigma: a design tension strategy’. This paper was submitted to the JMIR March 2015.

Section 6 concludes with the discussion of how a potential community of practice for healthcare designers could benefit from the contribution of the ‘Pointy versus Soft’ design lexicon, from the HealthMap persona-building methodology and from principles for social media design with stigmatized users.

2 Background

2.1 The HealthMap Study

The average age of Australians living with HIV is now 45 years and over. The number of Australians living with HIV who are aged 60 years or over has increased at 12% per year since 1995. People living with HIV experience earlier onset of the chronic diseases associated with ageing and these chronic co-morbidities makes caring for their HIV more complex and problematic. HIV care in Australia is transitioning from a primary care model to a chronic disease care model and needs systems to prevent and manage these chronic co-morbidities. Self-management support is integral to the large-scale practice change in chronic care management being driven by the National Primary Care Collaboratives and is a specific focus of the national Sharing Health Care Initiative. (HealthMap research proposal, internal document, 2008).

HealthMap is a National Health and Medical Research Council (NHMRC) funded technology-based intervention currently undergoing a two-year cluster-radomised control trial. The trial will evaluate: the effect of self-management support on cardiovascular disease (CVD) risk and other chronic condition outcomes in PWHIV; the patient and health care provider experiences and acceptability of interactive self-care plans and self-management support; and intervention cost-effectiveness and effect on health service utilisation.

The HealthMap project is led by a Monash University Infectious Diseases Unit (IDU) HIV researcher and treatment provider. The design team comprised of the hospital-based HIV clinician, a social researcher, two self-management researchers, one academic design researcher, a practising User Experience Designer with ten years experience in the USA health industry and myself, a User Experience Designer with one year's experience prior to joining HealthMap. My role on the design team was funded by Queensland University of Technology, Science and Engineering Faculty, through a Masters by Research scholarship.

2.2 My role in HealthMap: design practitioner

I joined the HealthMap team June 2012, eight weeks before a Design Intensive (see Figure 2.1 below)[1]. The HealthMap team had already collected data and done focus

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[1] 'Design Intensive' was a defined timeframe for Designer 3 to be co-located with the team and lead user-centred research and interaction design activities. The majority of interaction design was achieved during the Design Intensives.

group work to inform design. My initial role was to understand the project priorities and previous activities and to scope the design focus, with a view to conducting any design research or activities to support the scheduled generative stages of the HealthMap design. This led to planning and implementing design activities with the HealthMap team to create as full a data set as possible pre-Design Intensive, given the ethical and time constraints. It also required extensive ethics application work to allow concept and pilot testing with PWHIV. Discussion of this work is in Section 4: Methodology.

The original NHMRC grant budget allowed for software development, but did not specify a design-specific phase or allocate resources for design separate from development work. The driver for design to play a role in the project was the Department of Infectious Diseases clinical researcher / project leader. He had previous experience with designer-led project scoping and smaller scale software development. Although this particular HIV researcher was very design literate, and extremely open to the value of design, his experience of direct collaboration in design activities was limited. He invited the academic design researcher to give guidance on the recruitment of design practitioners and design research strategy. The other HIV researchers had no previous experience of technology co-design processes. This created a context for design where designers needed to address stakeholder design education and navigate numerous ‘knowledge boundaries’ (Brereton, 2009; Segalowitz and Brereton, 2009).

As User Experience designers, Designer 3 and I sought to prioritise invovlement from all and any ‘end-users’ in our research and design activities. The opportunities for collaboration with PWHIV and healthcare stakeholders varied and no specific design activities had been described or allowed for in the original grant application. At times there were strong cultural, institutional and practical barriers to including PWHIV and other users in design activities but as designers we persisted in seeking to discover, make explicit and prioritise the intrinsic needs and desires of PWHIV.

The final HealthMap design is typical of an enterprise information technology (IT) platform in that it reflects competing stakeholder priorities for content and functionality and is not primarily an ‘User-Centred Design’ technology. However, several features are grounded in the data from PWHIV user research and direct PWHIV critique of concepts and wireframes.

The HealthMap designers applied traditional User-Centred Design (UCD) methodologies and Service Design tools given the day-to-day opportunities and constraints of the project.

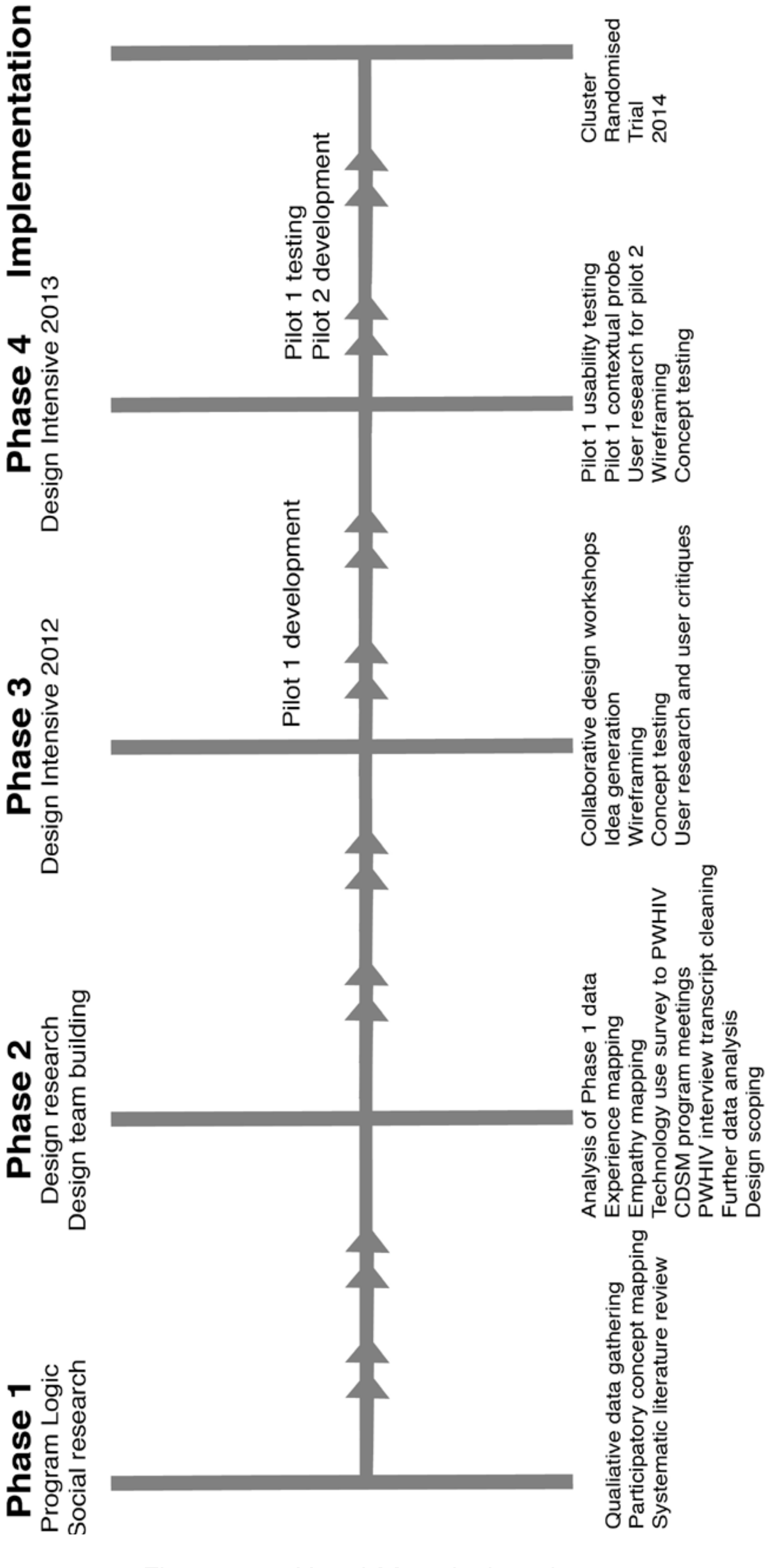


Figure 2.1 HealthMap design phases

2.3 My role in HealthMap: action researcher

The reflective research analysis began towards the beginning of 2013 as the HealthMap software development began, (see Figure 2.1). This required my 'switching hats' from authentic design practitioner to academic action researcher. Although I had sporadic involvement with the ongoing design work (for example, Pilot 1 usability testing), the scope of the data analysis and formation of research goals required my full-time attention. Details of how this reflective enquiry was conducted are in Section 4: Methodology.

2.4 HealthMap Design Phases

The HealthMap design evolved through four phases of research, design intensives and development across three years, from 2011–2014. Figure 2.1 shows the sequence of design phases.

The data for this thesis are mainly taken from Phase 2 and some from Phase 3. The design methods used were primarily rapid and lean methods that explored, analyzed, reflected upon and iterated ideas. Rapid and lean tools were required because of the extremely short lead times available, limited direct access to potential users due to ethical constraints, healthcare provider unavailability and budgetary constraints.

2.5 HealthMap design activities

The Phase 2 design research and design activities were conducted using Service Design tools to deal with the diversity and breadth of design questions facing the team. The initial Service Audit included: visiting technology-based chronic disease self-management programs, listening to the recordings of interviews with PWHIVs, distributing a survey on technology use and CVD risk indicators to three HIV clinics in Melbourne and a small number of interviews with healthcare providers. The team created a PWHIV Experience Map, a hospital HIV clinician Empathy Map and four PWHIV Personas based on the interviews as references for design discussions.

The Design Intensive initiated the Service Visioning phase. This began with a Customer Journey Map (CJM) that captured the Opportunity Areas (Touchpoints) for both the patient and provider around the regular scheduled HIV consultation, usually every three to four months. The CJM has three sections: Pre-Visit (pre-consultation), Visit (duration of consultation) and Post-Visit (post-consultation). This was used as the structure for idea generation processes that included divergent brainstorming to idealise the service and responses to physical design provocations. These exercises generated low fidelity maps, affinity diagrams and sketches, which were then synthesized into our design principles and a set of wireframes that describe an interactive service using SMS, a mobile application, a healthcare provider tablet, an online patient portal and a phone-based health coach service.

2.6 HealthMap development

HealthMap was designed to build in two phases, with the assumption that Pilot 1 would function as a minimal viable product (MVP). Pilot 1 was a web-based tablet application for use during the scheduled HIV treatment consultation. The aim of the application was to enrich and support a collaborative patient/provider conversation around chronic disease risk and lifestyle factors and offer a chronic disease management plan. Pilot 2 was the online patient portal to include rich information, personal self-management plans, and online health coaching.

HealthMap has become a web-based self-management tool accessible via smartphone, tablet or desktop. It helps patients manage their medications, health goals and connects them with health care providers. The cluster-randomized trial will run for two years at 12 clinics throughout Australia.

3 Literature

The literature review began with access to the HealthMap systematic review of literature on technology-based chronic disease self-management interventions. This systematic review and other emerging relevant literature informed Design Phases 2 and 3, as they were sought in response to design needs. A review of literature continued as a systematic reflexive exploration from Phase 4 onwards. Figure 3.1 below shows when the literature review took place in relation to HealthMap project design.

3.1 Research questions

The overall research goal was 'What can be learned from the HealthMap design project that offers insight to designers unfamiliar with healthcare as a domain for design?' The literature review was guided by two additional framing sub-questions with a practice-based, practical focus.

These framing sub-questions were: i) 'How can this literature help practising designers in the day-to-day processes of healthcare design work?' and more particularly as ii) 'How can this literature support designers inexperienced in healthcare design as they are engaged in their first healthcare project?'

These sub-questions questions shaped my literature selection and my literature critique. A result of this approach was the inclusion of a number of case studies and presentations from the User Experience Design industry as well as case studies reported in peer-reviewed journals and proceedings. It is with these questions in mind that I sought to understand the relevance of advice offered from those recently researching in the field of healthcare design and to identify areas in need of further exploration and evidence.

In taking a pragmatic approach (that is, valuing realistic and practical considerations above theoretical considerations) there is a limitation. The limitation is that by examining one-off case studies the results reported are mediated by the contextual design constraints of the work (such as availability of resources, unforeseen obstacles that impacted design, and time constraints). Another mediating factor is the design capabilities of the design teams and design researchers. Design is a practice where competencies grow over time.

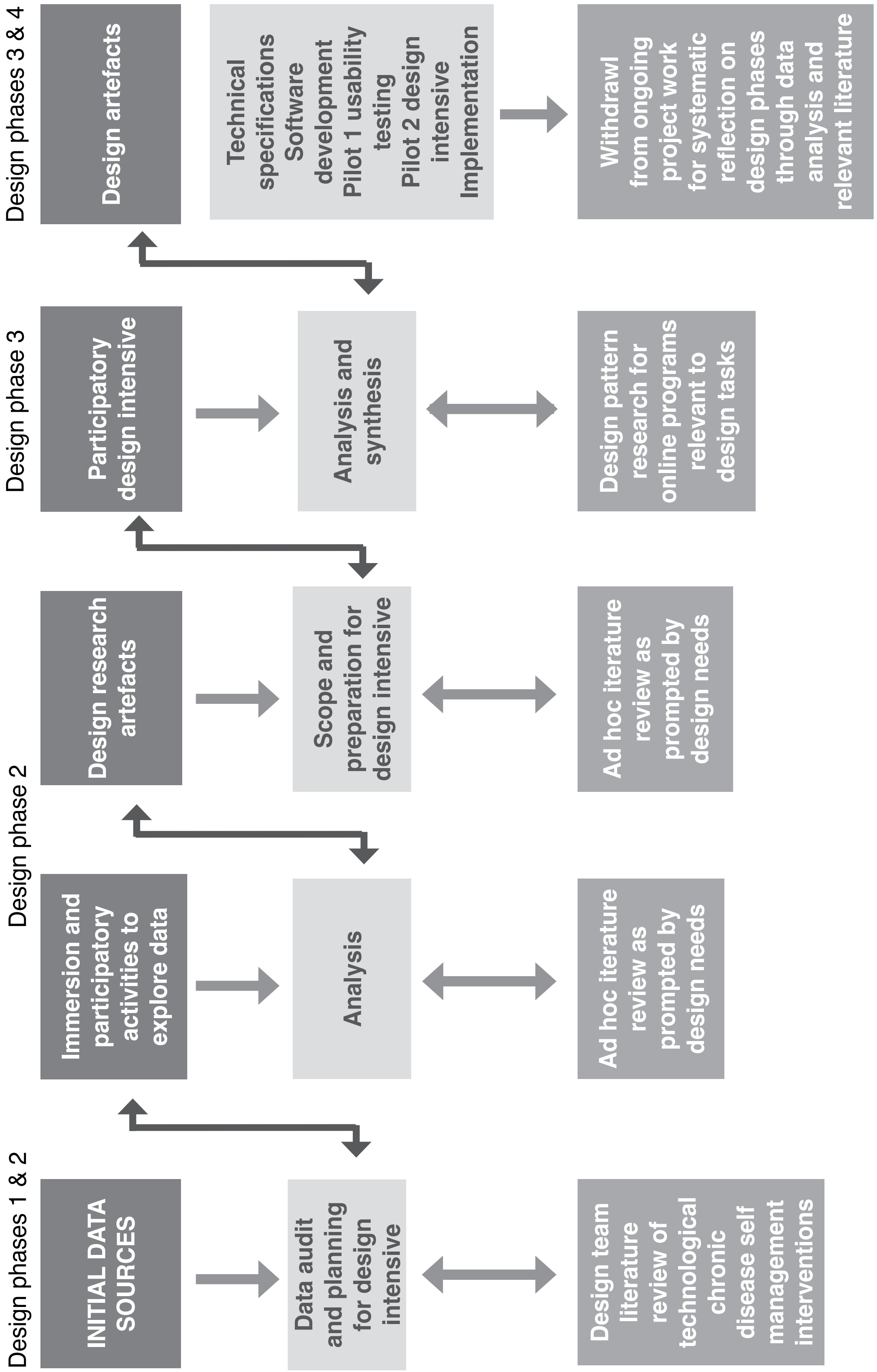


Figure 3.1 Healthmap literature review timeline

It may be safe to assume that case studies that report new or unexplored design territory for the participants will necessarily result in design decisions and methods that may have been different if executed by teams with more design experience in similar projects. This mediating effect is explored by Light and Akama, (2010) who point out that it is not meaningful to separate the designer from method since we cannot know participative methods without the person or people enacting them.

This limitation impacts on the suitability of case studies to inform the guiding questions. In asking the sub-question: 'How can this literature help practising designers in healthcare design?' judgements have been made regarding the transferability and relevance of case studies to the HealthMap intervention design context.

3.2 Overview

The following sections will discuss two themes that emerged from the literature and are relevant to the HealthMap design experiences: complexity and unfamiliarity. The literature suggests that unfamiliarity is a significant component of complexity and a barrier to designers coping with the complexity of healthcare as a design context.

These two themes are explored through an examination of industry case studies and research literature that specifically sought to inform an understanding of the issues and strategies employed to address the challenges of healthcare as a domain for many practising designers.

These criteria identified relevant research from the fields of Interaction Design, Healthcare User-Centred Design (UCD), Participatory Design (PD), Experience-Centred Design (ECD), Experience-based Design (EBD), Empathic Design and with reference to Cross-cultural Design (CCD). The most relevant case studies came from these diverse research backgrounds, but could include common values and shared processes. I have therefore drawn on different research disciplines in order to find those approaches that seem most relevant to the research question and the circumstances of the HealthMap Study project. The different approaches have proved helpful in understanding a range of viewpoints for evaluating design processes and design outcomes.

For consistency and clarity I will refer to the HealthMap Study design practice as 'User-centred Design' that incorporated experience-centred, empathic and participatory processes where practically possible.

3.3 Complexity

Stolterman (2008) reminds us that complexity is a staple of the Interaction Designer's working world:

> *Dealing with a design task in an unknown or only partially known situation, with demanding and stressed clients and users, with insufficient information, with new technology and new materials, with limited time and resources, with limited knowledge and skill, and with inappropriate tools, is a common situation for any Interaction Designer. Dealing with such messy and "wicked" situations constitutes the normal and everyday context of any design practice.*
>
> (Stolterman, 2008:55)

Sanders and Stappers (2008) describe the inherent complexity of initial exploratory design research as 'fuzzy', ambiguous and chaotic. They define this fuzzy phase as encompassing many activities that inform and inspire the exploration of open-ended questions without knowing whether the eventual design outcome will be a product, a service or some other entity.

Despite the acceptance of complexity as typical of design projects, some researchers attribute healthcare with a particularly high level of complexity as a design domain (Cottam and Leadbeater, 2004; Hasvold and Scholl, 2011; Jones, 2013; Mønsted and Onarheim, 2010; Sanders and Stappers, 2008).

Jones observes:

> *Healthcare is a massively complex system that deals with at least two irreducible sources of complexity: the institutional (distributed provider systems and hospitals) and the personal (the biological and social setting of the human body). Furthermore, these realms cannot be isolated, because the purpose of the institution is to serve individuals. An infinite variety of possible problems arise in the relationships between these two spheres of purposeful behaviour.*
>
> (Jones, 2013: xviii)

Mønsted and Onarheim (2010) attribute barriers for user participation in healthcare design activities to healthcare being a highly complex and heterogeneous domain. Sanders and Stappers (2008) place healthcare in the realm of emerging design practice that has outgrown traditional user-centred, product-focussed design. They describe emerging design as a combination of design disciplines that focuses on designing for a purpose, necessarily taking longer views and addressing larger scopes of enquiry.

A helpful illustration of the complexity of a healthcare institution is shown in Figures 3.2 and 3.3 – the diagrams below of departments and subspecialties at the Mayo Clinic– showing the growth from 1925 to 2010.

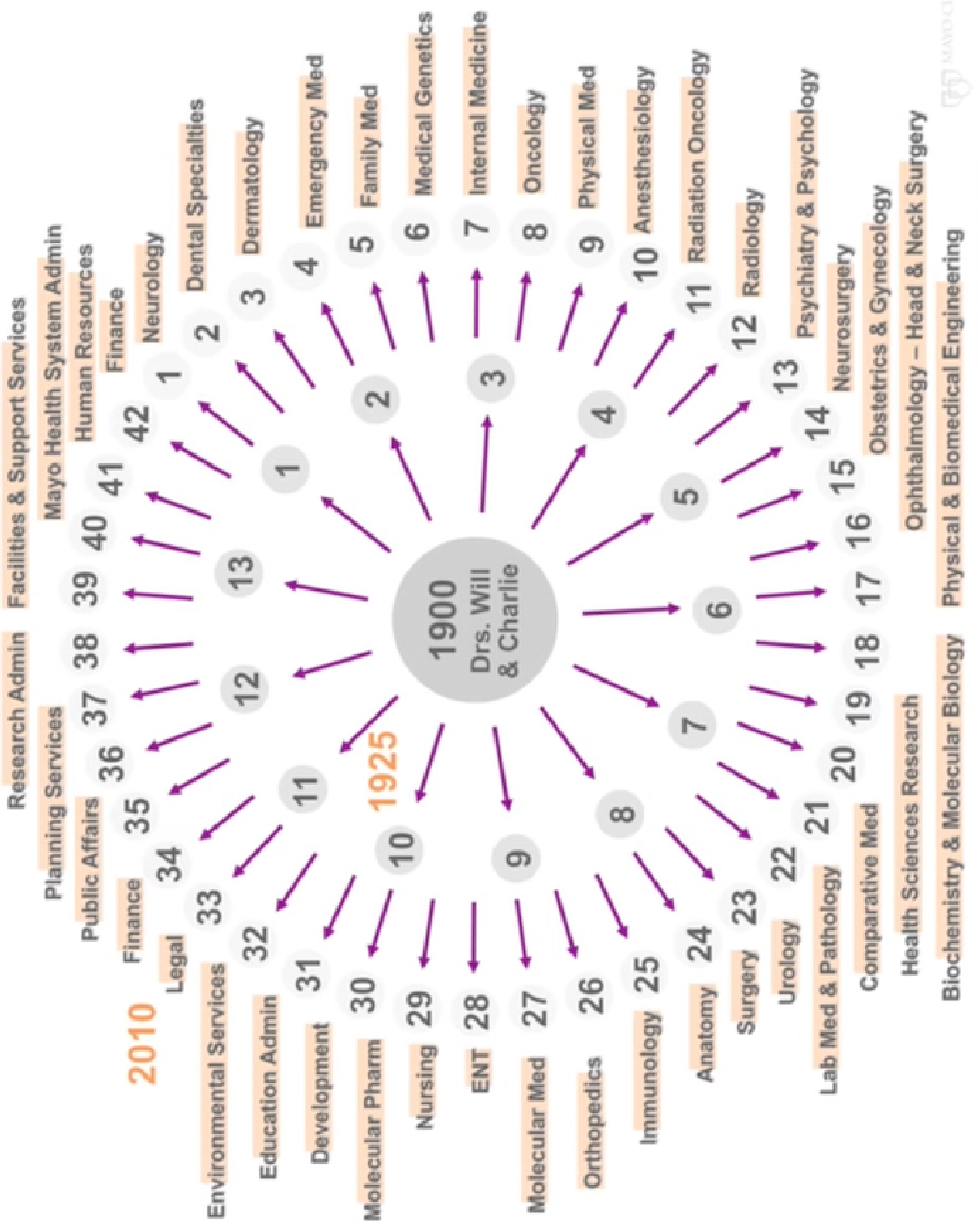


Figure 3.2 Mayo Clinic departments 1925–2010

(Ross, 2014) © MayoClinic

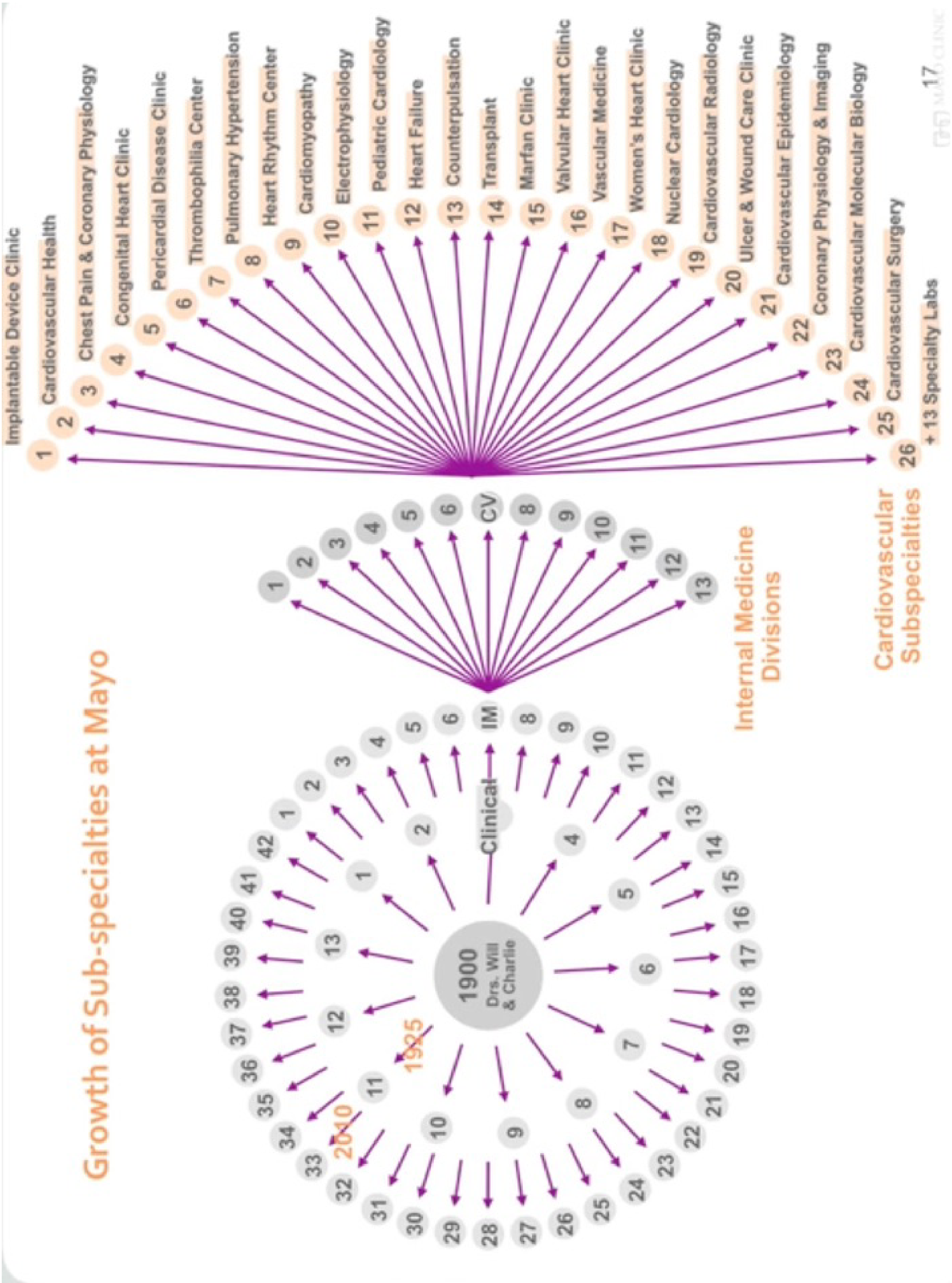


Figure 3.3 Mayo Clinic sub-specialties

(Ross, 2014) © MayoClinic

While these figures clearly display institutional complexity, healthcare is a deeply complex domain for design practice due to the inter-relationship between the complex institution and the physical and social complexities of patients and their carers.

The Mayo Clinic describes a 'patient spectrum' as defined by patient clinical

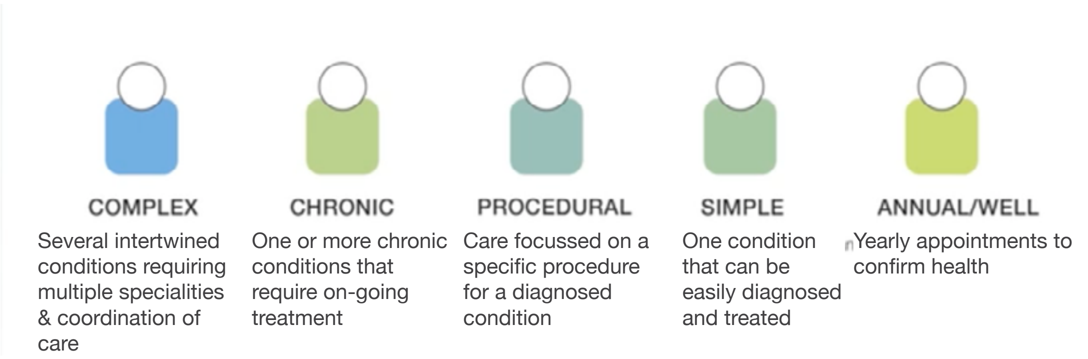


Figure 3.4 Mayo Clinic patient spectrum

(Ross, 2014) © MayoClinic

Ross, (2014) points out that many Mayo Clinic patients are 'poly-complex', with multiple chronic diseases and procedural care often intersecting. Such 'poly-complexity' can be an intimidating design context. Stolterman describes this intimidation as an *overwhelming* experience for designers:

> *...The designer has to make all kinds of decisions and judgments, such as, how to frame the situation, who to listen to, what to pay attention to, what to dismiss, and how to explore, extract, recognize, and chose useful information from all of these potential sources.* (Stolterman, 2008:57)

Ross has a longstanding career as a designer, researcher and innovator, with twelve years experience in healthcare. She clearly perceives healthcare as highly complex and challenging. I suggest that the challenge of this complexity is magnified greatly for designers with no experience or familiarity with the context of healthcare for design.

3.4 Unfamiliarity

One aspect of complexity that designers routinely address is unfamiliarity. Many design methods and design values are aimed at making sense of the unfamiliar and constructing a shared understanding between practising designers and non-designer participants. Wright and McCarthy (2010), in discussing Empathic Design, describe the designer's goal as to understand the nuances of place and person. Participatory Design is predicated on both the practising designer's exploration of context and the context-specific stakeholders' role as co-designers in order to surface tacit domain knowledge and build empathic understanding to inform creativity and support collaboration (Sanders, Brandt, and Binder, 2010; Sanders and Stappers, 2008; Simonsen and Robertson, 2012).

From the literature it would appear that a persistent barrier to designing for healthcare is the inherent unfamiliarity of the domain. Chen, Cheng, Tang, Siek, and

Bardram, (2014) describe the work of healthcare providers as 'invisible' to designers. They report that a Computer-Human Interaction (CHI) panel discussion intended to discuss the impact of technology on patient / provider interaction instead became focussed on questions regarding the daily practices of healthcare providers and how design researchers might gain access to study them. Faced with the CHI audience's unfamiliarity with the health domain Cheng et al. were 'inspired' to contribute some basic insights and address potential misconceptions around healthcare provider attitudes and behaviours.

Mønsted and Onarheim, (2010), identify barriers to user participation in Participatory Design for health. They describe these barriers as: a lack of user availability, conceptual barriers (in the mindsets of healthcare participants) and pragmatic barriers such as physical or cognitive restrictions and geographical and technological distribution. By describing these pervasive domain features as design barriers there is a suggestion that there is a disjunction between what the design researchers were intending (their model of user engagement) and what they identified as actual opportunities for user participation. I suggest that a lack of familiarity with health as a design context contributed to this disjunction.

Bowen et al. (2013) make a similar point (from their healthcare experience design research) by observing that the expectations of Participatory Designers can ...be naïve when working in unfamiliar and complex organisational contexts. (Bowen et al., 2013:242)

3.4.1 Cross-cultural Design: a response to unfamiliarity

The use of ethnographic techniques in Participatory Design assumes the influence of 'culture' in contexts for design projects. Understanding organisational cultures, and informal sub-cultures, is a strong contributing factor to successful Participatory Design (Sanders and Stappers, 2008; Simonsen and Robertson, 2012). Cross-cultural information technology design often seeks to design for economically, culturally and linguistically diverse settings. Such settings are often geographically remote, economically poor and culturally unfamiliar in relation to the researchers/designers working in information technology for development or human computer interaction (Brereton, Roe, Schroeter, and Hong, 2014; Winschiers-Theophilus, Bidwell, and Blake, 2012). They also often present the design researcher with complex layers of social and cultural dynamics in which to make sense of needs and opportunities for design (Winschiers-Theophilus et al., 2012). Consequentially Cross-cultural Design practitioners have often adapted their Participatory Design methods and practices to suit very particular cultural settings.

3.4.2 Healthcare as a cultural setting

Bowen et al., (2013) make a direct link between the work of Cross-cultural Design and the need to approach healthcare as a domain with strong distinctive cultural attributes. It follows then that some understanding of good Cross-cultural Design practice could be relevant and helpful to design for healthcare settings.

3.4.3 Good Cross-cultural Design collaboration

The Participatory Design and Cross-cultural Design literature offer some guidance on the qualities of 'good' design collaboration. For example, Brereton and Buur, (2008), indicate that

> *New formats of participation can be characterised by their sensitivity towards new types of network relations among people, the diverse motivations of people to participate, the subtle balance of values and benefits involved in collaborative endeavours, and the inherent power relations between participants.*
>
> (Brereton and Buur, 2008:112)

Some examples of practices identified as 'good' include: identifying and integrating existing participatory practices from within the domain, a value of mutual learning, and a willingness to enter into the communication and interaction methods of the domain (Winschiers-theophilus, Chivuno-kuria, Bidwell, Box, and Blake, 2010). Brereton et al., (2014) advocate for an approach where the purposes and modes of engagement are discussed and are mutually beneficial, that is, there is reciprocity in the relationship between designer/researchers and participants.

Brereton also introduces the term 'embedded research / embedded design'. Embedded design is characterised by a designer located within a design context for a long length of time. The aim of this co-location is to enter into the network of working relations that exist between people within the context for design and for the designer to gain legitimacy from a natural integration into the fabric of the target community (Brereton, 2009). Brereton demonstrates that an embedded approach allows for many of the qualities of good Cross-cultural Design participation to emerge and influence design iterations and implementation. The value of situated design is not a new insight, with the value of designing in situ long recognised in User Centred Design, (Wright and McCarthy, 2010), but there can be a sporadic or truncated quality to designers situated in a design context. Embedded design intensifies and enriches the value of in situ engagement through the integration of the designer within the fabric of existing networks, beyond designated design activities. Whether such embedded design activity is possible in healthcare for non-healthcare-provider designers is a question to ponder from the literature.

If we take healthcare as a complex design context, with strong cultural features that require design awareness and sensitivity, what are the implications for design practice?

In the following sections we will discuss how a designer might navigate the complexity and unfamiliarity of healthcare and how a designer might engage with healthcare stakeholders and patients. Possible barriers, opportunities and strategies will be raised with regards to the implications for future healthcare design practice.

3.4.4 Designers making sense of the unfamiliar – navigating healthcare complexity

In discussing healthcare culture, and the designer's engagement with healthcare culture, we encounter complexity, which is proposed earlier as a typical healthcare characteristic. From the literature it is designers' exploration of 'messy' healthcare problems by which the healthcare culture and healthcare stakeholder engagement is understood (Jones, 2013; Ross, 2014; Sanders and Stappers, 2008). In reflecting on their experiences healthcare designers share their growing contextual understanding and the findings for adapting their practice. The literature reveals designers often exercising 'reflection-in-practice' and 'reflection-on' practice' (as described by Schön) as they communicate their understandings of the healthcare domain. (Bowen, Dearden, and Dexter, 2014; Schön, 1992). The following discussion will examine a number of case studies with regard to how the authors report healthcare cultural features and their impact on design, specifically looking at: context, modes of engagement and design practice.

I will include the elements of good Cross-cultural Design collaboration – cultural sensitivity, shared values, mutual benefit, adaption of domain modes of engagement – in the discussion (Brereton, et al., 2014; Winschiers-Theophilus, et al., 2012; Winschiers-Theophilus, et al., 2010).

3.4.5 Describing unfamiliarity: The context of healthcare culture

A number of authors describe contextual features that are prominent in the healthcare domain.

Complex ecosystems

If we refer back to Ross' examples in Figures 3.1 and 3.2 we can see what Bowen et al. (2013) describe as strong professional hierarchies and high degrees of specialisation, which lead to working in silos (Ross, 2014).

For the designer, coming to grips with the details of organisational structure and the interconnectedness of institutional processes can have a significant impact on design activities. Designers may be required to make sense of a widespread ecosystem within the healthcare system and reaching beyond the boundaries of institutionalised medicine into communities of care (Jones, 2013). This is recognised in the literature as 'pervasive health' (Dearden et al., 2010; van der Linden, Waights, Rogers, and Taylor, 2012). Anticipating 'knock-on' effects, understanding the interoperability of systems and awareness of channels for resources and support are all potential challenges for a design team (Berryman, Haberman, and Lynn, 2011; Dearden et al., 2010; Hasvold and Scholl, 2011; Jones, 2013; Nilsson, Borg, Hofflander, and Eriksén, 2010).

Medical ethics

One feature of the medical 'landscape' is the need to apply for medical ethics committee approval. Grocott, Blackwell, Currie, Pillay, and Robert, (2013) relate a situation where the need for repeated ethical and research and development review created project-threatening time delays. In addition, the iterative nature of design work proved challenging for the regulatory agency to decide when the prototype would require approval. Ethics approval requirements, particularly the unfamiliarity of medical ethics committees with design methodologies, can be a cause for design project delays (Berryman et al., 2011; Bowen et al., 2013; Jones, 2013).

While ethics committee approval, and ethical considerations, are appropriate design values, how to configure design activities to suit a medical ethics protocol is an area that needs continued development (Simonsen and Robertson, 2012). For example the value of patient participation needs to be in harmony with a duty of care to not burden patients with a level of involvement that is physically, emotionally or socially burdensome (Bowen et al., 2013; Grocott et al., 2013; Jones, 2013).

Safety

Several designers report the significance of patient safety as a defining feature of healthcare culture. Avoiding risks to patient safety is not limited to a technical function or regulatory obligation; it is a pervasive cultural value that strongly influences healthcare provider attitudes and can affect willingness to collaborate in design activities.

Ross recounts an exchange with a surgeon where her [perhaps insensitive] enquiry for information was met with *well I could either be standing here explaining it to you, or I could be inside* [the operating theatre] *saving a life*. (Ross, 2014:31.00).

Berryman et al. give details on the strict compliance required for training about patient safety and also the strict protocols for the design team's potential exposure to pathogens and risk, including formal accreditation and immunisations. The authors contrast these strict protocols with the creative freedom of the cadaver room, where there is no risk to life, and designers, physicians and engineers enjoy a comparative freedom to experiment. They remark on the relaxed and easy atmosphere in the cadaver room.

For Pickles, Hide, and Maher, (2008) patients' perception of increased safety was a design goal aligned with the aesthetics of the desired patient experience as well as a functional requirement for work practices. We can see in their example how safety is a value that crosses boundaries between disparate healthcare disciplines and patients as a common priority. Healthcare providers were sensitive to (and respectful of) patients' need to feel safe, in addition to material risk to safety.

In these accounts of healthcare characteristics: complex ecosystems, medical ethics and the importance of safety, we find examples of designers engaging in good cross-cultural collaboration through cultural sensitivity and supporting shared values. However we know from the earlier discussion of healthcare as an unfamiliar domain for designers that developing awareness of cultural characteristics and identifying underlying values can be a challenge for designers, both newly engaged in healthcare and experienced practitioners, (Bowen et al., 2013; Chen et al., 2014; Mønsted and Onarheim, 2010; Ross, 2014).

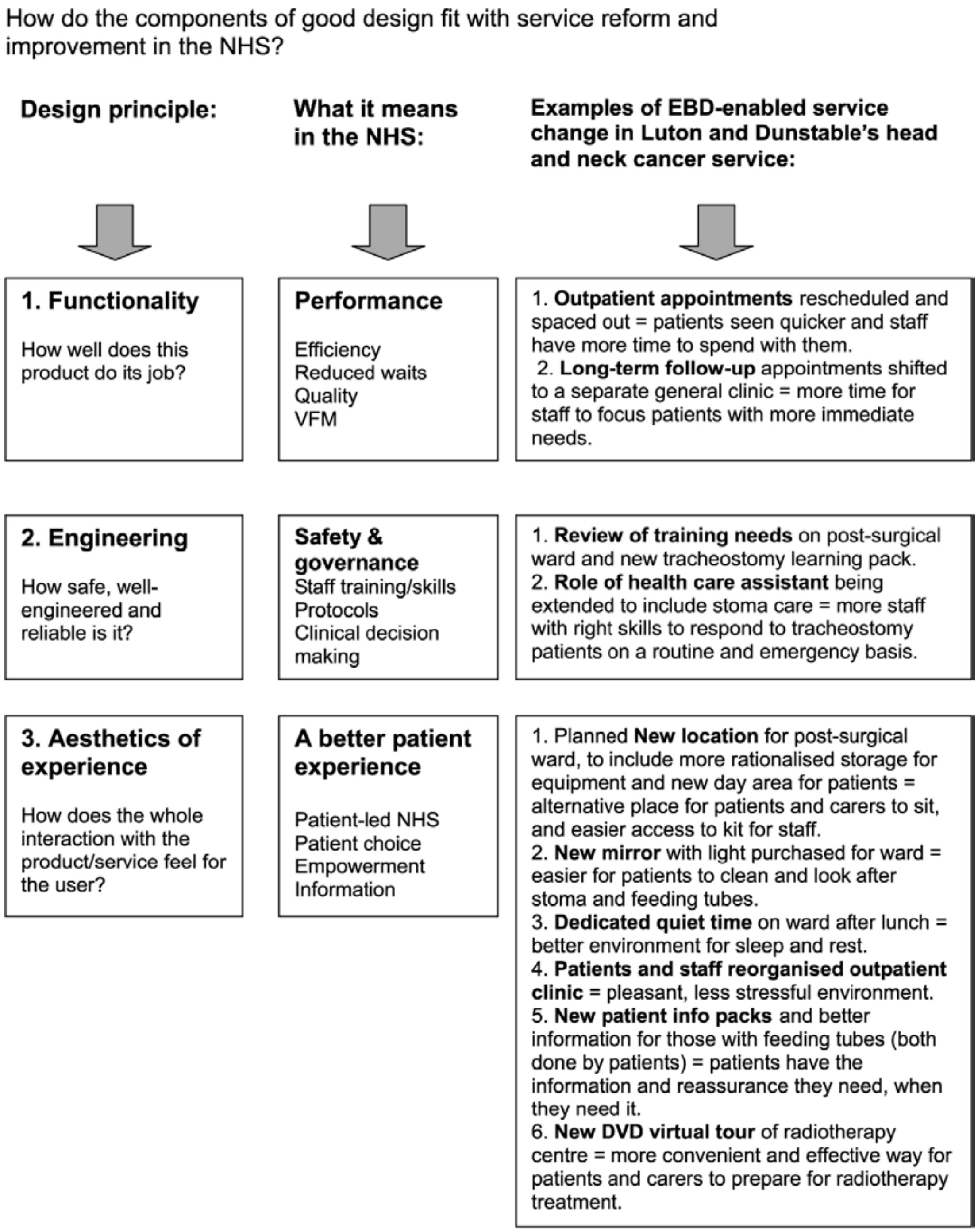
3.4.6 Making sense of unfamiliarity

A response to complexity can be to attempt to capture and 'fix' persistent elements. Stolterman, (2008) points out that our response to complexity is itself varied, including the urge to reduce complexity and exert control while at the same time possibly enjoying and benefitting from the richness and stimulus of complexity. Rogers, (2004) observes that attempts to reduce or control design complexity by applying theories or analytical frameworks can consume time and energy, thereby adding to the cost of complexity and making such approaches impractical for hands-on design practice.

Frameworks

One example of such a framework is given by Bate and Robert, (2006). They take the components of successful design as Performance + Engineering + Aesthetics, and they go on to equate successful healthcare experience design as Functionality + Safety + Usability. Pickles, Hide and Maher (2008) seem to blend the terms of these two frameworks and report that applying a framework of Functionality + Engineering + Aesthetics was helpful to evaluate their 'experience based design' process outcomes. See Figure 3.5 below.

The Pickles et al. case study described in Figure 3.5 is notable as Pickles was a clinical and departmental lead in the relevant British National Health Service (NHS) hospital department and consequently made significant 'political' power available to the design project. His influence can be inferred from his capacity to displace workload from the outpatient clinic to another 'separate general clinic'. This increased the time available for outpatient clinic appointments and delivered 'performance improvements'. It could be argued that the evident 'performance improvements' were a result of a key stakeholder's political power, rather than the power of participatory engagement. Although one can imagine the power of participatory methods to provide the evidence a key stakeholder might need to effect organisational change.



How do the components of good design fit with service reform and improvement in the NHS?

Design principle:	**What it means in the NHS:**	**Examples of EBD-enabled service change in Luton and Dunstable's head and neck cancer service:**
1. Functionality How well does this product do its job?	**Performance** Efficiency Reduced waits Quality VFM	1. **Outpatient appointments** rescheduled and spaced out = patients seen quicker and staff have more time to spend with them. 2. **Long-term follow-up** appointments shifted to a separate general clinic = more time for staff to focus patients with more immediate needs.
2. Engineering How safe, well-engineered and reliable is it?	**Safety & governance** Staff training/skills Protocols Clinical decision making	1. **Review of training needs** on post-surgical ward and new tracheostomy learning pack. 2. **Role of health care assistant** being extended to include stoma care = more staff with right skills to respond to tracheostomy patients on a routine and emergency basis.
3. Aesthetics of experience How does the whole interaction with the product/service feel for the user?	**A better patient experience** Patient-led NHS Patient choice Empowerment Information	1. Planned **New location** for post-surgical ward, to include more rationalised storage for equipment and new day area for patients = alternative place for patients and carers to sit, and easier access to kit for staff. 2. **New mirror** with light purchased for ward = easier for patients to clean and look after stoma and feeding tubes. 3. **Dedicated quiet time** on ward after lunch = better environment for sleep and rest. 4. **Patients and staff reorganised outpatient clinic** = pleasant, less stressful environment. 5. **New patient info packs** and better information for those with feeding tubes (both done by patients) = patients have the information and reassurance they need, when they need it. 6. **New DVD virtual tour** of radiotherapy centre = more convenient and effective way for patients and carers to prepare for radiotherapy treatment.

Figure 3.5 Experience-based Design evaluative framework

(Pickles, Hide and Maher, 2008)

These frameworks are useful to describe aspects of socio-technical healthcare systems and are helpful as high-level categorisation of systemic features. They are demonstrated as effective, reflexive, evaluative tools but I agree with Rogers, (2004) that they could be less helpful as pragmatic generative tools for designers 'in the wild' when confronted with the competing demands of a healthcare design project. While functionality, safety and usability are a tidy assessment of system-requirements, designing 'on the ground' can be far more 'fuzzy' (as described in Sanders and Stappers, 2008), with boundaries between these components blurred and priorities hard to balance. For example, if working in the mental healthcare field, a usability/aesthetics problem could lead to heightened anxiety, which could trigger an acutely distressing experience. What superficially was a usability issue could progress into a patient safety issue

These cautions notwithstanding, considering the natural human impulse to see patterns and make 'order' from 'chaos', and remembering the advice from Cross-cultural Design, I suggest that there is value in designers i) becoming familiar with the frameworks and concepts that have currency within their given healthcare domain and ii) looking for opportunities to arrive at shared meaning in design collaboration through the adoption of meaningful frameworks to support collective sense-making and collective priorities.

Collective sense-making: scientific rationalism and designerly intuition

As co-design methods in User-Centred Design evolve, toolkits are refined to support specific design contexts and individual designer practices. Methods for selecting and creatively applying ways of collaboratively 'making, telling and enacting' will need to be articulated and shared within the health design field (Bowen, Dearden, Wolstenholme, and Cobb, 2011; Jones, 2013; Sanders et al., 2010; Wolstenholme et al., 2010). A particular cultural challenge within healthcare design is in shifting dialogue from a scientific-oriented mode to a design-oriented mode. This is important for both design practice within healthcare and formal design research within healthcare. Stolterman puts this clearly when he observes: *dealing with design complexity involves almost fundamentally opposite goals and preconditions as does the scientific approach* (Stolterman, 2008:59). He goes on to contrast the scientific method for dealing with complexity (reductionist: focussing on one variable at a time) and the design approach to complexity, which requires that the whole composition be explored and insights relevant to design expressed in an accessible way. Science also values methodological rigour from agreed standards, while design values outcomes: success becomes apparent in location, in real use and over time (Stolterman, 2008).

The rationalist mindset of science can also contrast with the intuitive, creative processes and sense-making in design. Ross describes the impact of the scientific mindset on the Mayo Clinic Innovation Hub engagement with healthcare stakeholders. The Innovation Hub incorporates scientific phrasing into the design lexicon (layering in terms such as 'baseline' and 'sample size') while avoiding some 'trigger' words like *imagination* and *creative*, which elicit strong negative responses unhelpful to design dialogue (Ross, 2014).

Participatory Design aims to elicit tacit, non-explicit knowledge and latent needs from design participants in order to inform empathic design. The techniques employed to explore and frame the affective and experiential dimensions of a design problem necessarily relate to subconscious and subjective elements rather than the rationalistic and explicit. (Sanders, 2002; Simonsen and Robertson, 2012).

This places the healthcare designer in a counter-cultural position, which poses significant risk to productive design collaboration and requires strategic navigation and sensitivity. Practical methods for successful engagement between these knowledge boundaries would meaningfully contribute to the practice of healthcare design.

Remembering that good Cross-cultural Design collaboration includes integrating participatory practices from within the domain, and entering into domain methods of interaction, one can infer that scientific literacy is a skill required for healthcare design, not just to understand tacit domain knowledge and behaviours but to also successfully build relationships and legitimacy. For healthcare designers who have a background in healthcare provision this is an existing skill, for healthcare designers from a non-scientific background there is a need for openness to acquiring and respecting scientific literacy. However, there is a balance. Designers need to preserve their 'designerly' perspective in order to add value and contribute their own domain knowledge (Jones, 2013). Ross describes this as designers valuing the 'why' and having the skills to make explicit previously hidden valuable information. She emphasises that design is a *tool for understanding as well as for acting* and that designers need to be prepared to test the assumptions of healthcare professionals and critique healthcare practice, which is uncomfortable when faced with *heroic* work (Ross, 2014).

One area of commonality between design methods and a rationalist view is the value of empiricism (Paul Bate and Robert, 2006; Bowen, Dearden, Wright, Wolstenholme, and Cobb, 2010; Dearden et al., 2010). Good practice in User-Centred Design employs empirical methods for evaluation and concept testing, and includes direct end-user observation to identify human behaviour and contextual factors. Jones describes how healthcare design in some instances has evolved to become 'evidence-based design'; where gathering of formal research evidence, theoretical assessment and formal evaluation to test hypotheses become features of the design process (Jones, 2013).

Empirical approaches are important for the designer's role as critic. Challenging assumptions and changing perceptions require healthcare design stakeholders to be 'taken on the journey' to collaborate in data gathering and data analysis in order for the team to arrive at a collectively agreed understanding.

Lyng and Pedersen show how a 'shared realm of understanding' can develop between designers and health professionals through displaying the sensitivities and values advocated in Cross-cultural Design:

> *A physician and an anthropologist made observations in each of the three clinics taking part in the project. The observations were supplemented with ad hoc interviews with health professionals and secretaries in the clinics...It was clear that various stakeholders had various agendas. The requirement for collecting data for scientific purposes came from medical researchers, and the requirement for feedback came from those responsible for the training, while the end-users in the cardio team were focusing on interaction and robustness. The diversity of interests was negotiated both in workshops and in the steering group. We found it very helpful to include both technicians and health professionals in both groups, with the two informatician students with a health professional background serving as process facilitators*
>
> (Lyng and Pedersen, 2011:6).

3.5 Becoming familiar – entering the domain of healthcare

Like many design domains, in order to access rich and contextually relevant evidence, designers need to be situated in healthcare contexts (Simonsen and Robertson, 2012). A number of authors report their experiences of entering the healthcare domain, especially with regard to areas that required effort or where obstacles were found. Berryman et al. emphasise the qualitative difference in entering the healthcare domain in contrast to commercial design contexts. Figure 3.6 below is their illustration of this contrast.

Basic principles of research, analysis, synthesis and design are the same		**In medical, the learning curve for designers is steep and critical**
Skills are the same		Always have to learn about the industry, competitors, lingo, the problem, etc.
Tools are the same		
Outputs are the same:		This is more intense and challenging
Requirements	Wireframes	Consequences are different – especially for error prevention and recovery
User flows	Design comps	
Personas	Style guide	
Site maps	Etc.	
		Less clarity around ‘the user’
		Work is grounded and guided by very rigid laws and regulations
Context is different		Use error, not user error

Figure 3.6 Working in Medical: the unfamiliar side of familiar

© Echo Visual LLC (Berryman, et al., 2011)

As previously mentioned, design teams that include healthcare professionals can experience the benefits of ‘embedded-ness’ described by (Brereton, 2009). Establishing legitimacy is a challenge for designers with a non-health background as they enter the healthcare domain. Achieving the integrated and mutually beneficial relationships advocated by Cross-cultural Design researchers takes a strong and lengthy commitment.

3.5.1 Personal commitment

Several authors express a requirement for designers to enter the domain of healthcare, making a personal, long-term commitment to learning and adapting to the healthcare domain (Berryman et al., 2011; Jones, 2013; Sanders and Stappers, 2008; Ross, 2014).

Berryman, Haberman and Lynn describe the confronting and uncomfortable aspects of entering the surgical domain:

> *...people who work in medical assume that everyone works in medical, and they assume that everyone’s familiar with medical, and most of us are not... they don’t necessarily tell you that in the cadaver lab it’s not the whole human, it’s only the part you need...try to stay out of the splash zone...*
>
> (Berryman, et al., 2011:15.09).

They then go on to describe how the cadaver laboratory is a great opportunity to *get in close* for medical device testing in a low stress, (nobody can die) open, multidisciplinary environment.

Similarly they report that contextual observation in surgical environments is uncomfortable, the ambient temperature is cold and designers can spend hours and hours standing in one place only wearing underwear and scrubs. The sensory discomfort is predictable, but there is also a need to vigilantly stay out of the sterile field – and be prepared to alert staff if they have seen something that may have compromised sterility. They report the need for designers in the surgical theatre to understand what is going on and how it works, while at the same time enjoying observing *high velocity human factors* even at 6am.

3.5.2 Modes of engagement: learning work practices

Participatory Design research has consistently sought to identify how to meaningfully involve potential participants in workplace co-design collaboration (Martin, Mariani, and Rouncefield, 2009; Pilemalm and Timpka, 2008; Sanders et al., 2010; Simonsen and Robertson, 2012). From the literature it appears that the inclusion of staff from healthcare workplaces in design activities remains a challenge and requires a strategic approach informed by familiarity with workplace practices and sensitivity to workplace demands (Berryman, et al., 2011; Bowen et al., 2013; Dearden et al., 2010; Mønsted and Onarheim, 2010; Ross, 2014).

A common barrier described in the literature is lack of time availability. Several authors reported that often staff found it difficult to be released, limiting availability to break time access or other 'ad hoc' opportunities. (Bowen et al., 2013; Dearden et al., 2010; Jones, 2013; Lyng and Pedersen, 2011; Mønsted and Onarheim, 2010; Ross, 2014).

In contrast, senior healthcare providers and managers who initiate design activities can be in a position to offer both time and space for patient and staff involvement (Bate and Robert, 2006; Pickles et al., 2008)

3.5.3 Modes of engagement: dealing with diversity

One manifestation of complexity in healthcare is the diversity of people affected by a design. Jones gives this illustration of the diversity of stakeholders in healthcare:

> *Multiple stakeholders (from consumers and patients to clinical staff, administrators, and insurers) interact with multiple services (from primary*

> *care to academic institutional networks) in multiple sectors (from clinical practice to insurance and government).*
>
> (Jones, 2013:12).

Berryman et al. stipulate the need for healthcare institutional stakeholders to be viewed as partners, with the designers receiving guidance from stakeholders and responding to stakeholder evaluation priorities. The earlier example of Lyng et al portrays the sort of collective prioritising and cross-disciplinary reciprocity (for example, collecting relevant data for research projects) that is advocated in Cross-cultural Design research (Brereton et al., 2014). Wright and McCarthy, point out the value that diversity brings to design:

> *The need for reflection on practice, in evaluation, that pays particular attention to the diversity of voices heard in design and issues of control over which voices were heard...The critical value of dissimilarity of voices, values, and perspectives to understanding user experience and evaluating experience-centered design projects.*
>
> Wright and McCarthy, (2010:58)

Van der Linden, Waights, Rogers and Taylor (2012) advocate developing ‘pervasive healthcare’ through adopting technological, social and medical perspectives as designers, thereby helping to *integrate healthcare more seamlessly into everyday life* (Van der Linden et al., 2012:212).

For the healthcare designer there are many considerations to balance, between different, competing and pressing needs from a range of stakeholders such as: patients, ‘front-line’ healthcare staff, administrative staff, community health workers, health researchers and health information technology developers; all of whom could be characterised as ‘users’ at different times. A number of researchers discuss the challenges of participatory approaches for healthcare design as they relate to diversity of participants.

Pilemalm and Timpka offer a framework for conducting Participatory Design (PD) within large-scale systems design which identifies six barriers to successful PD and proposes six ‘change measures’ to overcome those barriers. Three of the barriers identified relate to practical difficulties in managing a diversity of stakeholders. These are: i) entire user groups and all stakeholders cannot be directly represented in one design group, ii) difficulties integrating different perspectives and different user groups into one design analysis, iii) difficulties retaining stability in the design group process

(Pilemalm and Timpka, 2008:331–332).

Bowen et al., (2013), describe the diversity of stakeholders as a cultural characteristic of healthcare, producing strong professional hierarchies and specialisations that lead to working in silos. These differences pertain to many issues for participation, not least the distribution of power within design processes, decision-making and implementation. A PD ethos enshrines a commitment to direct user participation in design, however the path to direct patient involvement and direct involvement of other stakeholders is often unclear in institutional healthcare contexts. For example, Grocott et al., clearly demonstrates how an uncritical commitment to direct patient participation can pose a risk to patient safety and undermine sound design practice. Given that their wound garment designs needed many iterations to establish basic fit, temperature control and moisture control, patients would have been overburdened with providing the level of feedback required. Instead surrogate users (who had participated in earlier wound care workshops) were selected to evaluate the prototypes.

The numerous practical and conceptual constraints for healthcare co-design and collaboration result in healthcare designers often needing to balance indirect with direct end-user participation. This brings to mind Buur and Matthews, (2008) caution that .

> *...To make user-driven innovation work as a practicable option for businesses, it is essential to understand not only the contribution that users can make to innovation and how this contribution can best be harnessed, but also the potentials and constraints that exist within the business organisations and how realistic these approaches may be to implement. (Buur and Matthews, 2008:256)*

The literature reveals the attempts made by designers to explore the ‘potentials and constraints’ of user participation in healthcare design and which approaches are realistic. Power imbalances and ambivalence or unwillingness to interrupt crucial front-line work with design activities are pervasive barriers to design participation within healthcare institutions. Current case-study reports share the varying expectations, challenges and strategies employed to optimise stakeholder participation, patient empowerment and successful implementation (Bowen et al., 2013, 2011; Dearden et al., 2010; Jones, 2013; Lyng and Pedersen, 2011; Nilsson et al., 2010; Pickles et al., 2008).

Hasvold and Scholl, (2011) and Weng, McDonald, Sparks, McCoy, and Gennari, (2007), describe the many configurations of design groups and modes of engagement required to manage the participation of diverse stakeholder groups over months and years. The design work clearly includes design of the design processes, what Vines, Clarke, Wright, Mccarthy, and Olivier, (2013) call 'configuration' of participation, and this management of multiple modes of engagement draws on many resources from the design project.

The need for this exploratory work continues. Techniques and insights transferrable to other healthcare projects and helpful to other design teams will help to build an emerging knowledge base for healthcare design practice.

3.6 Evolving design practice in healthcare

So far I have sought to address the framing sub-questions: i) 'How can this literature help practising designers in the day-to-day processes of healthcare design work?' and more particularly as ii) 'How can this literature support designers inexperienced in healthcare design as they are engaged in their first healthcare project?' I have done this by exploring the notions of complexity and unfamiliarity through discussing healthcare design industry case studies and research from a diverse body of design research literatuare.

A number of healthcare design researchers have observed that traditional User-Centred Design methods need to expand and evolve to address existing complex healthcare design needs and emerging pervasive health service design (Bowen et al., 2010, 2013; Jones, 2013; Ross, 2014; Sanders and Stappers, 2008; van der Linden, Waights, Rogers, and Taylor, 2012). Table 3.1 from Sanders and Stappers provides an overview of this evolution:

Table 3.1 A snapshot in time of traditional and emerging design practices

The traditional design disciplines focus on the **designing of** 'products'...	...While emerging design disciplines focus on **designing for** a purpose
visual communication design	design for experiencing
interior space design	design for emotion
product design	design for interacting
information design	design for sustainability
architecture	design for serving
planning	design for transforming

(Sanders and Stappers, 2008:7)

The following sections will discuss the evolution of User-Centred Design within healthcare. Specifically examining Experience-Centred Design, Experience-based Design and further works from Participatory Design literature as strategies for developing robust design practice in the health context.

3.6.1 Experience

Many designers have found the concept of 'experience' a useful way to approach design in a healthcare context. Health, loss of health and seeking for health exist as lived experiences. In designing for experience we are seeking to form objects and systems that deliver something positive to what is essentially an internal, subjective perception. The notion of 'experience' as something of value is ubiquitous in health literature and transcends the boundaries between medical, social, technical and design domains (Bate and Robert, 2006; Bowen et al., 2013; Petersen, Hallnäs, and Jacob, 2008; Pickles et al., 2008; Wright and McCarthy, 2008, 2010; Sutcliffe, 2010).

Experience Design as introduced by Shedroff, (2001) is designing for the sensation of an interaction and can encompass multiple physical and temporal dimensions, multiple senses and multiple internal perceptions. While a sensation or perception is clearly subjective, the claim of experience design is that there are 'knowables' and 'reproducibles' for successful experiences and these can therefore be designed. Bate and Robert, (2006) point out that, being an immaterial phenomenon, experience cannot be observed directly. Instead it needs to be understood via representations (for example, words), and expressed reflexively in order to be understood by another person. Jones frames the design 'space' for health/healthcare as 'designing for care'. He describes the patient as a 'health seeker'. In experiential terms the patient is seeking to improve their experience of health and the designer/healthcare provider is seeking to support the patient journey through offering care. As designers we can design to make care, and support for self-care, available. We cannot design the patient's own state of health.

Bate and Robert, (2006) also take the position of designing for an experience of care, necessarily grounded in a thorough understanding of the patients' health experiences and healthcare stakeholder experiences. They present the elements of successful design for healthcare as bringing user experience to healthcare improvement by co-designing services with patients. Taking the components of successful design as: Performance + Engineering + Aesthetics, Bate and Robert equate successful healthcare experience design as: Functionality + Safety + Usability.

Perhaps the most striking evidence for the prominence of 'experience' as a value in healthcare design is the adoption of Experience-Based Design (EBD) by the British NHS. The work of Bate and Robert and The Design Council (British) informed the Experience-Based Design Toolkit developed by the NHS Institute for Innovation and Improvement (now defunct since 2013). This toolkit was aimed at non-designers (mainly NHS management) and outlined various stages in an Experience-Centred Design process with accompanying templates and artefacts for adaptation and application by healthcare providers, researchers and other interested parties. Since the closure of the NHS institute several government and non-governmental agencies across the world have continued to develop the toolkit and train healthcare stakeholders in EBD, now referred to as Experience-Based Co-Design (EBCD).

The EBCD toolkit has been applied to many health projects by healthcare stakeholders. Healthcare providers are entering into the design domain, discovering for themselves the barriers and opportunities that one encounters when moving through a design process (Locock et al., 2014; Pickles et al., 2008; Tsianakas et al., 2012). The NHS EBD methodology has been tested and critiqued by Bowen et al., (2013), and (Dearden et al., 2010). Their findings were that the toolkit provided guidance for the early design phases of 'discover' and 'define' but much less guidance and support for the 'develop' and 'deliver' phases. As Sanders and Stappers, (2008) point out the exploratory 'pre-design' activities (what they calls the 'messy front end') are increasingly important for Experience-Centred Design, and socio-technical systems in particular. So while the EBD emphasis on these activities is understandable they are also in some ways the easiest part of design. Gathering qualitative data is a clear enough task, how to select the most helpful insights from those data and use the insights to inspire ideas and synthesise an actual product or service is when problems begin to be addressed.

Since their early work, Bate and Robert's discussion of EBD has evolved. We can see in their reports examples of how researchers from the domains of social research and health research develop their understanding of design techniques to approach the tools used in design practice. Examples are 'Experience-Based Co-Design' (EBCD), which marks a shift to the inclusion of participatory approaches, and also 'Accelerated Experienced-Based Design' which uses design provocations (in this case narrative contextual interview data) to prime participants for collaborative workshop activities (Locock et al., 2014). Some design researchers have employed the title 'Experience-

Centred Design', which clearly builds on the early EBD work, but I have not found a definition that differentiates the two (Wright and McCarthy, 2008, 2010; Wright, Wallace, and McCarthy, 2008). While Dearden et al., (2010) place experience and EBD at the centre of their approach but frame it as a central value of 'User-Centred Healthcare Design'.

The Experience-Centred Design (ECD) / EBD literature shows that the development and implementation of design projects for health is rarely straightforward and, because of this, the development and implementation of projects will often be protracted. A discipline of healthcare design practice that identifies likely delays and creates strategies to foresee and approach probable constraints is needed for design disciplines to make an optimal contribution to people's experiences in health seeking. It is often the multiple contextual features that shape 'functionality' and safety' that create these delays (Bate and Robert, 2007; Dearden et al., 2010; Grocott et al., 2013; Jones, 2013; Wright and McCarthy, 2010).

Remembering the discussion in section 3.3.6 around scientific rationalism and the attempts to specify 'evidence-based design' the recent symposium at the University of Oxford 'Experience as Evidence? A Symposium on the Sciences of Subjectivity in Healthcare, Policy and Practice' clearly demonstrates the potential for experience-centred concepts to play a role in healthcare innovation ("Experience as Evidence? – Symposium – 13-14 October 2014).

3.7 Literature Review conclusions

This review of case studies from the healthcare domain portrays an emerging design field that is still maturing and attempting to develop sound methodology towards co-designing with the multi-disciplinary, multiple stakeholders who could constitute 'users' in a healthcare service project.

There is a clear need for designers to enter the domain of healthcare and, over time, establish a shared understanding with patients and other healthcare stakeholders around a commonly held value of 'good' design.

Both of these tasks are complicated by the pervasive domain features of complexity and unfamiliarity, yet these also present rich opportunities for 'fresh' approaches to healthcare innovation and enabling a more human-centred experience for those seeking to support health and healing.

The conclusions are that further case-study research i) to illuminate areas of cross-disciplinary collaboration, ii) to support familiarity with the healthcare design landscape and iii) to report on the outcomes of applying design processes within a healthcare context would support practising designers in the day-to-day processes of healthcare design work and support designers engaging in their first healthcare project.

4 Methodology

Designers navigating the healthcare terrain

This thesis addresses the goal: ‘What insights can be offered from the HealthMap design project to designers unfamiliar with healthcare?’ My research aim was to find an evidence-based contribution to better understand what could constitute sound design practice for a highly stigmatised, medical context such as the HealthMap technology for people living with HIV (PWHIV). Reducing the lack of familiarity between the domains of design and medicine emerged as a significant contribution towards this aim.

Working in an unfamiliar context often impacts on a designer’s ability to understand and frame a design problem, and on their ability to productively engage with relevant stakeholders. Healthcare is relatively new territory for design practitioners, and much of the information technology (IT) development within healthcare has been led by engineering practice rather than design.

The HealthMap designers were working on a cross-disciplinary project funded as a medical intervention. This required design practitioners / researchers to conduct design activities that were acceptable to the HIV researchers and that delivered outcomes satisfactory to the HealthMap Study. The nature of trying to work with a multi-disciplinary team within the constraints of a time-pressured project created challenges in the application of design processes, especially in regard to direct access to PWHIV.

HealthMap designers addressed these challenges through active exploration of the HIV research domain and through flexibly responding to opportunities for collaborative engagement and design enquiry with doctors, nurses, health coaches and PWHIV. Collaboration with PWHIV centred around iteratively sharing concepts and paper wireframes. These artefacts supported design critique and research into PWHIV experiences around managing health and wellbeing.

This thesis presents the examination of two ‘snapshots’in time’ from a wider design process. These two workshops emerged from the Action Research (AR) data analysis as key activities that played a strategic role in requirements gathering, design iteration, and design team cohesion It also presents a critical enquiry into the role of designer empathy for the HIV research domain and it's potential value for envisioning design strategy for future work.

These mainly address modes of engagement within the HealthMap design team and the design processes that impacted on team dynamics and design synthesis. The modes of engagement with 'external' PWHIV and healthcare stakeholders are not the focus of this work.

4.1 Overview

Section 4: Methodology will briefly describe the HealthMap design phases and the activities comprising each phase, my role in those activities, and then the action research-based reflection that addressed the research goal: What can be learned from HealthMap that offers insights to designers unfamiliar with healthcare? This section describes the guiding questions for reflection, examples of tools employed and how insights emerged.

An overview is given by referring to Donovan's, (2011) diagram (Figure 1.1 in 1:Introduction) showing the relationship between action research and a design process. Using the diagram as a model, we can describe the HealthMap design process as a number of phases (the loops in the spiral) with the clouds representing the design activities (such as exploratory research or generative workshops) that move the design forward. The flags represent the emergent knowledge gained from design activities that informs the next phase of design. See Figure 4.1.below

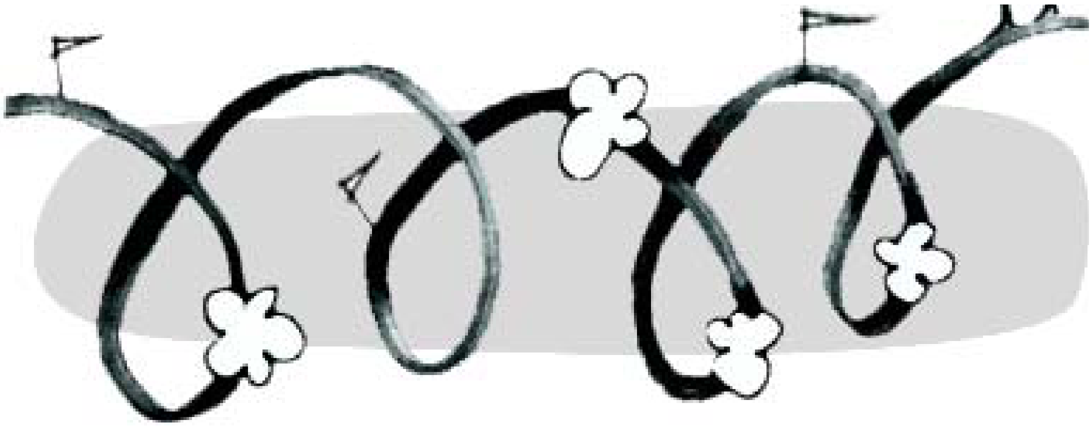


Figure 4.1 Activities and emerging knowledge in design

(Donovan, 2011:65)

Many of the activities in the HealthMap design phases were driven by framing questions as a tool for problematising the design challenge.

We can then use the second part of Donovan's diagram to model our reflexive approach in exploring the HealthMap design project. See Figure 4.2 below.

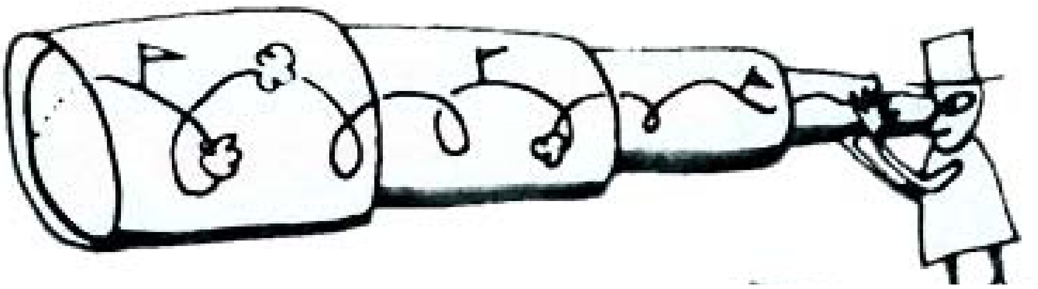


Figure 4.2 Reflection on the design process

(Donovan, 2011:65)

In employing the metaphor of a telescope Donovan points out that:

> *the telescope is not meant to imply precision in the act of looking back, but instead a 'telescoping' of events. When one looks back in this way, one sees patterns and connections between events that are not always apparent in their midst.*
>
> (Donovan, 2011:65-66)

Borrowing from the telescope metaphor this thesis presents this reflexive view of adopting two different telescopes with a number of lenses for each. One is the telescope of the HealthMap design evolution and the other is the telescope of my personal design practice development.

It is through this 'telescopic' viewpoint that the challenges of unfamiliarity and the responses to those challenges are identified and understood. Again, framing questions were used to 'focus the lens', providing a guide for data enquiry.

4.1.1 Cross-cultural research

Cross-cultural Design insights have proved useful when approaching healthcare as a design domain. Like geographically, culturally and linguistically unfamiliar situations, healthcare can seem a 'foreign' territory for many designers. Designers from the field of healthcare often report unforeseen constraints and poor grasp of strong cultural features, especially in the early stages of their engagement ((Berryman, Haberman, and Lynn, 2011; Ross, 2014). Designers pursuing formal research questions also describe some naivety and unrealistic expectations in approaching the socio-technical complexity of healthcare (Bowen, Dearden, Wolstenholme, and Cobb, 2011; Bowen, et al., 2013; Dearden, et al,. 2010; Mønsted and Onarheim, 2010).

From a cross-cultural perspective many of the activities described in the following section involve design practice that is seeking to develop effective modes of engagement in 'unfamiliar territory' with HIV researchers, HIV treatment providers and PWHIV. My design practice also required navigating the HIV research and healthcare specific cultural context. From a cross-cultural perspective, enquiries that probe the design process in terms of 'navigation', 'mapping' and 'journeys' are well suited.

4.1.2 Action research

Swann, (2002) advocates for a 'mature' action research methodology that requires a community of collaborating practitioners to pursue self-critique and self-reflection. My research aims are very much aligned with these values. Though I cannot claim to directly involve a whole community of design practitioners in this particular health technology case study, my goal is to identify insights via critical self-reflection that can lead to a deeper understanding of designing for health information technology situations. My aim is to share these insights, and their supporting evidence, with the design community, potentially contributing to a community of practice for healthcare design. Bowen, Dearden, and Dexter, (2014) describe Swann's framing of action research as a 'micro perspective' and compare it with Hayes', (2011) 'macro perspective' which relates action research to a broad socio-technical intervention formulated through collaborative research processes. This frames design work as one potential component in an action research programme. Both perspectives require a systematic and documented process to ensure transparency. HealthMap is a ready case study in complex socio-technical intervention design and is well suited to the Hayesian 'macro' perspective of action research. Importantly I envisage the HealthMap case study contributing to a community of practice that grows over time, especially with regard to the design strategies offered for further testing and refinement in Section 5: Results.

4.1.3 Research through design

A significant theme in designing and researching the HealthMap intervention was unfamiliarity as a component of complexity. The HealthMap Study is situated as a technology-based, medical and social intervention that has stringent technical, medical, ethical and scientific requirements. At the same time it is an attempt to support people managing their health in the deeply intimate, sensitive, politically-charged, socially stigmatised and personally challenging experiences of living with HIV – while also including the healthcare providers delivering their care. Finding a path through these very diverse but important factors was a major challenge to successful design.

Design is often described as a ‘fuzzy’ process and the HealthMap early design activities are well suited to that description (Sanders and Stappers, 2008; Stolterman, 2008; Visser, Stappers, van der Lugt, and Sanders, 2005). The HealthMap designers were often responding to needs as they emerged within very tight and inflexible timeframes. Quite often data collected or collaborative team discussions indicated gaps in knowledge that required a response and a suitable design inquiry would be initiated. Rapid, lean design tools were employed to ensure quick responsiveness and a ‘just enough’ result in order to facilitate the next stage in the design process (See Papers 1 and 2 in Section 5: Results). Although the methods were chosen according to what resources were to hand they were employed in a consciously sound, evidence-based fashion. As a multi-disciplinary design-team we were aware of the reliability (or otherwise) of what was ‘known’, where the knowledge gaps were, and what inquiries to prioritise in pursuing design goals. Therefore the design problem framing, design activities, design solutions and evaluations were pursued in what could be described as classic action research cycles of ‘plan, act, observe and reflect’.

There is also ‘fuzziness’ in my role on the HealthMap team. By working as a hired design practitioner and also by participating as a formal researcher the methods employed to research the HealthMap design project come from multiple perspectives. Bowen et al., (2014) describe this dual role as ‘wearing two hats’: those of the authentic designer and the academic researcher, what they term the ‘designer-researcher’. This dual role introduces a tension when conducting authentic design and a complexity when discussing the designer-researcher activities.

4.2 Methodology section structure – looking through the ‘telescope’

In presenting the reflexive research processes I will take a stepped approach, beginning with a high-level contextual and conceptual explanation, (‘authentic’ design, reflective practice and action research) then focus on methodological details through a number of perspectives (‘lenses’). The goal is to give a transparent explanation of how research questions emerged and how they were pursued.

The following sections will present the HealthMap design context, the artefacts generated within the project design processes, and the post-design research enquiry. Following the discussion of context, design artefacts and research enquiry I will introduce three methodological ‘telescopic lenses’ employing the metaphor of a journey: i) the domain empathy journey, ii) the design practice skills journey, and

iii) the academic research journey. These three perspectives will reveal the processes employed to gather data, analyse data and draw on the analysis in answering research questions.

4.3 The research context – ‘authentic’ design practice

4.3.1 Design team members

Initially the HealthMap research team comprised: a social researcher with many years experience in HIV research, a hospital-based HIV treatment provider / clinical researcher (who was the project lead) and an occupational therapy postgraduate researcher with special interest in HIV and chronic disease self-management. This domain expertise combined represents over 40 years of research and work with people living with HIV. The research team consulted with Designer 1, who provided high-level design strategy advice but was not co-located with the team. Designer 1 is a design researcher specializing in Participatory Design and Interaction Design and was known to the clinical researcher. These team members conducted the activities in Phase 1. In addition HealthMap has twelve chief investigators who receive reports and contribute to project decisions The design phases are shown in Figure 4.3 below.

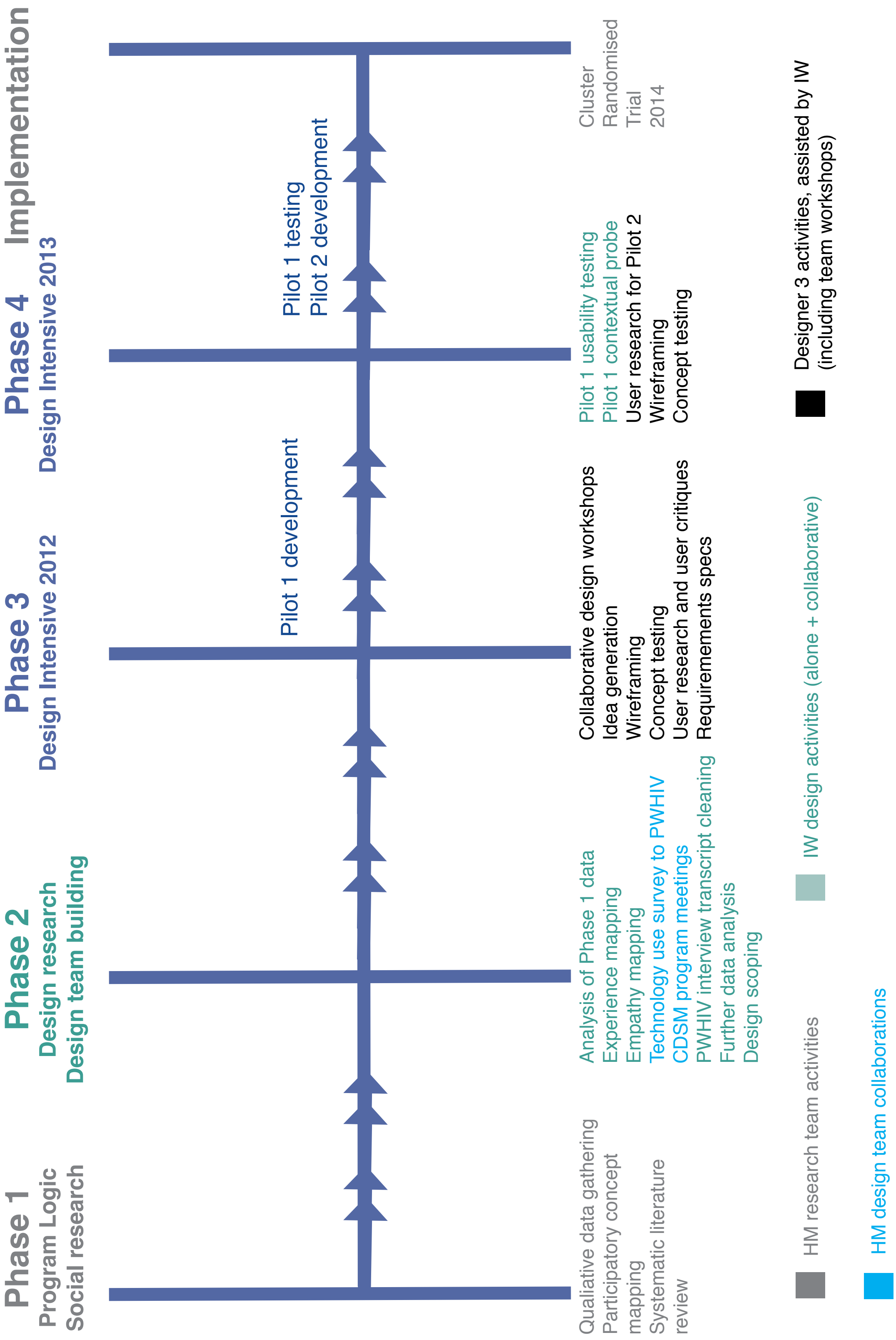


Figure 4.3 HealthMap design phases

(HM = HeatlthMap, IW = Irith Williams)

I was a User Experience Design practitioner (Designer 2) employed at the beginning of Phase 2. My role was to conduct design research, scoping exercises and project management in preparation for Phase 3. The Phase 2 timeframe was eight weeks. This was my first healthcare project. I was supported by Designer 1, who gave advice, liaised with the project lead and collaborated in early scoping activities.

Designer 3 is an Interaction Designer / User Experience Designer with over ten years experience designing for healthcare in the USA and was known to the clinical researcher via shared health technology networks. He had not worked on an HIV project. He was not co-located with the team except for the Phase 3, six-week design intensive, and twelve months later for a three-week intensive in Phase 4. Designer 3 is responsible for the HealthMap Interaction Design and user interface design. My role was to assist him during the design intensive and continue ongoing work supporting UI development and functional specification development.

The HealthMap implementation is managed by the project lead with additional input from chronic-disease self-management researchers and cluster-randomised control trial (RCT) managers. Designer 3 has continued to be engaged remotely for UI refinement. The RCT began recruiting patients in 12 clinics across Australia mid-2015.

4.3.2 Rapid and lean methods and artefacts

The HealthMap design is a case study in what Bowen et al., (2014) define as ‘authentic’ design. That is, a ‘real-life’ design project required to deliver a functional object or service, for a specific audience and to be subjected to a ‘real-life’ evaluation. (In this case a cluster-randomised trial.) From the perspective of the HealthMap Study priorities, creating a working design meeting the NHMRC defined project requirements was the main focus of the work undertaken. The concurrent research enquiries undertaken by the design researchers, qualitative researchers and clinical researchers were to be grounded in the data collected during the technology development project.

During the HealthMap design phases the focus was on pragmatic, rapid and lean methods that explored, analysed, reflected and iterated design ideas. Rapid and lean tools were required because of the extremely short lead times available, the limited direct access to potential users due to ethical constraints, healthcare provider unavailability and budgetary constraints. (Grant funds were available for software development. There was no funding for specific design activities).

This demanding and complex situation is not rare, indeed Stolterman, (2008) points out that having to address the situation at hand while accommodating limited time and resources are universal design project features and typical of design environments. Stolterman also points out the threat that complexity poses in potentially overwhelming the design team. This was a very real risk for HealthMap which gave rise to a consciously pragmatic, disciplined and focussed attempt by the designers to navigate the many questions and opportunities facing them in order to find the safest grounding of evidence and 'knowns'. This focus was applied via a number of design framing questions, such as: 'What will help people to manage their wellbeing, within the constraints of what we can deliver?' These design decisions and activities took place within timeframes measured in hours and days rather than weeks and months.

4.4 Reflective practice: reflection-in-practice

Figure 4.4 below summarises the HealthMap design Phases 1-3 (pre-development).

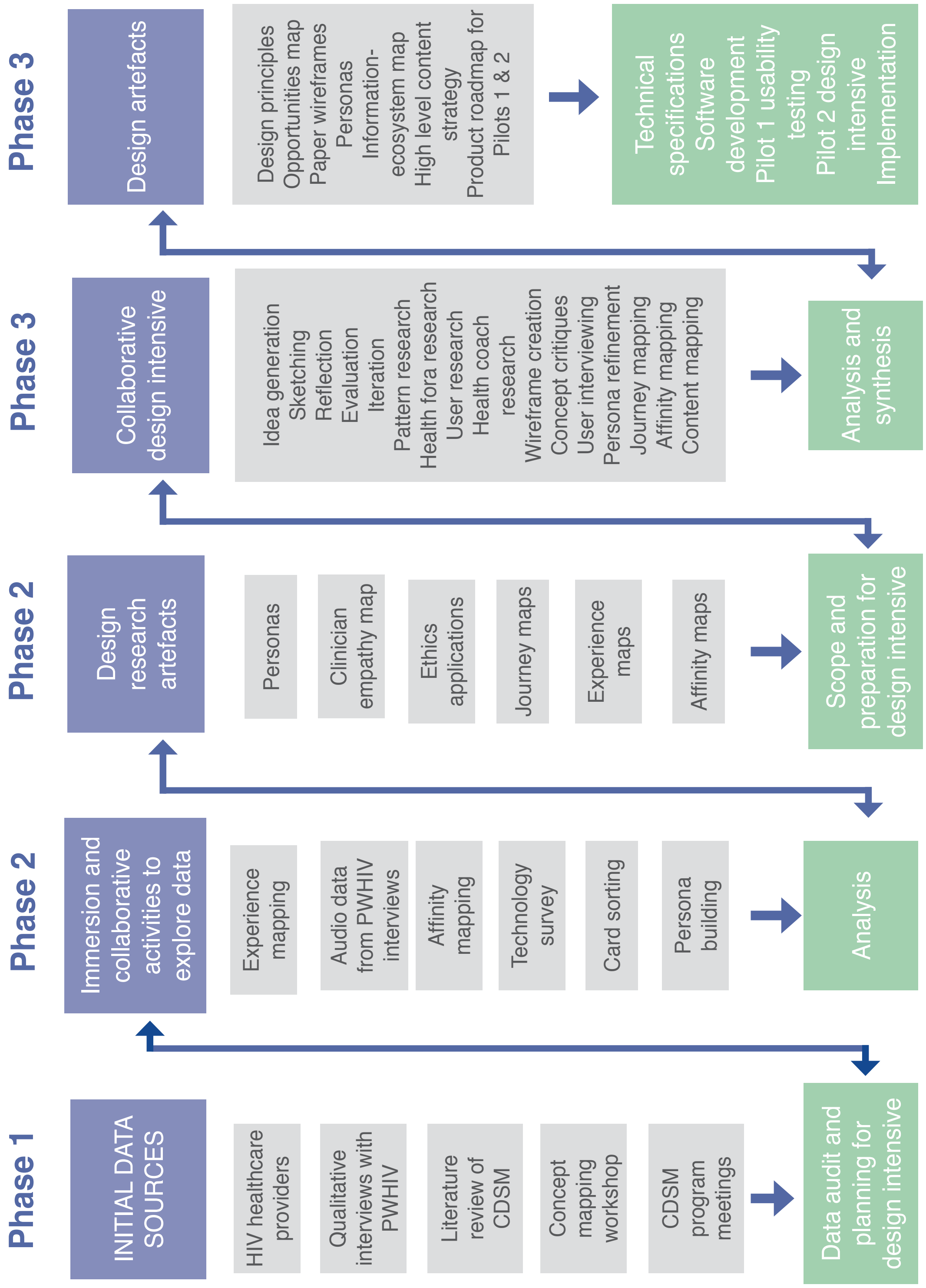


Figure 4.4 HealthMap design activities phases 1–3

As a designer-researcher engaged in authentic design practice, personal reflection on design problems and on my design practice was a consistent habit within these design phases. There are three reasons for this reflective approach: i) it is a characteristic of my personal design practice and I apply reflection habitually while engaged in projects, usually through note taking; ii) my limited experience in authentic design projects meant much about the project was unexpected and required quick 'sense-making' to facilitate design decisions and continue design activities; iii) reflective techniques are well established tools for analysis, synthesis and iterative cycles within design practice. Indeed, Bowen, Dearden and Dexter describe this as necessary for authentic design practice and frame it as reflection 'in' practice, bringing to mind Schön's notion of 'reflection-in-action' (Schön, 1992). Many of the user interviews, team workshops, wireframes and concepts developed during the design intensive prompted reflection that led to further design actions. This echoes Heyer and Brereton's, (2009) Reflective Agile Iterative Design pattern where

> *After an initial deployment of a rough prototype, use is passively observed and actively probed. Analysis and reflection on data can then take place, with the designer/researcher considering appropriate design and methodological responses*
>
> (Heyer and Brereton, 2009:2).

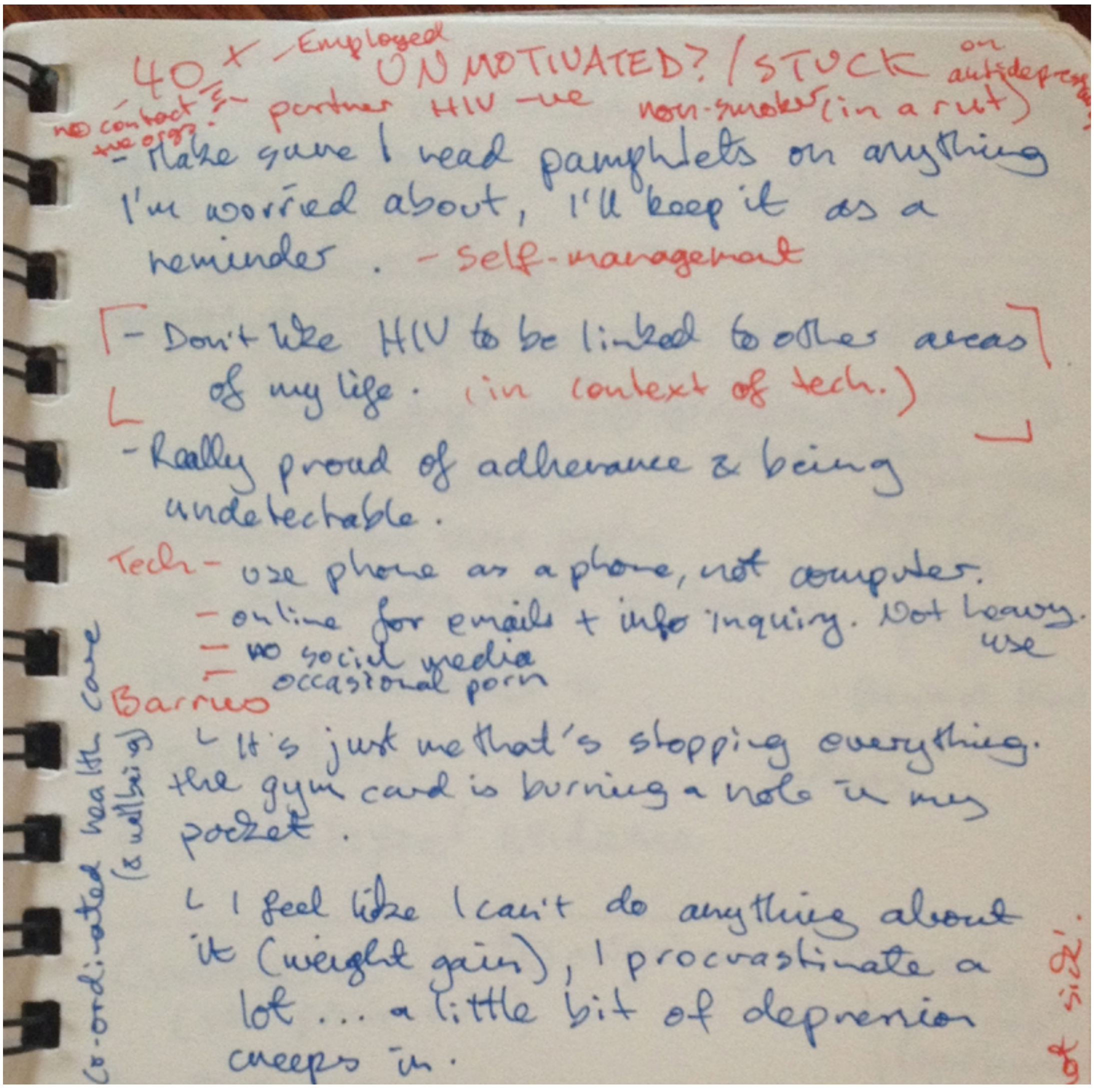
The word 'responses' here is key, as HealthMap was very much a project where opportunities and resources to conduct design activities were often not clearly understood in early stages. Designers were required to be nimble and resourceful in creating and using opportunities for design research, team workshops and design evaluation.

Bowen, Dearden and Dexter (2014) describe a tension between the style of reflection necessary for authentic design practice and the systematic reflexive enquiry employed in action research. They frame these dual modes as reflection 'in' practice (authentic design) and reflection 'on' practice as is necessary for research. I will adopt Bowen, Dearden and Dexter's terminology and discuss the methodologies in terms of 'reflection-in-practice' (authentic design reflection during HealthMap design activities) and 'reflection-on-practice' as the processes for data enquiry and analysis with a view to informing action research questions outside of the HealthMap design work.

4.4.1 Reflection-in-practice: example processes and artefacts

Figures 4.5 to 4.11 are a selection of the design artefacts generated during the

HealthMap design phases in order to support design exploration, analysis, synthesis and evaluation.



40 ✗ – Employed UNMOTIVATED? / STUCK (in a rut) on antidepres

no contact? – two orgs? – partner HIV –ve non-smoker

- Make sure I read pamphlets on anything I'm worried about, I'll keep it as a reminder. – self-management

[- Don't like HIV to be linked to other areas of my life. (in context of tech.)]

- Really proud of adherence & being undetectable.

Tech – use phone as a phone, not computer.
  – online for emails + info inquiry. Not heavy use
  – no social media
  – occasional porn

Barriers
  ∟ It's just me that's stopping everything. the gym card is burning a hole in my pocket.
  ∟ I feel like I can't do anything about it (weight gain), I procrastinate a lot ... a little bit of depression creeps in.

Co-ordinated health care (& wellbeing)

of size!

Figure 4.5 Notes for analysing interview data

This notebook is an example of Phase 2 analysis of the Phase 1 qualitative data from PWHIV interviews. Here I am using the data to explore themes that emerged from the interviews (around attitudes and capacity to manage cardiovascular disease risk factors, relationship with technology and demographic characteristics). This process allowed me to build a structured understanding around interview data and identify insights relevant to design. This knowledge was then tested and refined during the collaborative persona-building workshop in Phase 2.

Figure 4.6   Empathy map for hospital HIV treatment provider

This empathy map was created with the design team as a Phase 2 exploration to inform a gap in the existing data. It had emerged that whatever shape HealthMap took, patients and HIV healthcare providers would both be engaged as end-users, however we had little qualitative data for HIV healthcare providers, who were either infectious diseases clinicians or specially qualified GPs. The empathy mapping workshop was brief, about 30 minutes, and most of the input was from the HealthMap HIV clinician who was the project leader. The empathy map was useful to take the clinician out of his usual objective frame of mind and facilitate an exploration of the subjective, affective and emotional experiences of being an HIV healthcare provider. It was particularly powerful in eliciting relevant particularities of the provider experience but also making explicit the relatively large burden under ‘do’ compared with ‘seeing’, ‘hearing’, ‘saying’ etc. This disproportionate section helped to emphasise in both an explicit and a tacit way the unfeasibility of adding to the provider workload even in what would seem to designers the smallest of ways.

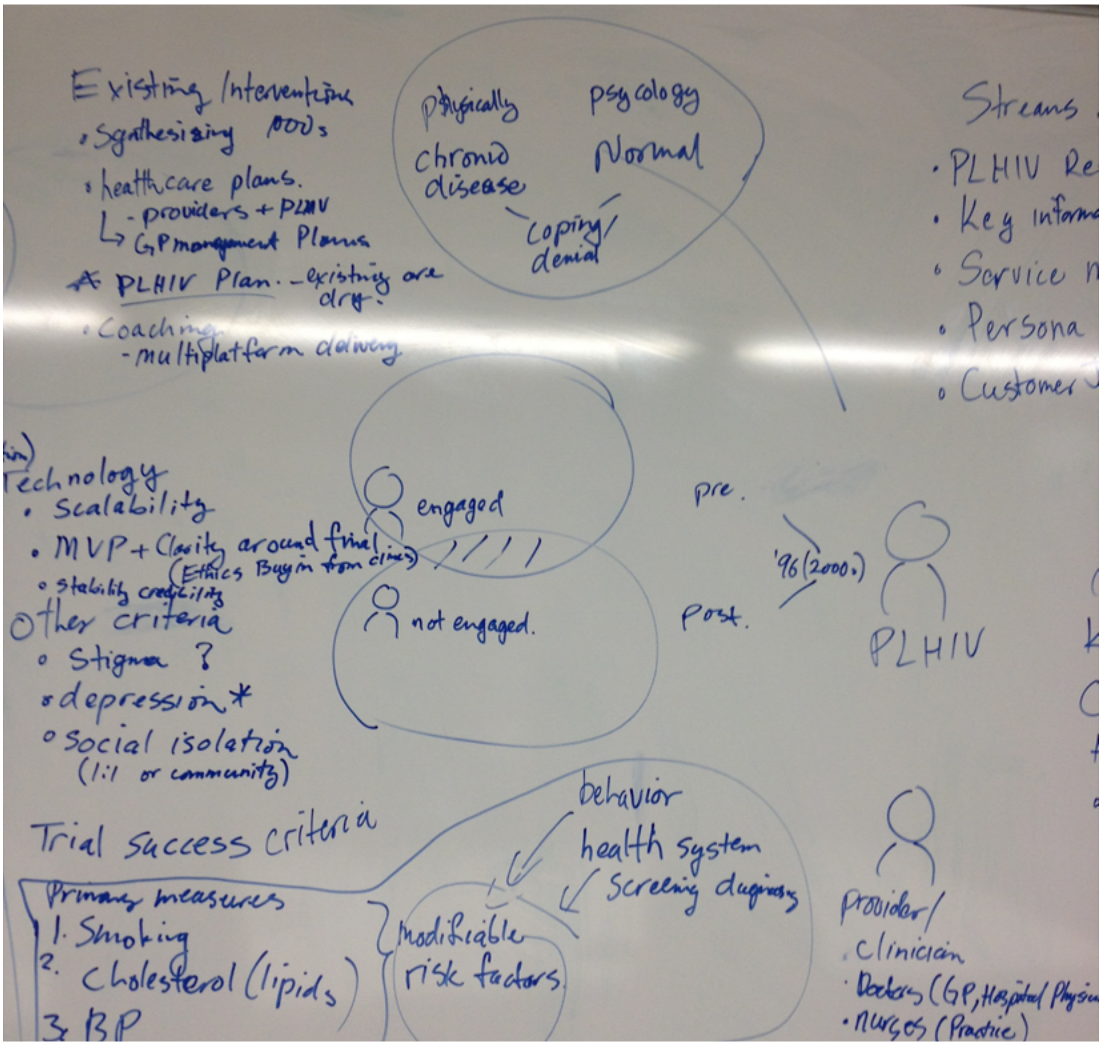


Figure 4.7 Kick-off meeting whiteboard

The kick-off meeting, facilitated by Designer 3, commenced the Phase 3 design intensive, (see Figures 4.3 and 4.4). It was an opportunity for the team to reiterate the agreed outcomes from Phases 1 and 2 in the context of scoping for the design intensive and it initiated Designer 3 into the design team's current thinking. Designer 3 then reflected on the kick-off meeting and facilitated a follow-up workshop to produce an opportunities map outlining a model for design strategy and planning further design research and design activities (see Figure 4.8 below).

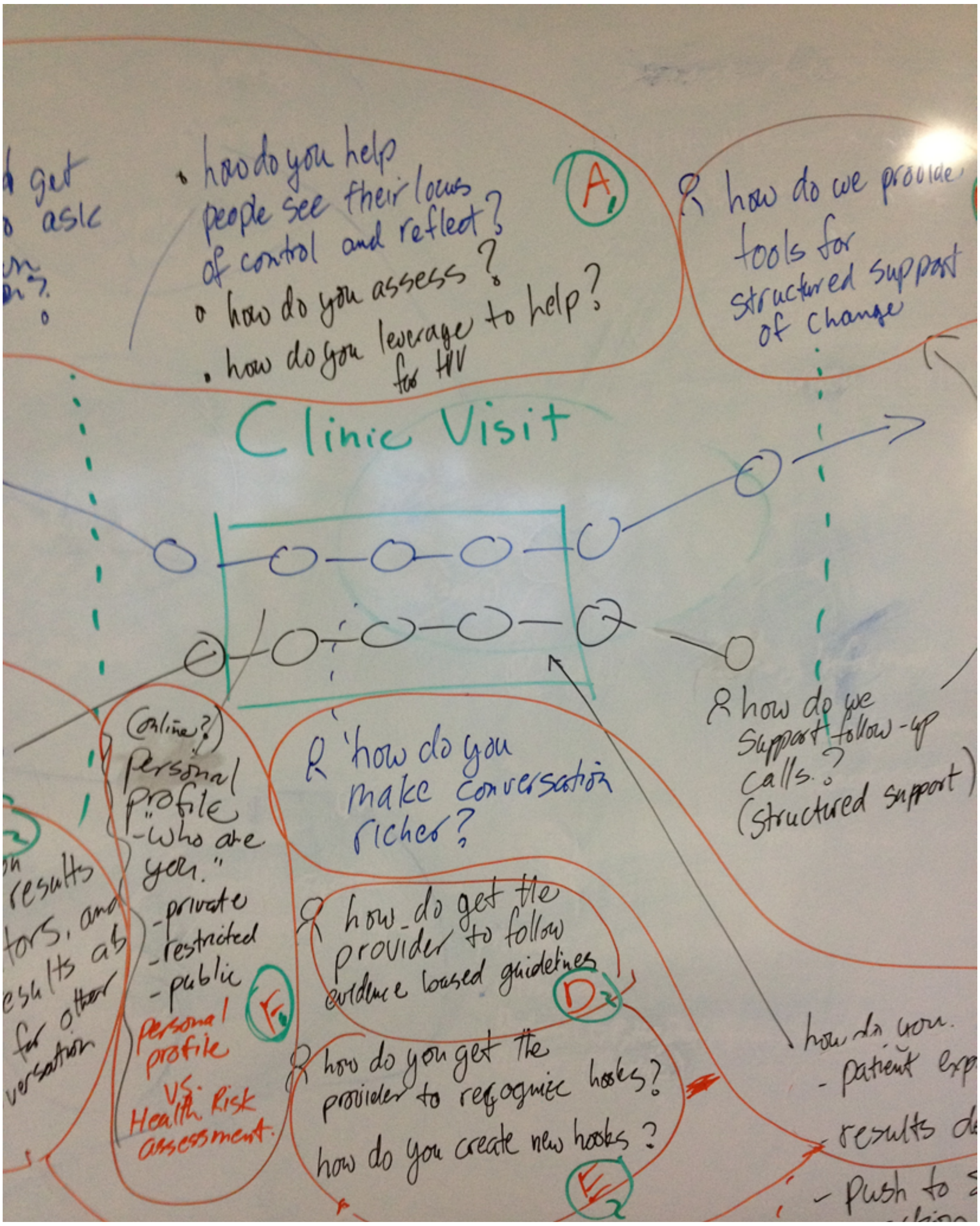


Figure 4.8 Phase 3 whiteboard from workshop on opportunities map

4.5 Research approach

We have seen from understanding HealthMap as a context for design that responses to practical design needs and generating useful design deliverables were paramount for the design team. In moving from the 'hands-on' daily activities of a digital design and engineering project to pursing the research questions relevant to the HealthMap design I needed to switch hats from a practising designer to a formal design researcher. This section will explain my underlying approach to design research, providing the strategic basis for the methodologies employed.

4.5.1 Pragmatic focus

Apart from personal professional development my interest in pragmatic and transferable outcomes comes from my perception that Interaction Design / User Experience Design is a relatively immature field compared to other professions (such as Architecture) and as an industry suffers from a degree of confusion around the suitability of methods and processes across a variety of contexts and project types. This led to the aim to contribute insights from the HealthMap design project that would support knowledge development for a healthcare design community of practice.

4.5.2 Action research – reflection 'in' and 'on' practice

Action research (AR) is an approach used in many fields to build iterative knowledge around domain practice. McTaggart (as cited in Hayes, 2011) describes AR as *not a "method" or a "procedure" for research but a series of commitments to observe and problematize through practice a series of principles for conducting social enquiry…* (Hayes, 2011:3) While AR is not a singular method it has defining characteristics that principally differentiate it from other research paradigms such as scientific research and social research. Hayes describes AR as

> *…explicitly democratic, collaborative, and interdisciplinary. The focus when conducting AR is to create research efforts "with" people experiencing real problems in their everyday lives not "for", "about", or "focused on" them. Thus, AR research focuses on highly contextualized, localized solutions with a greater emphasis on transferability than generalizability.*
> (Hayes, 2011:3).

The concept of 'design as research' as described by Swann, (2002) elucidates a similarity between authentic design practice (such as we conducted in HealthMap) and the principles and processes of action research. Swann's analysis of design practice, and comparison with action research characteristics, identifies several areas of overlap. These include: project aims that support social change; collaborative modes of enquiry, analysis, synthesis and evaluation; iterative cycles of plan, act, observe and reflect; and accountability, transparency and self-criticism. Swann also matches design practice outcomes with action research results, there being two types of results: i) action outcomes (the effects of the designed 'thing') and ii) research outcomes (new knowledge about design). Swann suggests that as designers offer innovative answers to conventional situations and make them transparent through self-critical case studies they build a body of knowledge of design practice. Taking these descriptions of AR into account I will discuss HealthMap design and reflexive research questions as a case study in action research.

Returning to the earlier descriptions of ‘reflection-in-practice’ and ‘reflection-on-practice’ I understand both activities to be components of AR.

4.6 Reflection-on-practice

The reflexive questions applied to the HealthMap design data were through two ‘telescopic lenses’: i) from the perspective of the HealthMap intervention lifecycle / design evolution and ii) from the perspective of my personal development as a practising designer. Although these two perspectives were explored they were often not approached separately, as discrete entities, but rather the project design reflection acted as a scaffold for the relevant personal observations, analysis and insights. These perspectives can also be understood as a series of journeys: i) the HIV research domain empathy journey, ii) the design practitioner development journey and iii) the academic research journey.

4.6.1 HIV research domain – empathy journey

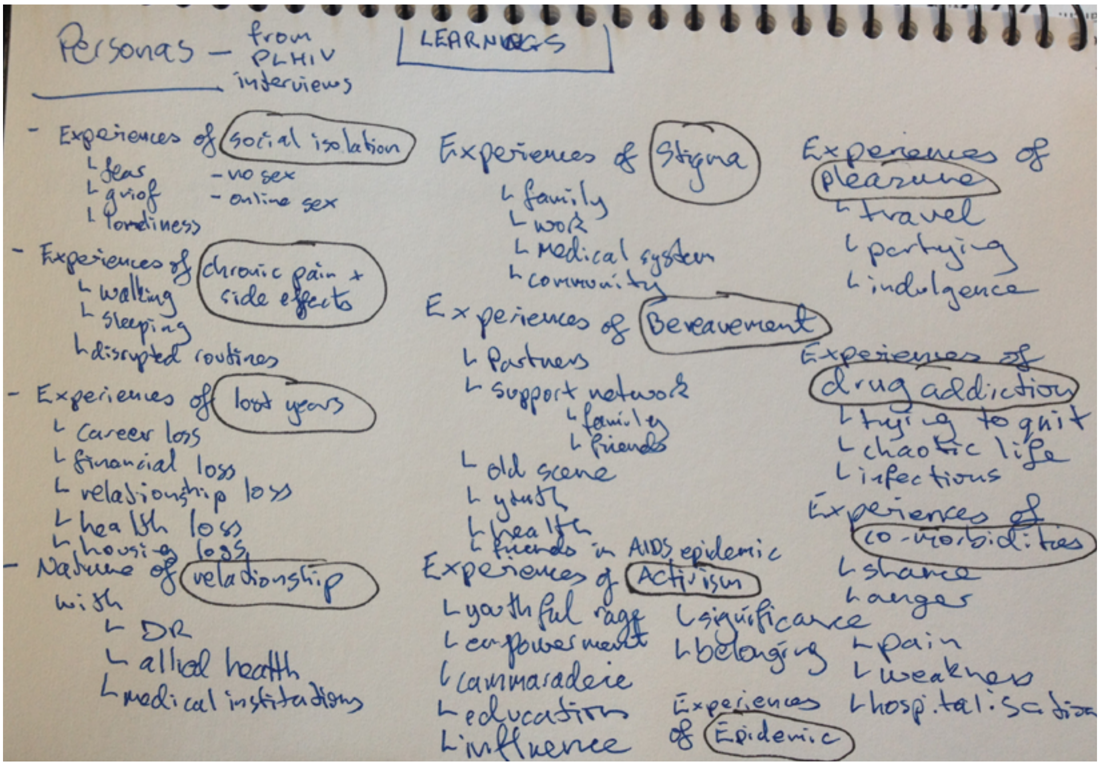
Given the value of empathy in User-Centred Design it is helpful to trace how it grew in my role as a HealthMap designer. My empathic understanding is grounded in the qualitative data collected in Phase 1 and has grown with continued collection of qualitative data and immersion in working with HIV researchers for over twelve months.

By mapping an empathy ‘overlay’ to the design phases I can describe where empathy for HIV research evolved. This journey is described in Table 4.1

Table 4.1 Empathy development during HealthMap design phases

Phase 2 →	**Phase 3** →	**Phase 4**
Grounding in qualitative data Immersion in HealthMap team My emotional reactions to qualitative data Analysis of Chronic Disease Self Management (CDSM) meetings Writing ethics approval applications	Personal sense-making Dialogical testing and exploration with the HealthMap Study (HM) team and design peers Fewer 'dumb' questions > increasing rapport with HIV researchers More data collection (qualitative and quantitative) from a deeper understanding Divergence from common industry-based designer attitudes re: designing for health and behaviour change, closer alignment with HIV researchers' tacit knowledge and assumptions	Personal identification with HIV research literature Participation in HIV ageing forum Confidence interacting with HIV social researchers and qualitative researchers around health behaviour Strong intuitive feelings applied to ideas for future HM design work Strong identification with HIV research domain Tacit knowledge employed in planning and writing research papers from HM data

The growth of personal empathy was observed through reflection-in-practice (I was aware of my increasing implicit understanding while immersed in HealthMap design work) and also made explicit through reflection-on-practice as a systematic research practice. See Figure 4.9 below.



Personas – from PLHIV interviews

LEARNINGS

- Experiences of social isolation
  - fear
  - grief
  - loneliness
  - no sex
  - online sex
- Experiences of chronic pain + side effects
  - walking
  - sleeping
  - disrupted routines
- Experiences of lost years
  - career loss
  - financial loss
  - relationship loss
  - health loss
  - housing loss
- Nature of relationship with
  - DR
  - allied health
  - medical institutions

Experiences of Stigma
- family
- work
- medical system
- community

Experiences of Bereavement
- Partners
- support network
  - family
  - friends
- old scene
- youth
- health
- friends in AIDS epidemic

Experiences of Activism
- youthful rage
- empowerment
- cammaradeie
- education
- influence
- significance
- belonging

Experiences of Epidemic

Experiences of pleasure
- travel
- partying
- indulgence

Experiences of drug addiction
- trying to quit
- chaotic life
- infections

Experiences of co-morbidities
- shame
- anger
- pain
- weakness
- hospitalisation

Figure 4.9 Notebook extract: analysing empathic understanding

4.6.2 Design practitioner journey

The opening comments of this Methodology section emphasise the unfamiliar territory of HealthMap as a design domain. Unfamiliarity is a significant component of the socio-technical complexity in healthcare design. Stolterman highlights the threat of ‘design paralysis’ when faced with a seemingly overwhelming complex problem and I certainly felt very challenged by the demand to deliver tangible and practical design insights and tools to the team within the space of eight weeks (in preparation for the Phase 3 design intensive).

When entering the HealthMap project I had a sound understanding of the theories and principles of User Experience Design as is discussed in industry but my practical experience had been limited to a small number of engagements in the previous year and my User Experience Design portfolio work.

I was forced to reflect on my understanding of design and design practice on a ‘day-to-day’ level as I endeavoured to collaborate with a team of non-designers and anticipate the requirements of the scheduled design intensive. Each week brought a new set of unanticipated problems, for example: writing ethics applications without prior experience, anticipating suitable design activities to comply with ‘low risk’ ethics applications and educating sceptical team-members around design thinking and design practice. On reflection, I identified a pattern where the many challenges I faced and the strategies I employed to ‘solve’ the problems they presented comprised an iterative cycle of challenge > reflection > solution testing > outcome > success or failure and refinement. This learning experience generated a more mature tacit understanding around design practice, which in turn informed my understanding of the HealthMap design processes and outcomes.

In the following journey description I will select some of the important touchpoints from my reflection-in-practice during Phase 2 that enabled me to frame a number of problems confronting my design practice and how I responded to them. These are outlined in Table 4.2 below.

Table 4.2 Design practice skills development: HealthMap Phases 2 and 3

Problem	Reflection	Response
How to start design work?	Exploratory dialogue with HM team members Exploration of online UX articles and resources	Realization that Service Design tools were appropriate for this early divergent/exploratory phase of the project Selected and applied various SD tools.
Introducing design activities and design thinking into team dynamic.	Discussion with design peers and reflection on existing design knowledge.	Felt validated and more confident, as if I had been ‘blooded’ as a designer
Team discomfort with lean, rapid tools and unconvinced by attention to specificities rather than generalization	Realization my experiences were commonly encountered by UX designers in industry and were well documented	Less emotion-focussed and more objective attitude Treated team cohesion/ design education issues as design problems requiring creative solutions
Early barriers accessing research data	“ “	“ “
Persistent difficulty arranging times for design research and activities.	Growing confidence in ability to use lean methods and growing comfort in ability to frame activities quickly according to problem presented. Growing comfort with open, divergent problem situations.	‘Opportunistically’ took advantage of ad hoc availability and short timeslots available to book for design work without having planned exact activity. Used objects and resources to hand.
Confronted by need to educate team in design thinking. Was uprepared and unenthusiastic about this ‘distraction’ from design work.	Looked to online resources for tips. Observed behaviour of Designers 1 and 3 when confronted with same challenges.	Became aware that this was another comon feature of collaborative design work. Accepted stakeholder education as a crucial component to successful design. Found advice online and observed Designers 1 and 3 as they facilitated team exploration and collaboration. Realised that one needs to miimise explanations and instead ‘take them on a journey’ of participatory exploration and decision making.

4.7 Academic research journey – action research

I frame my HealthMap research questions as 'reflection-on-practice' within the domain of health information technology design. By this I mean my exploration of my role as a designer and the nature of the HealthMap intervention as a design project, and the resulting insights. My reflection-on-practice began in Phase 2 as a response to an internal need to make sense of my experiences and then intensified post Phase 4, in a full-time systematic action research programme of data analysis and evaluation.

In order to support a rich, situated, grounded approach to action research without interfering with the 'flow' of authentic design activities as many data as possible were collected to capture the HealthMap design team's collaboration, processes, and outcomes. Photos of whiteboards, sticky notes, sketches and notebook pages were taken as well as audio recordings of HealthMap meetings, interviews and skype calls. All digital files were kept. Where possible the original design artefacts were also kept. These were a set of 'reflection-on-practice' data added to the original project design research data. Both were used for action research structured analysis. See Figure 4.10 below:

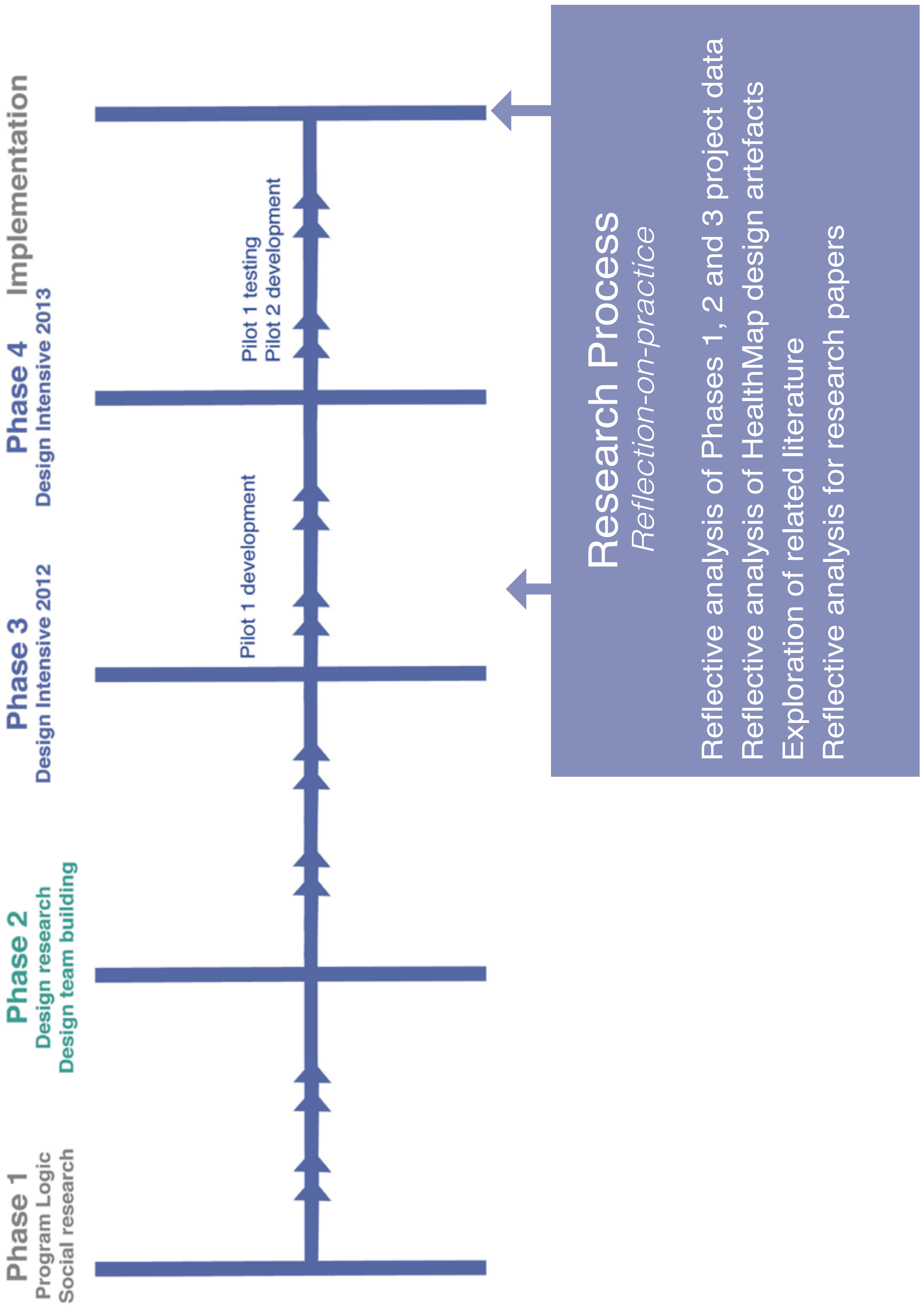


Figure 4.10 Reflection-on-practice processes

Earlier in section 4.5 I explained my research exploration as following two ‘telescopic’ perspectives: the HealthMap design project and my development as a practising designer. I employed a set of open, guiding questions for reflection on the data collected during the design phases and for further data analysis. My guiding reflexive questions for the design practice development journey related to RQ1 were the research ‘sub-questions’: ‘What would I have found useful coming into the HealthMap project?’ and ‘What will I find useful next time I am on a healthcare design project?’ These fed into RQ1 ‘How can we begin to map the healthcare cultural landscape?’

The data from Phases 1, 2 and 3 were used to support my reflection-in-practice and reflection-on-practice while working as a HealthMap designer over a period of ten months and then again later in the full-time research activities. Examples of these data are in figures 4.11 – 4.13 below.

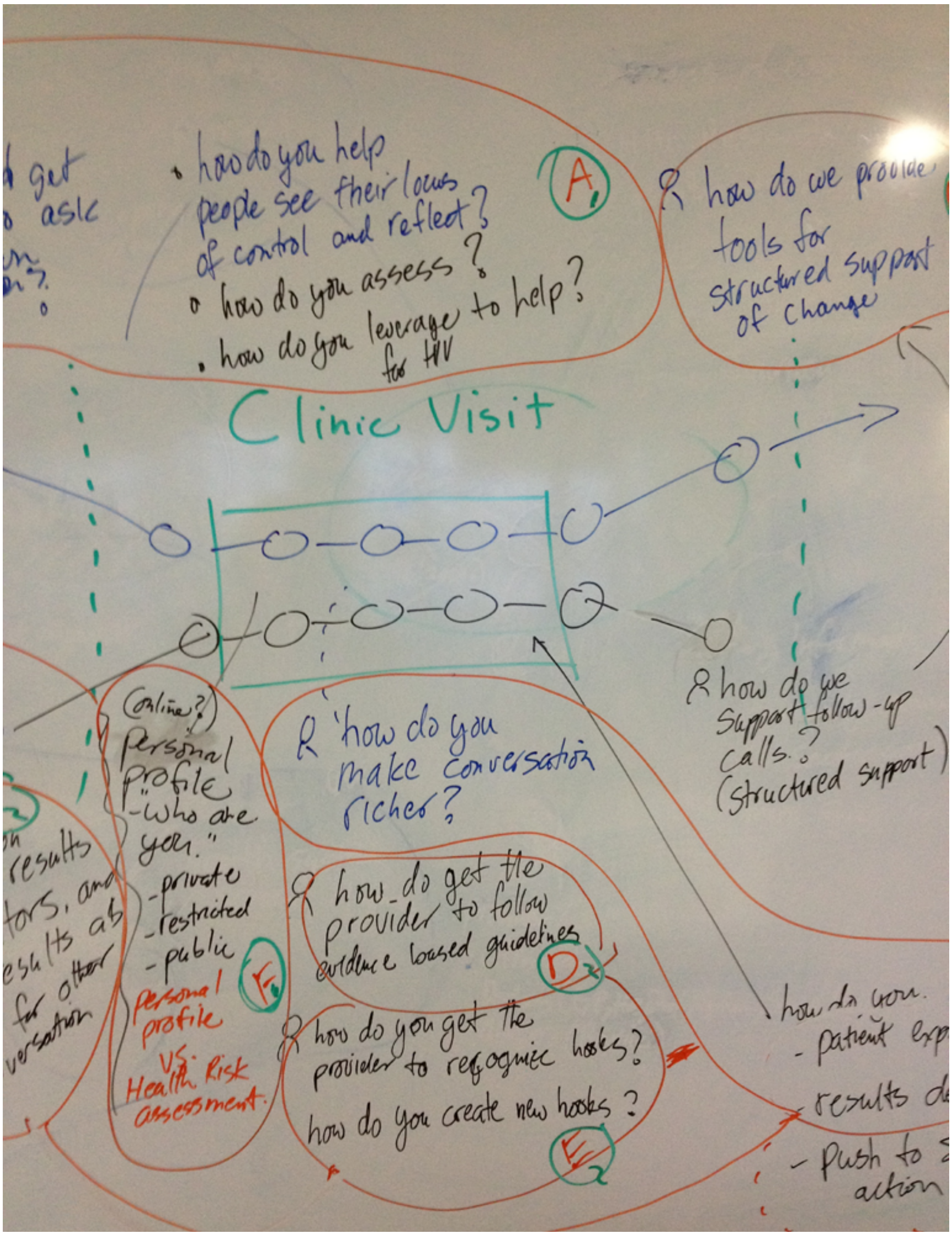
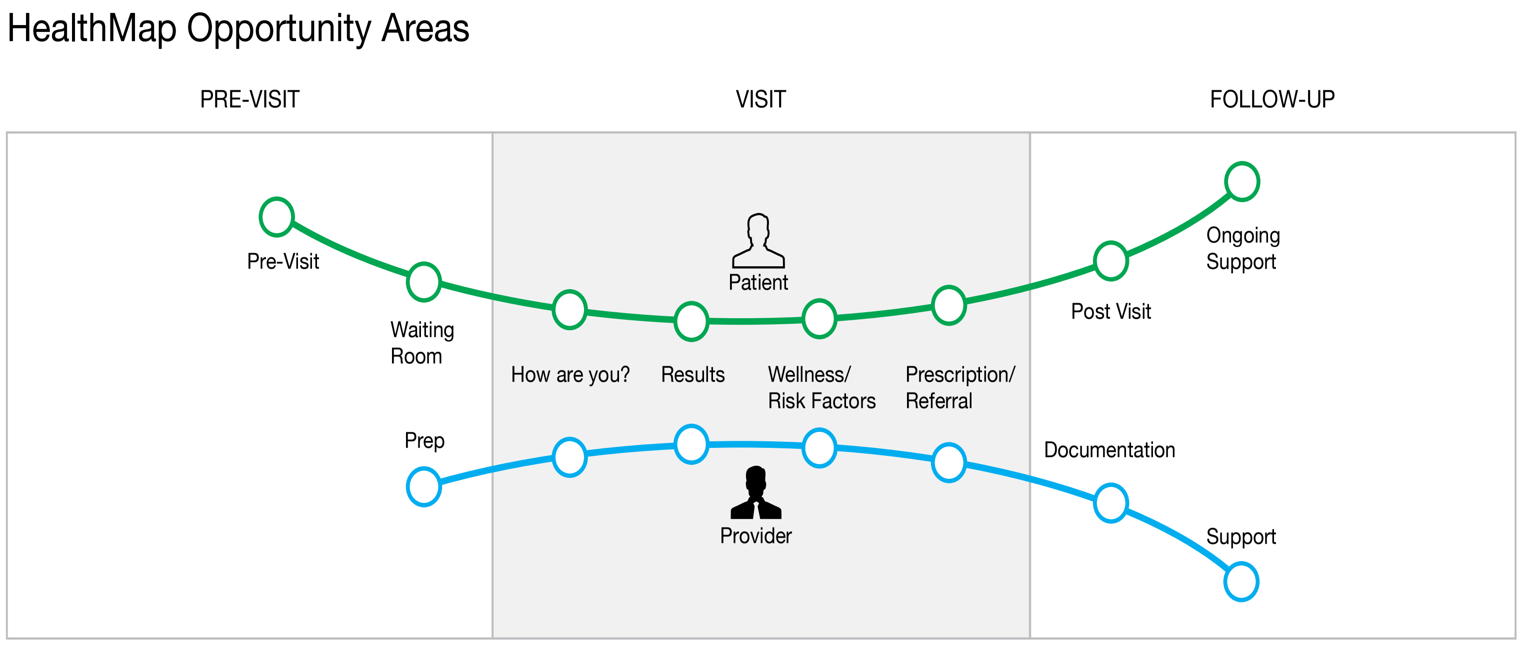


Figure 4.11 Phase 3 whiteboard from workshop on opportunities map



How do we get the patients to ask their own questions about health in a doctors visit?

How do we connect the patients broader desires and aspirations with their health information and health assessments?

How do we make the health risk assessment less medical and encompass the person as a whole? (personal profile vs. health risk assessment)

How do we help people see their locus of control and reflect? How do we assess this and leverage it to help people with HIV?

How do we make the conversation between patient and provider richer?

How do we create opportunities, “hooks” for the provider to discuss chronic disease risk factors. How do we get the provider to recognize those hooks?

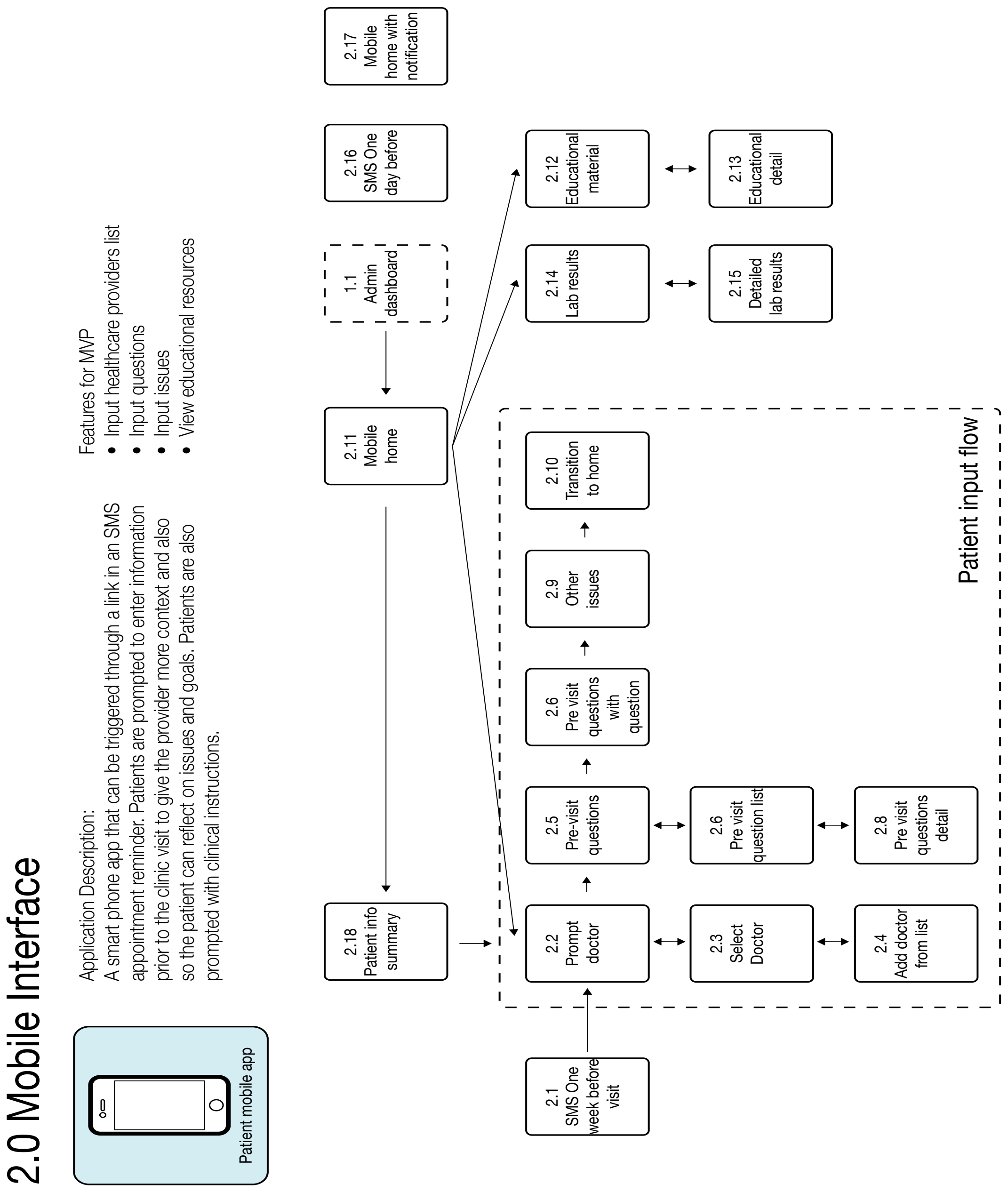
How do we represent results in a more meaningful way and use results as a hook for other conversations about risk factors?

How do we get the provider to follow evidence based guidelines?

How do we connect patient health information and patient health results to provide supports for them to take action?

How do we provide tools for structured support for behavior change?

Figure 4.12 Phase 3 opportunities map



2.0 Mobile Interface

Application Description:
A smart phone app that can be triggered through a link in an SMS appointment reminder. Patients are prompted to enter information prior to the clinic visit to give the provider more context and also so the patient can reflect on issues and goals. Patients are also prompted with clinical instructions.

Features for MVP
- Input healthcare providers list
- Input questions
- Input issues
- View educational resources

Figure 4.13 Phase 3 high-level information architecture

My reflection-on-practice during Phase 4 (the 2013 design intensive and following weeks) led to the position paper: *Pointy versus Soft: towards a design language for Chronic Disease Self-Management in Healthcare* This paper has been included in Section 5 to support the framing of the research context. The understanding expressed in *Pointy vs Soft* went on to guide the initial direction for the full time reflexive research enquiry.

4.7.1 Analysing the data

The following section will describe the reflexive 'telescopic lenses' through which I focussed my action research enquiry. My approach was to ask open-ended framing questions: i) 'What do I want to explore?' ii) 'How did we arrive at the HealthMap design?' iii) What impacted on design? iv) 'What were the *unknowns* pre-design and how did we address those knowledge gaps?

These framing questions were used to elicit insights into the HealthMap design processes and outcomes that could guide the scope of useful Research Questions to be discussed in the thesis. The insights derived from this open exploration identified the overarching theis goal and three Research Questions as areas where the data warranted further analysis and provoked further reflection. RQs 1, 2 and 3 emerged from this early enquiry: RQ1) How can we begin to map the healthcare cultural landscape? RQ2) What contributes to the effective use of design personas in a healthcare design project? RQ3) How can we envisage social media features for the highly stigmatised HIV positive population?

By 'telescoping' backwards and tracing the events that led up to the agreed design I identified the key junctures where fundamental design decisions were adopted and important design development occurred. I explored the design artefacts and records of design activities. These included audio recordings of design meetings, photos of white board meeting sketches and notes, affinity mapping with cards and sticky notes, photos of group sketching meetings, photos of design sketches and my personal notebook notes and sketches. In each case my process was to identify affinities, themes, patterns and significant indicators to produce inferences that could then be refined by further enquiry and testing against literature. Examples of these techniques are shown in Figures 4.14 – 4.15 below.

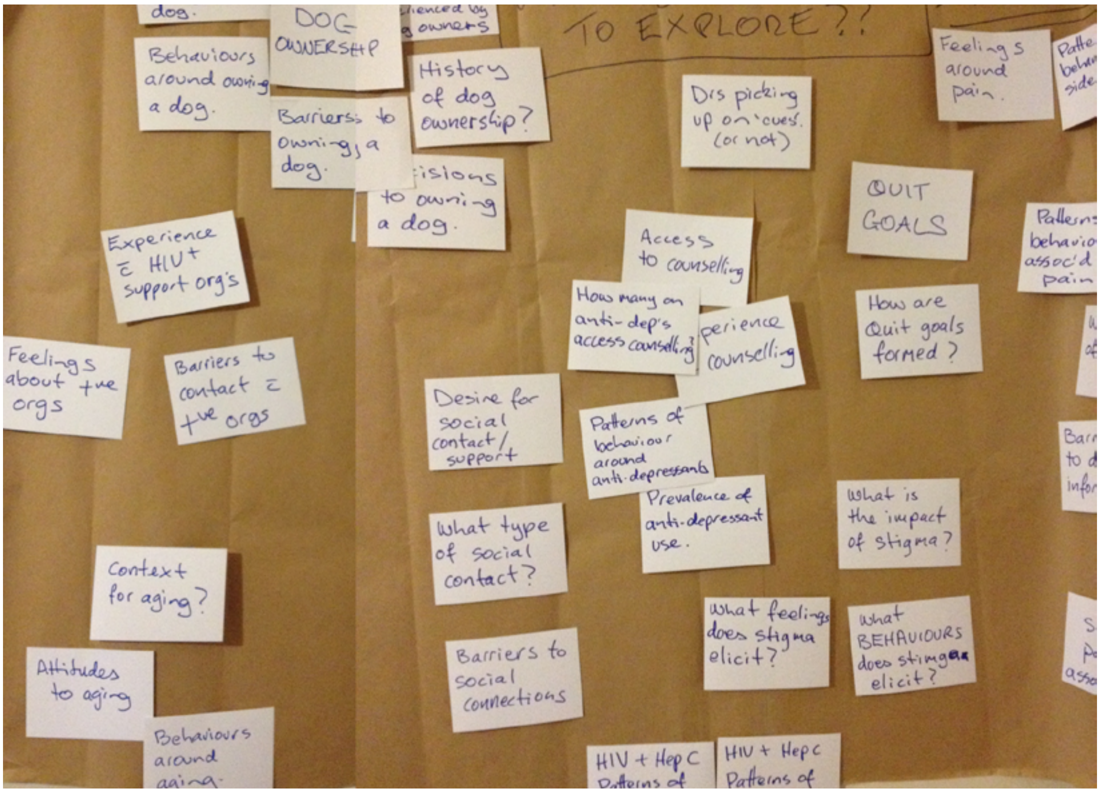
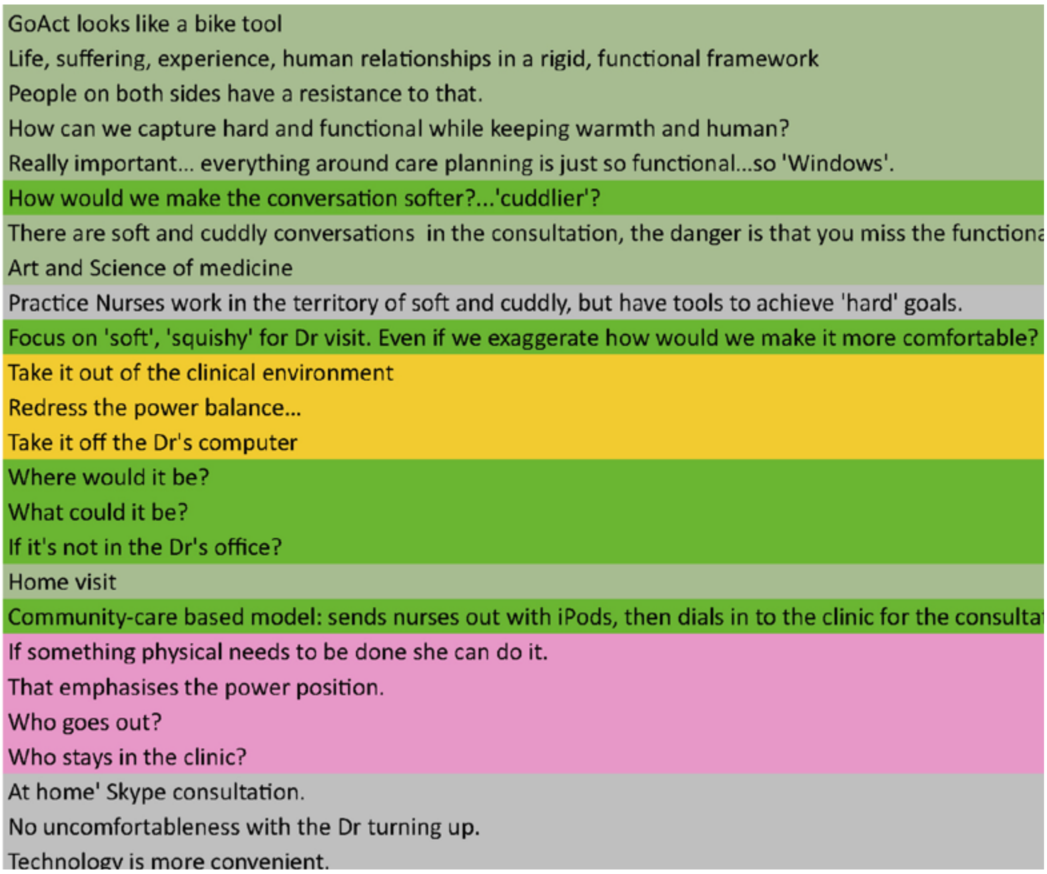


Figure 4.14 Framing question: what do I want to explore?

Figure 4.15 HealthMap design principles exploration



GoAct looks like a bike tool
Life, suffering, experience, human relationships in a rigid, functional framework
People on both sides have a resistance to that.
How can we capture hard and functional while keeping warmth and human?
Really important... everything around care planning is just so functional...so 'Windows'.
How would we make the conversation softer?...'cuddlier'?
There are soft and cuddly conversations in the consultation, the danger is that you miss the functiona
Art and Science of medicine
Practice Nurses work in the territory of soft and cuddly, but have tools to achieve 'hard' goals.
Focus on 'soft', 'squishy' for Dr visit. Even if we exaggerate how would we make it more comfortable?
Take it out of the clinical environment
Redress the power balance...
Take it off the Dr's computer
Where would it be?
What could it be?
If it's not in the Dr's office?
Home visit
Community-care based model: sends nurses out with iPods, then dials in to the clinic for the consulta
If something physical needs to be done she can do it.
That emphasises the power position.
Who goes out?
Who stays in the clinic?
At home' Skype consultation.
No uncomfortableness with the Dr turning up.
Technology is more convenient.

Figure 4.16 Workshop audio data colour-coded for conversation analysis

Figure 4.17 below shows the whiteboard question 'What impacts on design?' This was a persistent focal question as I worked and read relevant literature and the emerging diagram grew over time.

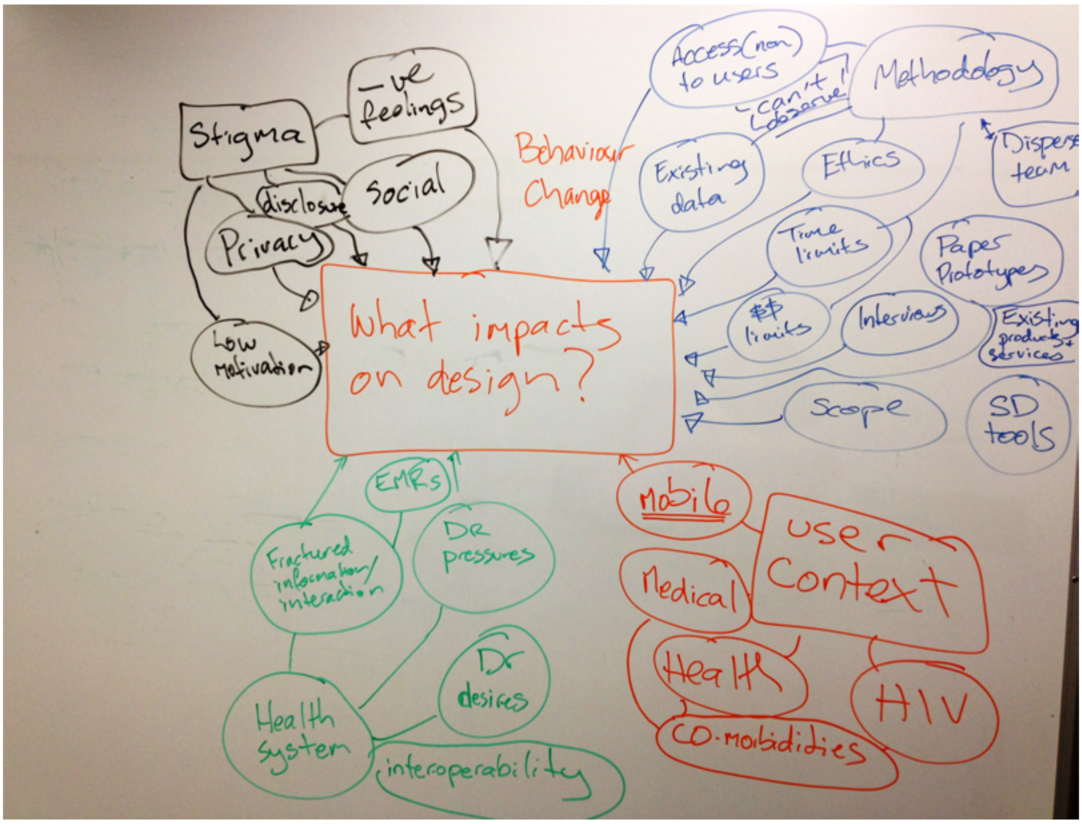


Figure 4.17 Framing question: What impacts on design?

4.7.2 Mapping

The 'telescopic' exploration of themes, patterns and indicators led to a process where the supporting data, design activities and working assumptions were mapped according to their contextual sources, and what investigations they prompted. I was particularly interested in analysing how the design team's working assumptions were compiled and how they drove the resulting design decisions. My analysis began by 'mapping' the data according to Context, Assumptions, Investigations and what Learnings they generated. The full mapping document is available in Appendix A. Figure 4.18 below shows an extract from the mapping document.

RCT Requirements *Primary Design Goal for HealthMap is to implement the intervention and satisfy the requirements of the RCT.*

Evaluation of CVD risk – has it been reduced?
Cholesterol levels
Blood Pressure
Smoking

Evaluation against secondary outcomes – have they been improved?
Mental health
Wellbeing
Self-efficacy

Context

- The effect of interactive self-care plans and self-management support on CVD risk and other chronic condition outcomes in PLHIV
- Evaluate patient and health care provider experiences and acceptability of interactive selfcare plans and self-management support.
- Evaluate intervention cost-effectiveness and effect on health service utilisation

Assumptions

1. Most effective intervention for Chol and BP is medication > HM needs to increase treatment uptake > need to design path to increased treatment
2. Smoking has similarly high impact on CVD risk > HM needs to target Smoking Cessation
3. Most CVD risk response is seen in the 50+ population > in order to demonstrate maximum effectiveness HM needs to target the 50+
4. Secondary outcomes will need to be demonstrated (i.e. measureable)
5. Secondary outcomes will need to demonstrate formal theoretical basis
6. What are the known issues around CDSM as they relate to mental health, wellbeing, self-efficacy?
7. The Transtheoretical Stages of Change could be important for HM design.
8. Can we plug into existing CDSM programs?

Investigation

- Do we need to reinvent the wheel and have a bespoke HM smoking cessation component? Can we plug into, direct users to, existing programs?
- Qual Data re: SmCess experiences
- Literature review of SmCess programs
- Design Team visit to Quit Victoria
- Designer meeting with existing SmCess designer
- Qual Data regarding these issues
- CDSM program meetings with HM Team – Arthritis, Diabetes, health insurance company, CDSM platform for GPs
- Literature Review
- Scraping online patient peer-support fora (e.g. patientslikeme.com)

Investigation Results (re RCT working assumptions)
Smoking Cessation (SmCess)

- Many PLHIV smokers have had contact with smoking cessation programs but the contact was fractured, inconsistent > would be open to follow up
- Evidence for technology based SmCess services is mixed. Some evidence for well designed SMS-based services.
- Personal goals and motivations will keep PLHIV persisting with SmCess attempts
- Some older PLHIV are not motivated re: SmCess because of past addiction history.
- Some PLHIV do not count SmCess as a priority.
- There is ongoing design work in the Australian SmCess field. This is on a ‘State by State’ basis. New programs are emerging.
- Successful SmCess means learning to be a non-Smoker.
- SmCess can be like ‘killing your best friend’.

Figure 4.18 Example of assumptions mapping

This mapping exercise was combined with my personal reflection to select significant points in the HealthMap design evolution to explore further in the light of relevant literature.

These descriptions of 'telescopic' journeys: the HealthMap project design evolution, my personal development and the academic research journey make transparent the types of cyclical, iterative enquires into the rich data from which, over time – in consultation with literature and academic peers via seminars – significant insights emerged. Sharing the formative ideas for research papers helped me to better understand the interests of design and HCI researchers and what stimulated their interest. Submitting papers for peer review to conferences and journals gave me access to valuable critique and guided the emphasis and scope of the work. Exposing my work to external criticism enabled my assumptions to be objectively tested and validated the selections and decisions I made regarding the potential value of my contribution.

4.7.3 Outcomes

In reflecting on data to pursue the research goal 'What insights can be offered from the HealthMap design project to designers unfamiliar with healthcare?' a number of insights emerged with regard to the strategic value of growing familiarity with the healthcare research domain, of shifting from a disparate multidisciplinary team to a functional design team and of the impact of accumulated tacit knowledge on creatively envisioning new patient-centred social technology.

How these insights were understood and offered to the design practice community is presented in 'Section 5: Results'.

5 Results

Making sense of HIV research as a domain for design

The overarching goal of the HealthMap design research is to understand ‘What can be learned from the HealthMap design project that offers insight to designers unfamiliar with healthcare as a domain for design?’

The following three papers take a pragmatic approach to address the three Research Questions: RQ1) How can we begin to map the healthcare cultural landscape? RQ2) What contributes to the effective use of design personas in a healthcare design project? RQ3) How can we envisage social media features for the highly stigmatised HIV positive population?

5.1 The journey through the unfamiliar HIV research domain

The three papers in the following sections can be understood as different points on a journey through the unfamiliar HIV research context. The journey encompasses approaching unfamiliarity, moving through unfamiliarity and emerging from unfamiliarity (into a more familiar and tacit domain knowledge).

Analysis of the results is presented in each submitted paper. Overall conclusions and implications for future work are discussed in ‘Section 6 – Conclusions’.

Paper 1 – *Pointy versus Soft: towards a design language for chronic disease self–management in healthcare* is a description of the HIV research domain as a context for the HealthMap design processes; it describes ‘approaching’ unfamiliarity and uses the metaphor of mapping features on a landscape to discuss the emerging understanding of healthcare as a design domain.

Paper 2 – *A Collaborative Rapid Persona-Building Workshop: Creating Design Personas with Health Researchers* describes ‘moving through’ unfamiliarity towards shared cross-disciplinary design understanding within the HealthMap design team. It does this by analysing the efficacy of a collaborative Persona building process.

Paper 3 – ’*Dipping a toe in the water’: addressing the effects of stigma and avoidance when designing social media features for people with HIV* describes ‘emerging from’ unfamiliarity to empathically explore a specific ‘How might we?’

probing question for social media design and idea generation in the context of a highly stigmatised user group. This supports the task to 'envisage' as stated in RQ3.

References for each paper remain within the three papers and are repeated in the overall Bibliography for the thesis.

Please note, each paper retains the journal style for the original submission document. Headings and text style will differ from the other sections of the thesis.

5.2 Paper 1

Submitted: OzCHI2013 – Human Factors and Ergonomics Society of Australia (HFESA) conference, short paper. Pervasive Health 2014 – 8th International Conference on Pervasive Computing Technologies for Healthcare, short paper. Revised to incorporate comments from conference reviewers and wider literature review. Submitted to Journal of Medical Internet Research (JMIR), March 2015.

Statement of Contributions of Joint Authorship

Williams, I (Candidate) Writing and compilation of manuscript, established methodology for reflexive action research, data analysis and discussion.

Brereton, M (Principal Supervisor) Supervised and assisted with manuscript compilation, co-author of manuscript

Donovan, J (Assistant Supervisor) Supervised and assisted with manuscript compilation, co-author of manuscript

Tam, A (Research Colleague) Established methodology for field data generation, generated field data, commented on manuscript

Karalyn McDonald (External Supervisor) Participated in data generation, commented on manuscript

Tanya Millard (Research Colleague) Participated in data generation.

Elliott, J .H. (External Supervisor) Project leader, participated in data generation, supervised and commented on manuscrip

Pointy versus Soft: Towards a Design Language for Chronic Disease Self–Management in Healthcare

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ABSTRACT

Background

Design practitioners engaged in healthcare information technology projects can often come from non-medical backgrounds and find the healthcare domain an unfamiliar and complex context. Such unfamiliarity can introduce barriers to healthcare system engagement, but at the same time offer innovative solutions to healthcare design challenges.

We report on the HealthMap Study design project to support People With HIV (PWHIV) in self-management of cardiovascular disease and the chronic diseases of ageing. A design researcher and two practising designers in a mulit-disciplinary design team with HIV researchers facilitated the HealthMap design processes. Understanding the unfamiliar contextual and cultural factors influencing co-design processes was an important element of successful collaboration between the domains of design and HIV / chronic disease self-management research.

Objective

In order to better understand the ‘ingredients’ that led to successful cross-disciplinary engagement and designer navigation of an unfamiliar domain we conducted a reflexive analysis of the HealthMap design processes. Our goal is to offer actionable understanding for design through articulating a framing tool helpful to the HealthMap design processes. We aim for this understanding to contribute to a potential ‘community of practice’ of designers engaged in healthcare design projects.

Methods

Using an Action Research approach we reflected on the design artefacts and design process data collected during the early HealthMap design phases. This identified the significant impact of a co-design 'service envisioning' workshop held with designers and stakeholders to understand key contextual and human-centred influences for effective care provision and to develop framing concepts for an effective self-management design intervention.

We compared the outcomes of this workshop with literature that discussed the contextual features of healthcare as a domain for technology design and tested our emerging findings through formal research seminars with HCI and Participatory Design researchers.

Results

On reflection we have found that the thematic metaphor that emerged from the co-design workshop can be understood as a socio-technical design strategy for the healthcare sector more generally. This paper introduces the metaphor of 'Pointy versus Soft' as a framing tool for design dialogue.

The 'pointy' landmarks are: systemic time scarcity, the requirement of metrics, and software interoperability. These 'pointy' aspects exist within the pervasive human and social 'soft terrain features' such as stigma. Both pointy landmarks and soft terrain features require explicit strategic design attention. These 'pointy landmarks' and 'soft features' give key framing concepts for design work in chronic disease self-management (CDSM) support and potentially comprise a strategy transferable to other designs for healthcare

Conclusions

The 'Pointy versus Soft' metaphor can be employed in two ways: i) as a coherent design vernacular that supports initiating designers into the unfamiliar healthcare domain and ii) as a strategy for cross-disciplinary dialogue that bridges knowledge boundaries and builds cross-disciplinary tacit design knowledge. This design vernacular and the design strategy potentially act as cross-disciplinary knowledge bridges to support healthcare design knowledge management and contribute to an emerging community of practice for healthcare design.

Keywords

Participatory Design; Health IT; Chronic Disease Self-Management; Co-design, Knowledge Barriers

BACKGROUND

This paper presents a case study describing some implications for the entry of design practice into healthcare. It discusses the HealthMap Study, an Australian National Health and Medical Research Council funded information technology intervention. The aim of HealthMap is to reduce chronic disease risk factors for People living with HIV (PWHIV) by creating interactive self-management plans. The project is led by the Alfred Hospital / Monash University, Department of Infectious Diseases. It is evaluated in a cluster-randomized control trial (RCT) over two years, commencing 2014. Smoking is the highest risk factor for developing chronic disease with a prevalence of smoking of 42% among PWHIV. (Heart Foundation, n.d.)

A chronic disease management approach includes support for self-management, service coordination and integration. Thus information and communication systems will play a crucial role in chronic disease management (Internal document ID No. 1012459, HealthMap grant application).

The role of design practice in healthcare

Healthcare systems all over the world are littered with information technology programs that are under utilized, poorly integrated, or abandoned. (S. P. Bate and Robert, 2002; Mockford, Staniszewska, Griffiths, and Herron-Marx, 2012). As Kaplan and Salamone report, *Despite best practice research that identified success factors for health information technology projects, a majority, in some sense, still fail. Similar problems plague a variety of different kinds of applications, and have done so for many years.* (Kaplan and Harris-Salamone, 2009:291).

The persistent challenges in implementing healthcare information technology have meant that health IT projects have looked beyond traditional engineering paradigms to a broader, multidisciplinary approach that includes design practice. In particular the role of co-design, where design methodologies are employed by multidisciplinary stakeholders (ideally including all system users, including patients), often facilitated by design practitioners, is seen as a key strategy for avoiding the errors of past technology design failure (Bate and Robert, 2006; Gonzales and Riek, 2013; Pickles, Hide, and Maher, 2008; Tsianakas et al., 2012). Co-design is a central tenet of a Participatory Design approach and how to conduct successful Participatory Design within a healthcare context is an ongoing research agenda for designers engaged on healthcare projects (Berryman, Haberman, and Lynn, 2011; Jones, 2013; Ross, 2014;

Sanders, 2002; Sanders and Stappers, 2008; Simonsen and Robertson, 2012).

At the same time the burden of increased chronic diseases means governments all over the world face rising healthcare system demands, with ageing populations and the spread of lifestyle influenced diseases. The User-Centred Healthcare Design (UCHD) project in the UK suggests that *new models of healthcare that re-define the institutional and social context of care are required if we are to meet the challenge of chronic illness*. UCHD describes designing for pervasive healthcare as *a focus on individuals, their experiences, practices and social relationships, in order to understand how these effect their self-management.* (Dearden et al., 2010:8)

As a context for design, health and healthcare have particularities that present complex problems encompassing the personal and intimate, the social, the physical and the institutional. It also inherently requires designing an experience across time and space. These complexities and sensitivities present a natural need for design that is human-centred, participatory and experience led. The value of design processes in healthcare innovation have been recognized for many years, with the British NHS development of the 'Experience-Based Design' toolkit a striking example of institutional adoption of design methodologies (Bate and Robert, 2007; Bowen, Dearden, Wright, Wolstenholme, and Cobb, 2010; Dearden et al., 2010; NHS, n.d.; Julier, 2013.; Pickles et al., 2008).

Despite the strong drivers towards co-design, successful healthcare technology ecosystems success is often sporadic and significant gaps remain between desired outcomes and common experiences in developing healthcare technology (Jones, 2013; Mockford et al., 2012; Pilemalm and Timpka, 2008).

There is ongoing dialogue amongst design researchers/practitioners and healthcare providers that seeks to articulate healthcare as a design domain. They propose principles and practices to establish a body of understanding and expertise in developing successful health experiences and sustainable health supporting systems (Berryman et al., 2011; Bowen, Dearden, Wolstenholme, and Cobb, 2011; Bowen et al., 2010; Dearden et al., 2010; Dexter et al., 2010; Jones, 2013; McHattie, Cumming, and French, 2014; Pickles et al., 2008; Ross, 2014; Wright and McCarthy, 2010). The work of the UK based 'Lab4Living', a multidisciplinary research centre combining art and design research with health and social care research, is one example of designers and health researchers exploring the relationship between design, health and wellbeing (Lab4Living, n.d.).

As a project the HealthMap Study is placed exactly in this space. It involves a patient group with complex medical and psychosocial needs, who are ageing, who experience enormous stigma from a variety of sources and who are permanently engaged with the healthcare system. HealthMap's potential is to support the day-to-day wellbeing of people living with chronic disease while facilitating a meaningful and efficiently delivered engagement with the healthcare system.

The following sections will introduce the HealthMap design phases over time, indicating the types of activities and artefacts generated within each phase, and then introduce the HealthMap design team members.

HealthMap design phases

Figure 1-A (below) shows the HealthMap design cycles within four design phases:

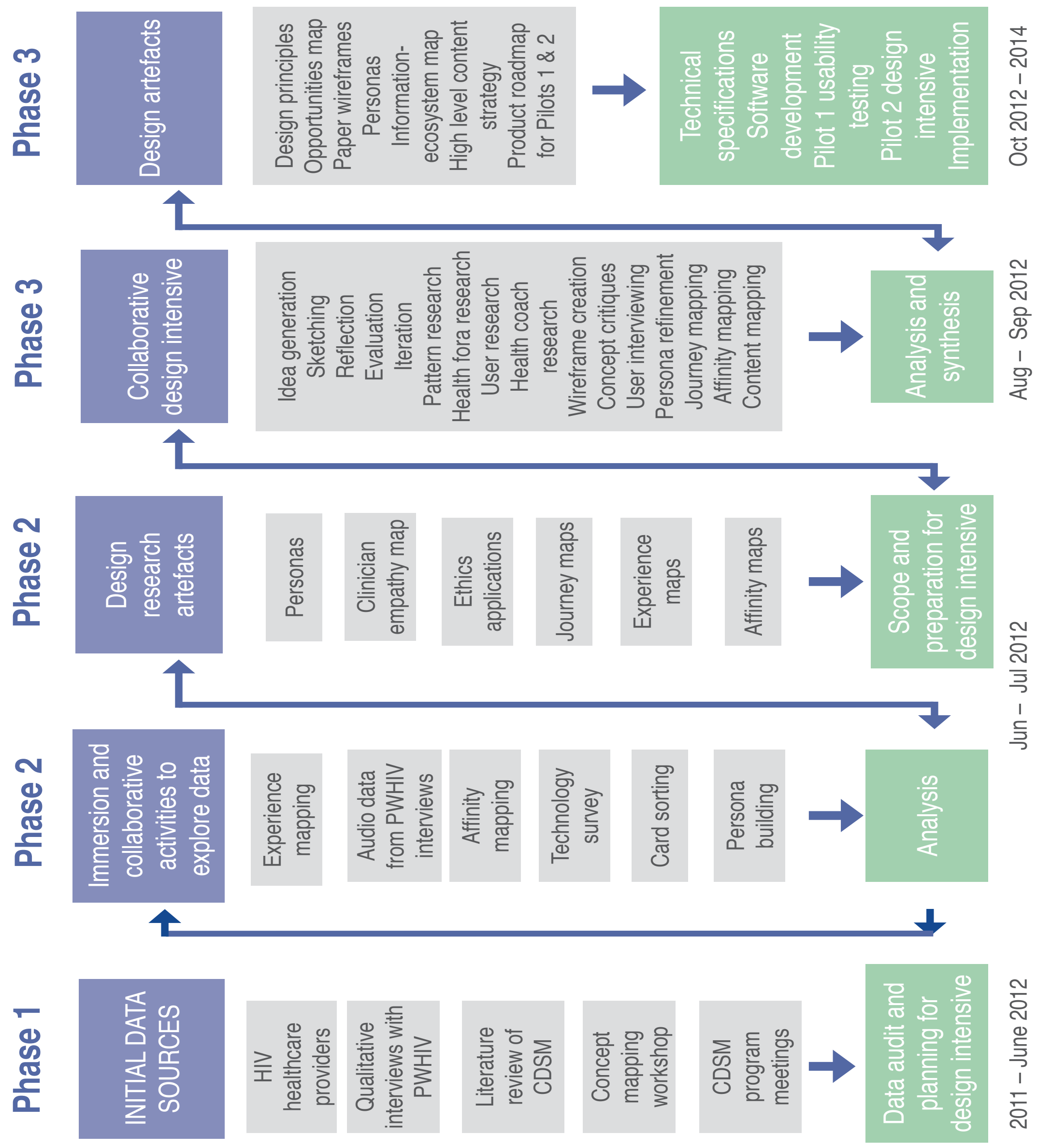


Figure 1-A HealthMap design phases

HealthMap design team

Initially the HealthMap team comprised: a social researcher with many years experience in HIV research, a hospital-based HIV treatment provider / clinical researcher (who was the project lead) and an occupational therapy postgraduate researcher with special interest in HIV and chronic disease self-management. This domain expertise combined represents over 40 years of research and work with people living with HIV. The research team consulted with Designer 1, who provided high-level design strategy advice but was not co-located with the team. Designer 1 is a design researcher specializing in Participatory Design and Interaction Design and was known to the clinical researcher. These team members conducted the activities in Phase 1, (see Figure 1-A, above). Designer 2 is a User Experience Design practitioner employed at the beginning of Phase 2. Her role was to collaborate with the HealthMap team to conduct design research, scoping exercises and project management in preparation for the 6-week design intensive in Phase 3 and to participate in ongoing design work.

Designer 3 is an Interaction Designer with over ten years experience designing for healthcare. HealthMap is his first HIV project. He works on HealthMap remotely, but was co-located for the Phases 3 and 4 design intensives.

In addition HealthMap has twelve chief investigators who receive reports and contribute to project decisions.

OBJECTIVE

Given the challenges facing healthcare technology design, and the challenges facing institutional healthcare globally, the work in designing HealthMap using a collaborative, human-centred model, can demonstrate a design contribution to knowledge development and to building expertise for an emerging community of practice for healthcare service design.

By reflexively analysing the HealthMap co-design experiences we offer a case study to contribute transferable knowledge and actionable insights relevant to other design work for chronic disease self-management and potentially for wider healthcare service design.

Healthcare as a context for design

Managing chronic disease needs an integrated service interface between people's experiences of life, suffering and human relationships and the socio-technical system of healthcare (Jones, 2013). Jones calls for a new methodology of service design that can address these complex practices and institutional contexts.

Following the recommendations of Greenhalgh, Robert, Macfarlane, Bate, and Kyriakidou, (2004) and Jones, (2013) to describe contextual features that impact on healthcare design, we describe some of the medical and institutional influences on the HealthMap design and suggest contextual generalities (landmarks) that might be common when designing for healthcare. We describe these landmarks to help build a body of knowledge and design strategies for healthcare technology designers.

While these contextual landmarks might appear easily anticipated, it is still useful to have them articulated within design strategy. Their very ubiquity runs the risk that they are overlooked and taken for granted, rather than approached strategically from the earliest stages of a design project.

A vernacular design strategy for healthcare – towards a healthcare design lexicon

In analysing the HealthMap contextual factors we employ the 'Pointy versus Soft' design strategy developed by the multidisciplinary HealthMap team. This strategy had several functions across the design lifecycle. We describe the evolution and the functions of the 'Pointy versus Soft' design strategy as an example in successful cross-disciplinary dialogue and design knowledge co-creation.

In order to support cross-disciplinary dialogue knowledge barriers between diverse domains of expertise must be overcome (Carlile, 2004; Segalowitz and Brereton, 2009). Segalowitz and Brereton describe the negative impact of knowledge barriers between different domains of expertise on Participatory Design projects (Segalowitz and Brereton, 2009). Design projects in healthcare contexts are particularly prone to knowledge barriers as the highly specialized nature of medical institutions and the contrasting approaches of traditional medicine (scientific) and traditional design (intuitive and creative) all have an impact on how design teams members make sense of design problems and how they envisage design solutions (Bowen et al., 2011; Sanders and Stappers, 2008; Stolterman, 2008). By analysing the creation of the 'Pointy versus Soft' design strategy within HealthMap we offer i) a framing tool for adoption in other healthcare design projects, and ii) a potential design 'lexicon' specific to an emerging field of healthcare design.

METHODS

Action Research

In analysing the HealthMap design processes we have taken a reflexive action research (AR) approach, employing critical reflection both during design work and as a retrospective systematic 'reflection-on-design' through exploration of collected design artefacts and project data (Bowen, Dearden, and Dexter, 2014; Koshy, Koshy, and Waterman, 2011; Schön, 1992). AR is an appropriate approach for collecting, exploring and analysing data for collaborative, problem-focused and practice-based design research questions.

Action research data

The main focus of the HealthMap design team was to create a working platform to deliver the NHMRC defined project requirements. The subsequent reflexive AR processes are grounded in the data collected during the technology project development and through reflexive analysis of design artefacts, workshop audio recordings and with reference to relevant literature.

Tables 1-A and 1-B give an overview of the data used for the reflexive analysis:

Table.1-A *Action Research data from design phases 1 – 2*

DESIGN ARTEFACT	DESIGN PHASES 1–2 DATA
Technology Survey of PWHIV	
	access to devices
	access to health information
	access to social media
	SMS use
	cardiovascular disease risk factors
Notes from meetings with existing technology-based CDSM programs	
	Diabetes
	Arthritis
	smoking cessation
	GP management plans
	health insurance clients
	affinity diagrams
Design workshop artefacts	
	PWHIV Experience Map
	HIV clinician empathy map
	collaborative persona-building workshop audio recordings
PWHIV qualitative data – semi-structured interview questions – recordings and transcripts	
	impact of HIV
	interactions with healthcare providers
	use of technology

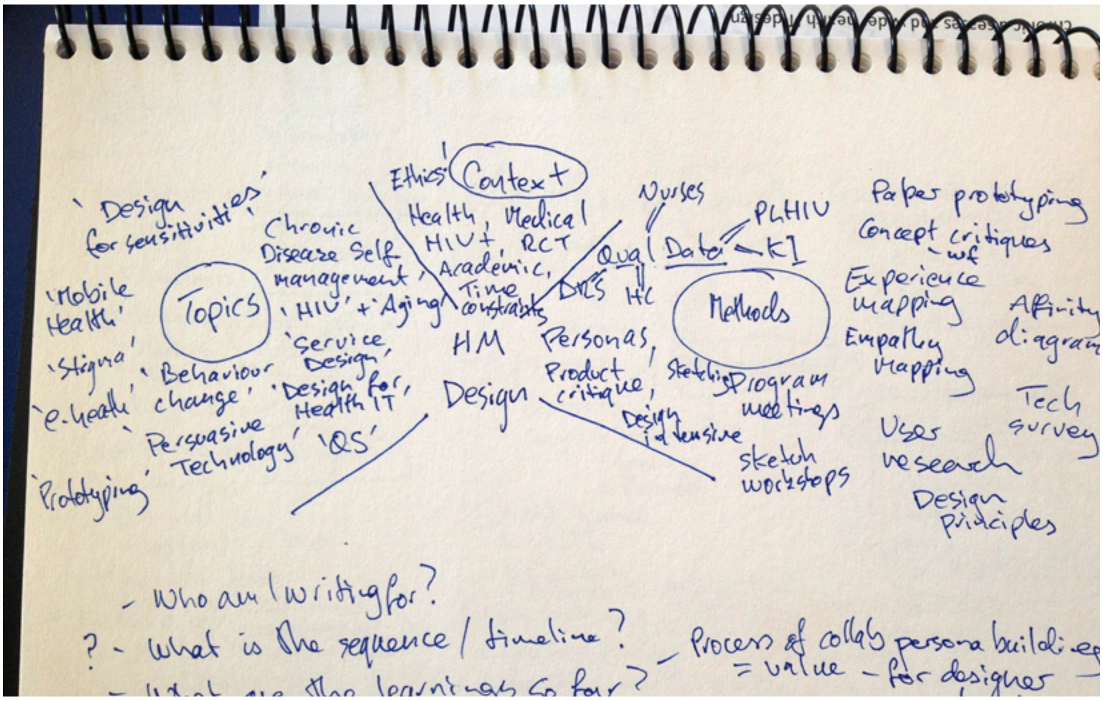
Table.1-B *Action Research data from design phase 3*

DESIGN ARTEFACT	**DESIGN PHASE 3 DATA**
Design workshop artefacts	
	patient personas
	collaborative idea generation workshop sketches
	collaborative idea generation workshop audio recordings
	Collaborative brainstorming workshop sketches
	Collaborative brainstorming workshop audio recordings
	content brainstorming workshop audio recordings
	content brainstorming workshop notes
PWHIV interviews	
	user interviews – concept critique audio recordings
	user interviews – concept critique notes
HIV treatment provider interviews	
	user interviews – concept critique audio recordings
	user interviews – concept critique notes
Health coach interviews	
	Health coach interview audio recordings
	Health coach interview notes
Paper-based artefacts	
	user journey maps
	user interface sketches
	health coach interviews
Digital artefacts	
	online health coaching research
	affinity diagram photos
	design pattern research
	static concept diagrams
	static wireframes

These data were reviewed with a view to identifying important project milestones and to identify patterns and themes.

Data analysis

Rapid and lean design techniques were used for data analysis, employing the same techniques employed for the HealthMap design processes (such as note-taking, sketching and affinity diagramming). A number of framing questions were used to guide the exploration and organization of data into themes and to identify significant factors influencing design. Examples of these questions are given below (Figures 1-B – 1-C).



- Who am I writing for?

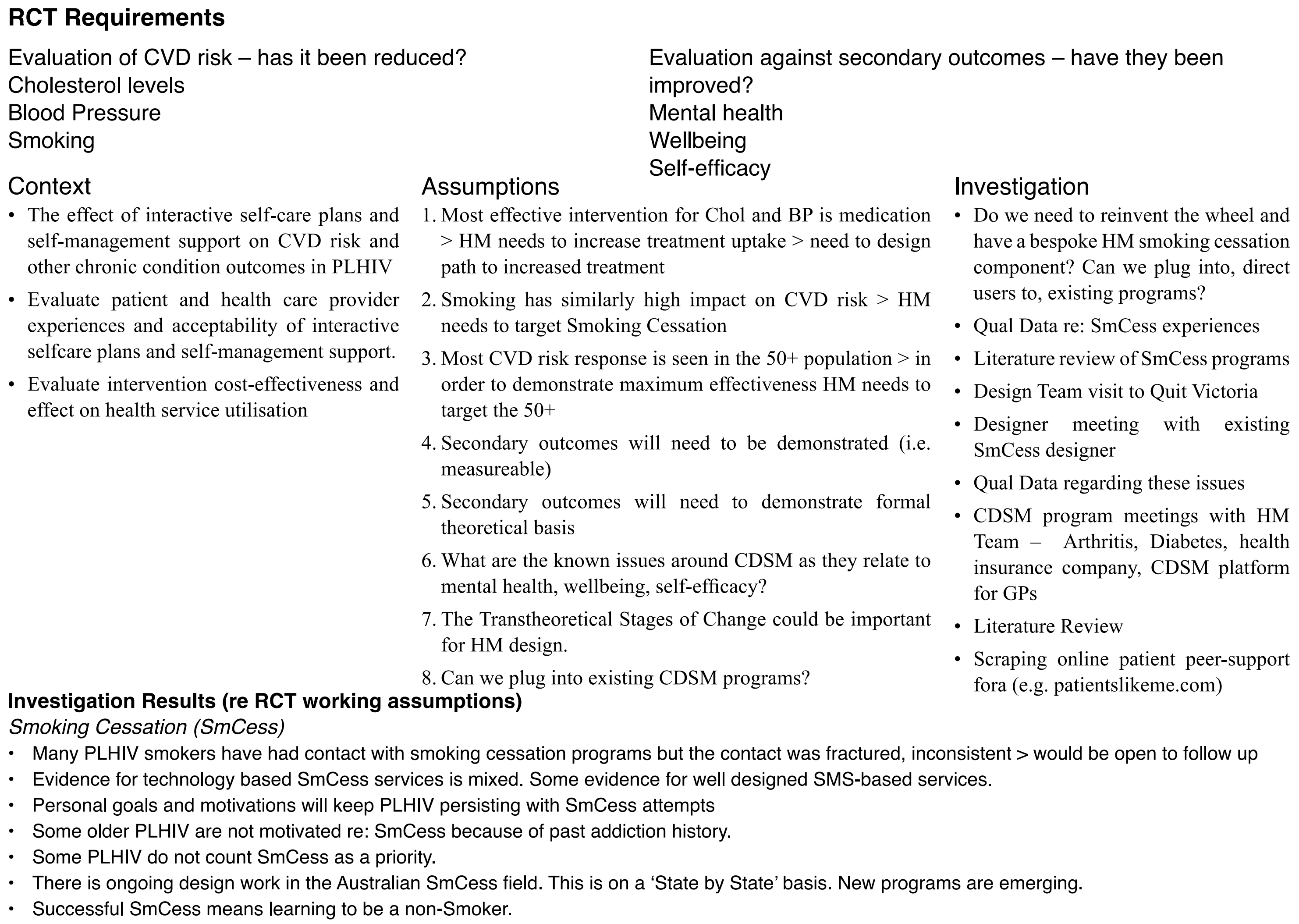
? - What is the sequence / timeline?

- What are the learnings so far?

- Process of collab persona building
= value - for designer -

Figure 1-B Notes from data exploration

We used framing questions such as ‘How did the HealthMap design principles evolve?’ and ‘What are the learnings so far?’ to chronologically review the design activities timeline. We used the technique of mapping the design team working assumptions from the earliest phase 1 activities until the beginning of phase 4. An extract of a working assumptions map is below (Figure 1-C).



RCT Requirements

Evaluation of CVD risk – has it been reduced?
Cholesterol levels
Blood Pressure
Smoking

Evaluation against secondary outcomes – have they been improved?
Mental health
Wellbeing
Self-efficacy

Context

- The effect of interactive self-care plans and self-management support on CVD risk and other chronic condition outcomes in PLHIV
- Evaluate patient and health care provider experiences and acceptability of interactive selfcare plans and self-management support.
- Evaluate intervention cost-effectiveness and effect on health service utilisation

Assumptions

1. Most effective intervention for Chol and BP is medication > HM needs to increase treatment uptake > need to design path to increased treatment
2. Smoking has similarly high impact on CVD risk > HM needs to target Smoking Cessation
3. Most CVD risk response is seen in the 50+ population > in order to demonstrate maximum effectiveness HM needs to target the 50+
4. Secondary outcomes will need to be demonstrated (i.e. measureable)
5. Secondary outcomes will need to demonstrate formal theoretical basis
6. What are the known issues around CDSM as they relate to mental health, wellbeing, self-efficacy?
7. The Transtheoretical Stages of Change could be important for HM design.
8. Can we plug into existing CDSM programs?

Investigation

- Do we need to reinvent the wheel and have a bespoke HM smoking cessation component? Can we plug into, direct users to, existing programs?
- Qual Data re: SmCess experiences
- Literature review of SmCess programs
- Design Team visit to Quit Victoria
- Designer meeting with existing SmCess designer
- Qual Data regarding these issues
- CDSM program meetings with HM Team – Arthritis, Diabetes, health insurance company, CDSM platform for GPs
- Literature Review
- Scraping online patient peer-support fora (e.g. patientslikeme.com)

Investigation Results (re RCT working assumptions)

Smoking Cessation (SmCess)

- Many PLHIV smokers have had contact with smoking cessation programs but the contact was fractured, inconsistent > would be open to follow up
- Evidence for technology based SmCess services is mixed. Some evidence for well designed SMS-based services.
- Personal goals and motivations will keep PLHIV persisting with SmCess attempts
- Some older PLHIV are not motivated re: SmCess because of past addiction history.
- Some PLHIV do not count SmCess as a priority.
- There is ongoing design work in the Australian SmCess field. This is on a ‘State by State’ basis. New programs are emerging.
- Successful SmCess means learning to be a non-Smoker.

Figure 1-C Example of assumptions mapping – RCT impact on design

This shows the reflection on the role of the cluster-randomized control trial in shaping the HealthMap design. It notes the factors from the RCT that directly guided design requirements. It then summarises contextual factors relevant to RCT evaluation points, the working assumptions arising from the evaluation points and the investigations conducted to test those working assumptions.

Focused reflection – the role of the service-envisioning workshop

Our reflective data analysis identified the significant role of a service-envisioning co-design workshop that took place during design phase 3, facilitated by Designer 3. This section will briefly describe the workshop activities. The outcomes from analysing the workshop audio data, design artefacts and impact of the workshop on HealthMap design work will be discussed in the following 'Results' section.

Service Envisioning Workshop

'Pointy' versus 'Soft'

This section describes a participatory service-envisioning workshop that took place a couple of weeks into the phase 3 of the HealthMap design lifecycle. The workshop began with an exploratory exercise using two randomly chosen objects with opposing attributes to provoke creativity and discussion. The two objects were: a bicycle repair tool (Figure 1-D below) and a soft, green, stuffed toy representing a neurone (Figure 1-E below). Boer, Donovan, and Buur, (2013) discuss the value of embodying tensions to support collaborative analysis and design explorations among stakeholders. In this respect, we were fortunate in that although the objects for the exploratory exercise were chosen at random, by virtue of their contrasting qualities they seemed to call forth discussion of tensions within the design context and differing perceptions among workshop participants.

The workshop moved from collaborative team discussion around the two objects and how their characteristics related to patients' experiences of health and healthcare to a series of guided sketching and critique exercises. The sketching generated high-level ideas for services and technology screens that were then selected for the 'best' ideas. These best ideas were used to instigate a further sketching workshop the following day.

Figure 1-D Bike repair tool - 'Pointy'

Figure 1-E Toy neuron - 'Soft'

Exploratory reflection – literature and discussions

Parallel to our formal reflexive data analysis we consulted relevant literature from the design research and health design research fields. This informed our understanding of how the HealthMap design processes and outcomes related to other case studies.

We also engaged with Interaction Design research colleagues through seminar presentations and informal dialogue as well as informal dialogue with industry-based User Experience Designers and with reference to user experience industry media.

RESULTS

The exploratory reflection raised the role of context, specifically HIV treatment and the lived experiences of people with HIV, as foundational both to the HealthMap design work and discussion of the HealthMap design research. That is, it became clear that without articulating and describing important contextual elements much of what underpinned the HealthMap design decisions would be unclear to other designers.

The service-envisioning co-design workshop discussions provoked by the bike repair tool and the soft toy soon adopted the metaphor of ‘pointy’ versus ‘soft’. ‘Pointy’ referred to functionality: task oriented, measurable, predictable, medical aspects of PWHIV experiences and ‘soft’ referred to the experiential: psychosocial, wellbeing, quality of life aspects of PWHIV. This ‘soft’ value aligned with a premise of User-Centred Design, which is that ‘softness’ (affective elements and quality of experience), can be crucial to successful human interactions with technology (Wright and McCarthy, 2008; Wright, Wallace, and McCarthy, 2008).

We therefore saw a convergence between the important role of the ‘Pointy versus Soft’ workshop in capturing contextual elements for the HealthMap design and the ongoing need to articulate contextual elements for clarity in design discussion.

The results of this action research reflexive inquiry focusing on the service-envisioning co-design workshop have identified outcomes at several levels. The macro level outcomes are: a co-created cross-disciplinary design language, a descriptive design strategy for contextual factors influencing design, an analytical design strategy for contextual factors influencing design, and an ongoing design lexicon for the HealthMap design and development team. The more detailed ‘micro’ level outcomes were identified though the application of the ‘Pointy versus Soft’ design strategy to the action research analysis. Both ‘macro’ and ‘micro’ outcomes are discussed below.

Macro level outcomes

A HealthMap design language

The service-envisioning workshop found the ‘Pointy versus Soft’ metaphor a useful design strategy for service idea generation. However, on reflection, much was gained from the process of collaboratively building shared terms to capture the many elements from the medical and personal spheres of patient and provider experiences. This dialogical co-construction of a shared understanding facilitated cross-disciplinary ‘sense-making’ (Qu and Hansen, 2008). The workshop activities allowed the ‘Pointy versus Soft' terms to be suggested, explored, defined and employed to develop a cohesive, tacit agreement on their usefulness in describing the many contextual and experiential factors workshop participants sought to discuss.

The conversation was able to depart from the medical, the academic and the anecdotal into a simple vernacular to succinctly and accurately capture complex contextual factors that were significant for design work and necessary for ongoing design planning and design critique.

The co-creation of this language for design (separate from the domains of health research and social research) essentially bridged the knowledge boundaries between the multiple disciplines represented in the HealthMap team and facilitated mutual understanding, collaborative idea generation and constructive criticism. Carlile's framework for knowledge management across domain boundaries is helpful in understanding these dynamics (Carlile, 2004). The dialogical exploration and co-construction of a design language can be described as 'bridge-building' between the knowledge boundaries that exist between diverse domains of expertise. Developing strategies and skills for knowledge boundary 'bridge building' is a persistent requirement for Participatory Design practitioners in healthcare (Segalowitz and Brereton, 2009).

The 'pointy' and 'soft' terms are still used by HealthMap team members as a useful 'short-hand' language to discuss design opportunities, constraints and contextual factors.

The Pointy versus Soft design strategy: a tool for understanding context

Many design projects seek to make explicit contextual and experiential factors that influence human behavior, shape socio-technical systems and ultimately impact on the success of program implementation. While design practice techniques exist for understanding contextual influences, contexts that are particularly complex, or particularly unfamiliar, can prove very challenging for traditional User-Centred Design practitioners (Sanders and Stappers, 2008; Stolterman, 2008; Rogers, 2004). Healthcare is a demonstrably complex context for design projects. This complexity is further compounded by the technological ecosystems that can provide a ubiquitous healthcare engagement.

Any tool that supports a simple and practical exploration of complex contextual factors is potentially highly valuable to healthcare design practice. The usefulness of 'Pointy' and 'Soft' as a design language is not just in the simplicity and aptness of the terms, it is in their flexibility when exploring complex, multi-faceted contextual factors. Pointy and Soft have the ability to accommodate many nuances that pervade healthcare as a context for design. The 'Yin and Yang' section below gives an example of this flexibility.

The Yin and Yang of 'Pointy'

Sometimes the same 'pointy' aspect of healthcare can provide both design opportunities and barriers. The parallel design opportunity and design constraint of healthcare providers pressed for time is an example. While it is difficult to successfully disrupt patterns of workflow, and to risk adding to a consultation workload, if there is opportunity to add efficiency, or to add so much extra value that the pressure on time is seen as worthwhile, this raises the possibility for provider adoption.

Two HIV treatment provider values identified during HealthMap design research were continuity of data and patient motivation. These were both designed for and tested during the concept critiques. While continuity of data is a complex challenge, and will be partially addressed, improved patient motivation was enough of a priority for providers to accommodate a certain level of disruption to their workflow. If patients are enthusiastic towards an application then many providers will support its adoption, assuming adoption is reasonably straightforward. Thus the 'soft' factor of patient motivation relates to the 'pointy' factor of provider time-scarcity as a potential opportunity for design. It also reinforces the priority of patient-motivation beyond a 'soft' consideration to a strategic 'pointy' value.

The Pointy versus Soft design strategy: a tool for evaluation

The 'Pointy versus Soft' design strategy was used as a reflexive action research tool for design practice evaluation. It supported a reflexive analysis of both contextual features and the HealthMap design process. This allowed us to 'tease apart' interwoven and sometimes conflicting factors which impacted the HealthMap design.

Having identified significant contextual factors we were able to explore their impact on design and propose future design strategy for HealthMap and potentially wider healthcare design projects. In this way the Pointy versus Soft design strategy supported clear strategic design guidance and actionable insights for further design work.

The 'Micro level outcomes' section below presents the results of this 'Pointy versus Soft' analysis.

Micro level outcomes

Based on the 'Pointy versus Soft' evaluation of the HealthMap design project we describe how 'soft' and 'pointy' factors influenced HealthMap design processes and suggest how they might be generalizable as landmarks when designing for the healthcare system. The 'pointy' influences identified were: metrics, interoperability, and systemic time scarcity and the 'soft' influence was stigma. These 'pointy' and 'soft' contextual landmarks for design are discussed below.

HealthMap Pointy Influences

Metrics

The evaluation of HealthMap is the cluster RCT in 2014. This automatically requires that quantitative data be delivered from the HealthMap design. It also dictates what those data will be, such as cholesterol levels and blood pressure, thus the designers are tasked with envisioning a system that can deliver those data.

Many designers work for clients who want to measure their return on investment, however, for health technology a certain approach to evaluation is common. Understanding the project evaluation points and thinking about how to deliver meaningful data is an early design task.

Not all health care technology is subjected to a randomised control trial, yet projects need to support stakeholders' reporting requirements. Awareness of data points and delivering early reporting can be a pathway to meeting these requirements.

Bowen, et al., (2013) discuss the limitations of the NHS 'Experience Based Design' guidelines in providing for adequate evaluation, observing that evaluation is prioritized but under developed. We suggest that early understanding of stakeholders' evaluation is useful for the design planning and for the designers' own evaluation.

Interoperability

Healthcare systems all over the world are littered with information technology programs that are under-utilized, poorly integrated or abandoned. Kaplan and Harris-Salamone, (2009) report that the majority of health IT projects fail to some extent. Much of this failure has been attributed to the inability of technology platforms and applications to operate together. In the era of pervasive health the need for interoperability still exists at the micro level of software and devices, but it also expands to the macro level of the changing contexts of health: from the institutional to the personal and mobile.

For the HealthMap design phase 3, scoping the necessary level of interoperability was an important constraint and shaped many design decisions. It led to early guidance on feasibility and exploration of ways to overcome barriers, which, in turn, encouraged a 'minimal viable product' design approach to the strategy for piloting and implementation. These constraints ran from identifying medical practice electronic medical record software requirements to surveying patient access to technology and technology-based information and social interaction. In HealthMap's design research with healthcare providers there was evidence of great sensitivity to the threat of poor interoperability. Often providers cited examples of useful tools that lay idle because they could not be integrated into existing systems. Bowen et al., define this macro and micro interoperability as: 'providing an ecology of systems and services that relate to the person as embodied in ever changing contexts'. (Bowen et al., 2011:158)

Systemic Time Scarcity

We have alluded to the inherent time constraints in designing for healthcare provider/patient interaction. This paucity of time pervades the whole medical landscape and impacts every stage of the Participatory Design process. Accessing users for research activities, for collaborative exercises, or critique and testing is a challenge to Participatory Design. Understanding these chronic constraints and strategies to overcome them is an important tool for designing in healthcare. Time unavailability and ethics approval delays both become 'design problems' in themselves that require planning for creative and adaptable solutions. The HealthMap team's ability to identify and respond to healthcare provider availability was key to our participatory approach. Situated in a medical teaching school, close to an Infectious Diseases Unit and specialist HIV General Practices allowed us to make use of lunch-time and ad hoc user availability. Raising project awareness with staff and hierarchy was also important to support ongoing design research and collaboration. Dearden et al., (2010) describe similar challenges in accessing staff and the negative impact on staff workload from time spent in design participation. In healthcare, patient needs are a constant and inflexible demand. For the healthcare service designer, access to staff as participants is a critical challenge to be faced as early as possible.

HealthMap 'Soft' Influences

Discrimination and Stigma

Stigma is from the 'soft' domains of the emotional, social, mental health and quality of life. For PWHIV, it can be so pervasive and so bound up with experiences accessing medical care and health information, that it cannot be separated from health design considerations. It is a 'soft terrain' feature that intertwines with the medical and institutional, thus sensitivity to stigma must be considered foundational to any design work for PWHIV.

Mahajan et al., (2008) point out that stigma continues to present barriers to disease prevention and accessing care and treatment for HIV. For PWHIV, these barriers persist into all aspects of health and wellbeing. Yet many people living with chronic disease also share these experiences of stigma, and the associated barriers to care, to some degree. Earnshaw and Quinn, (2012) describe the experiences of stigma, especially in the context of healthcare, for people living with a variety of chronic diseases. In addition to HIV and chronic disease, ageing brings its own experiences of stigma. Slater et al., point out how ageing PWHIV 'must also deal with multiple stigmas related to their sexual orientation, HIV status, and age'. (Slater et al., (2012:9) Reidpath and Chan, (2005) describe this as the layering of stigmas that can affect a patient's access to healthcare and support. We would suggest that any healthcare-based service needs to become aware of the specificities of stigma affecting their particular user group(s) as a design priority. Although people with other diseases and medical needs do not necessarily experience the level of stigma experienced by HIV-positive patients, there will be a set of vulnerabilities and sensitivities particular to each medical condition. In a sense each condition can have an accompanying set of its own commonly experienced sensitivities. Understanding these particularities and the 'culture' unique to that set of patients is a crucial 'soft' design requirement and an important area for designers to research at the earliest opportunity. Gathering a body of data to inform the intuitive practices of design is a crucial step for patient-centred design efforts.

For health IT designers, gaining awareness of specific sensitivities will involve design research that requires ethics approvals. In Australia many health projects are embedded in academic funding models. While design researchers encounter these protocols as a matter of course, there is still unfamiliarity in human ethics committees with design vernacular and design practices. Thinking about what are the most low-risk and easily executed design activities and data treatment is an important additional early task for 'soft' health technology design.

Conclusions

In designing the HealthMap chronic disease self-management platform for people living with HIV a cross-disciplinary design strategy of 'Pointy versus Soft' was implemented. This strategy emerged from a collaborative service-envisioning workshop and served several useful functions: i) it played a pivotal role in bridging the boundaries between design practice, medical research and social research through co-creation of a plain, accessible, mutually agreed lexicon, ii) it successfully explored and captured complex contextual influences and articulated them in an accessible and systematic way, iii) it enabled a scaffold for reflective analysis of contextual features to 'tease apart' interwoven and sometimes conflicting factors which supported clear strategic design guidance and actionable insights, iv) it provided the HealthMap design team with a design language to apply to ongoing design work, both generative and evaluative.

We suggest that early identification of the 'soft' and 'pointy' influences on a particular project with an appropriate pragmatic design strategy to address them will support realistic design scoping and decisions. Furthermore, this method enables project designers to approach service implementation from an informed position.

By applying the 'Pointy versus Soft' design strategy as an action research evaluative tool we identified the following three characteristics of the 'pointy' medical and institutional contextual 'landmarks' and a pervasive 'soft terrain' feature. These are characteristics of a persistent context for healthcare design:

Metrics as a requirement

In healthcare design many projects must address evaluation points (Jones, 2013; Lyng and Pedersen, 2011). Identifying, understanding and designing for project evaluation points are an early design task to address. This early prioritization will help to create useful data to satisfy evaluation.

Interoperability – from the micro to the macro

Acknowledging the barriers to interoperability in the whole ecosystem of a service is key to discovering the opportunities for feasibility and possible implementation (Dearden et al., 2010; Jones, 2013). Exploration of interoperability problems and decisions around strategic partnerships needs to occur in the early stages of a project lifecycle in order to scope a design that has any chance of real adoption.

Systemic time scarcity

In healthcare designers often suffer from a lack of time availability with project stakeholders and patients. Designers need to plan strategies that are time efficient and flexible in order to utilize the short notice and small amounts of user availability that are presented. Planning, and seeking approval for, informal, opportunistic and nimble engagement with users will be a valuable early investment in supporting a Participatory Design process (Bowen et al., 2013; Dearden et al., 2010; Grocott, Blackwell, Currie, Pillay, and Robert, 2013; Jones, 2013).

'Soft' terrain: stigma as a pervasive experience

Most people living with chronic disease experience stigma (Earnshaw, Quinn, and Park, 2012; Earnshaw and Quinn, 2012). Patient enthusiasm for any healthcare service is predicated on a sensitive engagement that supports feelings of vulnerability and reduced confidence. Designing for the health or wellbeing of a person living with chronic disease requires design that addresses how stigma may influence engagement. Designing for patients in any context means designing for particular sensitivities and requires an explicit, strategic set of design priorities and a deeply empathic, tacit understanding that permeates the design lifecycle (Jones, 2013; Wright and McCarthy, 2010).

In summary, we introduce the metaphor of 'pointy' landmarks and 'soft' terrain as a design strategy to describe the healthcare context and as a design vernacular for healthcare. By reviewing the HealthMap case study, we suggest that this design strategy can begin to help designers anticipate and recognize important pointy landmarks and soft terrain features relevant to their projects. Once these landmarks have been identified the appropriate approaches to navigate, and exploit, these touchpoints presents an opportunity for design strategy. We invite further design strategy expansion and descriptions of features that may comprise persistent healthcare contextual landmarks.

Broader implications: toward a community of practice for healthcare design

The 'Pointy versus Soft' cross-disciplinary design lexicon for healthcare is distinct from the existing medical and engineering based terminology, such as 'safety' and 'functionality' (Bate and Robert, 2007a). The value of a specific lexicon for 'designerly' thought and activities is recognised in current design practice (Spool, 2012). Successful design techniques for bridging knowledge boundaries within healthcare design support both Participatory Design practice and the search for a cross-disciplinary community of practice for 'design for health' (Carlile, 2004; Segalowitz and Brereton, 2009; Simonsen and Robertson, 2012).

A co-created design lexicon aligns with Lave and Wenger's framework for communities of practice: which describes the value of shared construction of a shared understanding and shared repertoire of methods and concepts. This repertoire can act as a resource for further design engagement (Wenger, 1998).

Limitations

As this is a reflective paper from one case study the 'Pointy versus Soft' design strategy and design lexicon are untested in other healthcare projects. The value of 'Pointy versus Soft' to the HealthMap design may be a result of team dynamics and productive collaboration rather than inherent value in the design strategy.

We recommend further design work and research to evaluate how the 'Pointy versus Soft' design strategy and design vernacular can support health technology design strategy.

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REFERENCES

Bate, P., & Robert, G. (2006). Experience-based design: from redesigning the system around the patient to co-designing services with the patient. *Quality & Safety in Health Care*, *15*(5), 307–10. doi:10.1136/qshc.2005.016527

Bate, P., & Robert, G. (2007a). Toward More User-Centric OD: Lessons From the Field of Experience-Based Design and a Case Study. *The Journal of Applied Behavioral Science*, *43*(1), 41–66. doi:10.1177/0021886306297014

Bate, P., & Robert, G. . (2007b). *Bringing user experience to healthcare improvement: The concepts, methods and practices of Experience-based Design* (pp. xi, 207). Oxford, UK: Radcliffe Publishing Ltd. ISBN 9781846191763

Bate, S. P., & Robert, G. (2002). Knowledge management and communities of practice in the private sector: lessons for modernizing the National Health Service in England and Wales. *Public Administration*, *80*(4), 643–663. doi:10.1111/1467-9299.00322

Berryman, M. S., Haberman, V., & Lynn, B. (2011). User Experience Design in a Surgical Environment. In *UX Australia*. UX Australia. http://www.slideshare.net/micberryman/ux-design-in-a-surgical-environment Retrieved November 2014

Boer, L., Donovan, J., & Buur, J. (2013). Challenging industry conceptions with provotypes. *CoDesign, International Journal of CoDesign in Design and the Arts*, *9*(2), 73–89. doi: 10.1080/15710882.2013.788193

Bowen, S., Dearden, A., & Dexter, M. (2014). Wearing Two Hats : Reflecting Alongside Authentic Designing. In *Proceedings of DRS 2014*. Umea, Sweden: Design Research Society. Retrieved from http://www.drs2014.org/media/647964/0161-file1.pdf

Bowen, S., Dearden, A., Wolstenholme, D., & Cobb, M. (2011). Different Views : Including Others In Participatory Health Service Innovation. In J. Buur (Ed.), *PINC 2011: Participatory Innovation Conference 2011*. Sonderborg: University of Southern Denmark. Retrieved from http://shura.shu.ac.uk/3536/

Bowen, S., Dearden, A., Wright, P., Wolstenholme, D., & Cobb, M. (2010). Participatory Healthcare Service Design and Innovation. In *Proceedings of the 11th Biennial Participatory Design Conference* (pp. 155–158). Sydney, Australia: ACM. doi:10.1145/1900441.1900464

Bowen, S., McSeveny, K., Lockley, E., Wolstenholme, D., Cobb, M., & Dearden, A. (2013). How was it for you? Experiences of Participatory Design in the UK health service. *CoDesign*, *9*(4), 230–246. doi:10.1080/15710882.2013.846384

Carlile, P. R. (2004). Science An Integrative Transferring , Translating , and Transforming : Framework for Managing Knowledge Across Boundaries, *Organization Science 15*(5), 555–568. doi:10.1287/orsc.

Dearden, A., Wright, P., Bowen, S., Rahman, F., Cobb, M., & Wolstenholme, D. (2010). User-centred design and pervasive health: A position statement from the User-Centred Healthcare Design project. *Proceedings of the 4th International ICST Conference on Pervasive Computing Technologies for Healthcare*, 8–11. doi:10.4108/ICST.PERVASIVEHEALTH2010.8837

Dexter, M., Cobb, M., Bowen, S., Dearden, A., Rahman, F., Wolstenholme, D., & Wright, P. (2010). Participatory Design Methodologies Used to Effect Change in a Healthcare Environment. In *Design Research Conference*. Retrieved from http://conferences.wsu.edu/conferences/design/default.aspx

Earnshaw, V. A, & Quinn, D. M. (2012). The impact of stigma in healthcare on people living with chronic illnesses. *Journal of Health Psychology*, *17*(2), 157–68. doi:10.1177/1359105311414952

Earnshaw, V. A, Quinn, D. M., & Park, C. L. (2012). Anticipated stigma and quality of life among people living with chronic illnesses. *Chronic Illness*, *8*(2), 79–88. doi:10.1177/1742395311429393

Gonzales, M., & Riek, L. (2013). Co-designing Patient-centered Health Communication Tools for Cancer Care. *Proceedings of the 7th international conference on Pervasive Computing Technologies for Healthcare and Workshops,* (pp.208-215) Venice, Italy: EAI. doi:10.4108/pervasivehealth.2013.252109

Greenhalgh, T., Robert, G., Macfarlane, F., Bate, P., & Kyriakidou, O. (2004). Diffusion of innovations in service organizations: systematic review and recommendations. *The Milbank Quarterly*, *82*(4), 581–629. doi:10.1111/j.0887-378X.2004.00325.x

Grocott, P., Blackwell, R., Currie, C., Pillay, E., & Robert, G. (2013). Co-producing novel wound care products for Epidermolysis bullosa; an empirical case study of the use of surrogates in the design and prototype development process. *International Wound Journal*, *10*(3), 265–73. doi:10.1111/j.1742-481X.2012.00972.x

Heart Foundation, (n.d.). Cardiovascular wellness for people living with HIV. Retrieved from http://www.heartfoundation.org.au/SiteCollectionDocuments/Cardiovascular-wellness-for people-living-with-HIV.pdf

Jones, P. H. (2013). *Design for Care: Innovating Healthcare Experience*. New York: Rosenfeld Media. ISBN 9781933820231

Julier, G. (2013, March 11). Experience-based design, innovation and the NHS. Social Design Talks on WordPress.com [Web log post]. Retrieved from http://socialdesigntalks.org/2013/03/11/experience-based-design-innovation-and-the-nhs-report/

Kaplan, B., & Harris-Salamone, K. D. (2009). Health IT success and failure: recommendations from literature and an AMIA workshop. *Journal of the American Medical Informatics Association : JAMIA*, *16*(3), 291–9. doi:10.1197/jamia.M2997

Koshy, E., Koshy, V., & Waterman, H. (2011). *Action Research in Healthcare*. London, UK: Sage Publications Ltd. ISBN 978-1-84860-189-5

Lab4Living. (n.d.). Lab 4 Living | Cultural, Communication and Computing Research Institute | Sheffield Hallam University. Retrieved from http://www.shu.ac.uk/research/c3ri/projects/lab-4-living

Lyng, K. M., & Pedersen, B. S. (2011). Participatory design for computerization of clinical practice guidelines. *Journal of Biomedical Informatics*, *44*(5), 909–18. doi:10.1016/j.jbi.2011.05.005

Mahajan, A. P., Sayles, J. N., Patel, V. A., Remien, R. H., Sawires, S. R., Ortiz, D. J., … Coates, T. J. (2008). Stigma in the HIV / AIDS epidemic : a review of the literature and recommendations for the way forward. *AIDS, 22(2),* 67–79. doi:10.1097/01.aids.0000327438.13291.62

McHattie, L.-S., Cumming, G., & French, T. (2014). Transforming patient experience: health web science meets medicine 2.0. *Medicine 2.0*, *3*(1), e2. doi:10.2196/med20.3128

Mockford, C., Staniszewska, S., Griffiths, F., & Herron-Marx, S. (2012). The impact of patient and public involvement on UK NHS health care: a systematic review. *Journal of the International Society for Quality in Health Care / ISQua*, *24*(1), 28–38. doi:10.1093/intqhc/mzr066

NHS. (n.d.). Experience Based Design for Clinical Commissioning Groups and the Engagement Cycle. NHS Patient Experience Portal. Retrieved August 15, 2014, from http://patientexperienceportal.org/article/experience-based-design-for-clinical-commissioning-groups-and-the-engagement-cycle

Pickles, J., Hide, E., & Maher, L. (2008). Experience based design: a practical method of working with patients to redesign services. *Clinical Governance: An International Journal*, *13*(1), 51–58. doi:10.1108/14777270810850634

Pilemalm, S., & Timpka, T. (2008). Third generation Participatory Design in health informatics--making user participation applicable to large-scale information system projects. *Journal of Biomedical Informatics*, *41*(2), 327–39. doi:10.1016/j.jbi.2007.09.004

Qu, Y., & Hansen, D. L. (2008). Building Shared Understanding in Collaborative Sensemaking. Position paper presented at the sense-making workshop at the ACM Conference on Human Factors in Computing Systems 2008, Florence, Italy Retrieved from http://scholar.google.com.au/scholar?cluster=11793863688532387146&hl=en&as_sdt=2005&sciodt=0,5

Reidpath, D. D., & Chan, K. Y. (2005). A method for the quantitative analysis of the layering of HIV-related stigma. *AIDS Care*, *17*(4), 425–32. doi:10.1080/09540120412331319769

Rogers, Y. (2004). New Theoretical Approaches for HCI.In Cronin (Ed.) *Annual Review of Information Science and Technology (ARIST), 38*. ASIS&T ISSN 0066-4200 Retrieved from http://www.editlib.org/p/97535/

Ross, L. (2014). FjordKitchen talks: Lorna Ross “Service Design in Health and Health Care.” Vimeo. Retrieved from http://vimeo.com/88746452

Sanders, E. B. (2002). From User-Centered to Participatory Design Approaches Sanders. In J.Frascara (Ed.), *Design and the Social Sciences*.(pp. 1–8) London, Taylor & Francis. ISBN 0-415-27376-5

Sanders, E., & Stappers, P. J. (2008). Co-creation and the new landscapes of design. *CoDesign*, *4*(1), 5–18. doi:10.1080/15710880701875068

Schön, D. A. (1992). Designing as reflective conversation with the materials of a design situation. *Research in Engineering Design*, *3*(3), 131–147. doi:10.1007/BF01580516

Segalowitz, M., & Brereton, M. (2009). An examination of the knowledge barriers in Participatory Design and the prospects for embedded research. In *OzCHI '09 Proceedings of the 21st Annual Conference of the Australian Computer-Human Interactin Special Interest Group.* (pp. 337–340) ACM New York, NY, USA. doi:10.1145/1738826.1738890

Simonsen, J., Robertson, T., (2012) *Routledge International Handbook of Participatory Design*. Taylor and Francis, Hoboken, e-book, ISBN 978-0-203-10854-3>.

Slater, L. Z., Moneyham, L., Vance, D. E., Raper, J. L., Mugavero, M. J., & Childs, G. (2012). Support, Stigma, Health, Coping, and Quality of Life in Older Gay Men With HIV. *The Journal of the Association of Nurses in AIDS Care : JANAC 24*(1),1–12. doi:10.1016/j.jana.2012.02.006

Spool, J. M. (2012, May 16). From Critique, A Language Emerges. User Interface Engineering: Brain Sparks. [Web log post] Retrieved from http://www.uie.com/brainsparks/2012/05/16/from-critique-a-language-emerges/

Stolterman, E. (2008). The Nature of Design Practice and Implications for Interaction Design Research. *International Journal of Design*, *2*(1), 55–66. Retrieved from http://www.ijdesign.org/ojs/index.php/IJDesign/article/view/240/148

Tsianakas, V., Robert, G., Maben, J., Richardson, A., Dale, C., Griffin, M., & Wiseman, T. (2012). Implementing patient-centred cancer care: using experience-based co-design to improve patient experience in breast and lung cancer services. *Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer*, *20*(11), 2639–47. doi:10.1007/s00520-012-1470-3

Van der Linden, J., Waights, V., Rogers, Y., & Taylor, C. (2012). A blended design approach for pervasive healthcare: bringing together users, experts and technology. *Health Informatics Journal*, *18*(3), 212–8. doi:10.1177/1460458212442934

Wenger, E. (1998). *Communities of practice: learning, meaning and identity* (1st ed., p. 318). Cambridge: Cambridge University Press. ISBN 978-0-521-66363-2

Wright, P., & McCarthy, J. (2008). Empathy and experience in HCI. In *Proceeding of the Twenty-Sixth Annual CHI Conference on Human Factors in Computing Systems - CHI '08*, 637. doi:10.1145/1357054.1357156

Wright, P., & McCarthy, J. (2010). *Experience-Centered Design: Designers, Users, and Communities in Dialogue. Synthesis Lectures on Human-Centered Informatics* (Vol. 3, pp. 1–123). doi:10.2200/S00229ED1V01Y201003HCI009

Wright, P., Wallace, J., & McCarthy, J. (2008). Aesthetics and experience-centered design. *ACM Transactions on Computer-Human Interaction*, *15*(4), 1–21. doi:10.1145/1460355.1460360

5.3 Becoming familiar: Co-design with HIV researchers

Having described the contextual influences from the unfamiliar domain of HIV research, I continue the design journey into HIV research. The following papers describe and evaluate our Participatory Design practices with HIV researchers and with qualitative data from people with HIV.

5.4 Paper 2

Williams I, Brereton M, Donovan J, et al. (2014) A Collaborative Rapid Persona-Building Workshop: Creating Design Personas with Health Researchers International Journal of Sociotechnology and Knowledge Development; 6(2):17–35. DOI: 10.4018/ijskd.2014040102, http://www.igi-global.com/article/a-collaborative-rapid-persona-building-workshop/114106

Statement of Contributions of Joint Authorship

Williams, I (Candidate) Writing and compilation of manuscript, established methodology for reflexive action research, data analysis and discussion, co-facilitator of collaborative persona-building workshop

Brereton, M (Principal Supervisor) Supervised and assisted with manuscript compilation, co-author of manuscript, co-facilitator for collaborative persona-building workshop

Donovan, J (Assistant Supervisor) Supervised and assisted with manuscript compilation, co-author of manuscript

Karalyn McDonald (External Supervisor) Collected qualitative data, participated in collaborative persona-building workshop, commented on manuscript

Tanya Millard (Research Colleague) Participated in collaborative persona-building workshop, collected early design phase data and literature review.

Tam, A (Research Colleague) Gave early guidance on persona-building, refined draft personas post-workshop, commented on manuscript.

Elliott, J .H. (External Supervisor) Project leader, managed design phase data collection, participated in collaborative persona-building workshop, supervised and commented on manuscript.

5.5 Emerging from unfamiliarity

So far on my ‘journey’ I have discussed the ‘Pointy versus Soft’design strategy found useful for understanding the unfamiliar HIV research domain, and the participatory practice of collaborative persona-builiding with HIV researchers. The activities and analysis that comprised these ‘sense-making’ and ‘design-making’ work laid the foundation for a growing tacit knowledge of the HIV research domain. That is, as a design practitioner I found myself entering the HIV research domain and finding common ground with the tacit assumptions of HIV researchers. This alignment with some attitudes of the HIV researcher team members began to find me at odds with the tacit assumptions of many user experience industry design colleagues (as revealed from informal conversations).

Noticing how I had diverged from a common industry viewpoint to a, more informed, HIV research specialist viewpoint I decided to examine more closely the validity and value of this new empathic perspective. Paper 3 describes how this examination was framed and conducted.

5.6 Paper 3

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Statement of Contributions of Joint Authorship

Williams, I (Candidate) Writing and compilation of manuscript, established methodology for reflexive action research, data analysis and discussion

Brereton, M (Principal Supervisor) Supervised and assisted with manuscript compilation, co-author of manuscript

Donovan, J (Assistant Supervisor) Supervised and assisted with manuscript compilation, co-author of manuscript

Karalyn McDonald (External Supervisor) Collected qualitative data, commented on manuscript

Tanya Millard (Research Colleague) commented on manuscript

Tam, A (Research Colleague) commented on manuscript

Elliott, J .H. (External Supervisor) Project leader, managed design phase data collection, supervised and commented on manuscript.

‘Dipping a toe in the water’: addressing the effects of stigma and avoidance when designing social media features for people with HIV

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Abstract

Background

For many people living and ageing with HIV, stigma detrimentally affects their quality of life, particularly contributing to social isolation. When designing the HealthMap chronic disease self-management technology for People With HIV (PWHIV) the issue of social isolation was recognized as an important factor influencing people’s self-efficacy in managing chronic disease risk factors.

Objective

In order to better understand the potential for social media technology to support PWHIV experiencing social isolation, we explored the role of stigma in the potential adoption of social media applications for participants in the HealthMap cluster randomised control trial.

Methods

First we reflected on two main sources of data: (i) the working assumptions that developed during the design immersion, and (ii) the qualitative data collected for HealthMap design.

Second we compared our experiences with examples from the literature on the effects of stigma on chronic disease self-management, HIV stigma, stress and coping strategies, ageing with HIV, online trust building, and support seeking.

Third we draw on the analysis of the HealthMap qualitative data for the impact of stigma with regards to social connections, health support and social media technology. The qualitative data were 33 semi-structured interviews with PWHIV from NSW and

Victoria. Accounts relating to social isolation, social media, HIV positive community organisations, stigma and seeking support for health were extracted from eighteen of the transcripts. We used rapid, lean, affinity mapping to identify patterns of behaviour and attitudes around the relevant topics.

Results

Our findings are presented as two design strategies: i) 'Designing in the face of stigma: design tension' and ii) 'Finding meaningful support in the face of stigma: a design strategy'. We use these framing tools to illustrate the significance of avoidant behaviour in coping with stigma. We developed the 'Finding meaningful support' design strategy to include sensitivity to avoidant behaviour coupled with 'meaningful activity' as a means to encourage technology-based social experiences for PWHIV.

Conclusion

Our working assumption that 'off the shelf' social media features are not suitable for PWHIV experiencing social isolation is supported by the analysis of the HealthMap qualitative data and by the relevant literature. We describe the role of avoidant behaviour as a key coping strategy and how avoidant behaviour is a barrier to adoption of social media. Based on analysis of the HealthMap data, and inferences from the literature, we recommend accommodating users' avoidant behaviour while offering meaningful activity as an opportunity to override an avoidant response and access support.

Background

People with HIV and on antiretroviral treatment are facing a future unprecedented in human history. While the medical establishment and healthcare system adapt from managing HIV in an acute care model to a chronic disease care model, the experiences that PWHIV face are largely uncharted territory. There are no precedents for ageing on HIV treatment and care pathways for people to follow are unclear.

The HealthMap project

HealthMap is an Australian National Health and Medical Research Council funded randomised control trial to investigate how to support people with HIV in self-management of cardiovascular disease and the chronic diseases of ageing. The HealthMap intervention is aimed at those most at risk of cardiovascular disease, namely smokers over the age of fifty. In Australia 80% of people with HIV are men who have sex with men.

At present HealthMap does not include social media features. It offers social support for health through phone-based health coaching, web-based health coaching modules and moderated online selective live-chat programs.

Stigma

The stigma associated with HIV and AIDS has been present since the earliest days of the AIDS epidemic of the 1980s. Although the discrimination faced by many PWHIV in the 80s has diminished considerably, HIV stigma persists as a multifaceted and multilayered psychosocial experience (MacDonald, Elliott and Saugeres, 2013; Mahajan, et al., 2008; Slavin, 2012). In developed countries HIV stigma can include stigmas relating to sexual orientation, sexual behaviour, drug use, ageing, body dismorphia, medical co-morbidities, treatment side effects, financial hardship and loss of social status (Mahajan, et al., 2008; Slavin, 2012; Vance, Moneyham, Fordham and Struzick, 2008).

Stigma is a complex socio-cognitive and socio-cultural phenomenon that has been observed and discussed from a number of viewpoints since Goffman's seminal work in the 1960s. This work defined stigma as a socially discrediting attribution of 'deviance' that compelled the stigmatiszed individual to view themselves, and others to view them, as undesirable (Goffman, 1990). The concepts of external stigma and internal stigma, experienced stigma and anticipated stigma, enacted stigma and felt stigma, and structural stigma/structural violence have all been applied to HIV/AIDS stigma (Earnshaw and Quinn, 2012; Quinn and Chaudoir, 2009; Slavin, 2012). The complexity and variability of HIV stigma has long proved a challenge to designing effective HIV prevention and treatment programs (Mahajan, et al., 2008).

The presence of stigma can have a detrimental effect on health outcomes for PWHIV, in particular through diminished access to healthcare and diminished access to social support (Earnshaw and Quinn, 2012). Stigma also negatively affects mental health and wellbeing directly as a stressor and by eroding resilience and the capabilities to maintain mental health Slavin, 2012.

Stress coping

When analysing the impact of stigma on PWHIV it can be useful to understand stigma as a stressor in the lives of PWHIV (Slater, Moneyham, Vance, Raper, Mugavero and Childs, 2012). A number of HIV stigma studies have used stress as a defining characteristic of stigma (Chenard, 2007; Earnshaw and Quinn, 2012; Quinn and Chaudoir, 2009; Slater et al., 2012; Slavin, 2012). The stress coping strategies described in the Lazarus and Folkman's Stress Coping Theory have often been reported from the experiences of PWHIV, with avoidant behaviour a common way to manage anticipated stigma (Lazarus and Folkman, 1984; Quinn and Chaudoir, 2009).

Anticipated stigma is the extent to which people expect to experience stereotyping, prejudice, and discrimination directed at them from others in the future (Earnshaw and Quinn, 2012; Earnshaw, Quinn and Park, 2012; Farnham and Churchill, 2011; Quinn and Chaudoir, 2009). Anticipated stigma plays a key role in the stigma management coping behaviours of PWHIV because HIV is often a concealable stigmatised identity (Earnshaw and Quinn, 2012; Earnshaw, et al., 2012; Quinn and Chaudoir, 2009). For concealable stigmas the avoidance of disclosure often becomes a primary motivation for individuals. The appearance of normalcy is a high priority and can become a guiding motivation (Earnshaw and Quinn, 2012; Chenard, 2007). In order to avoid anticipated disclosure many avoidant behaviours can be employed, including limiting social interactions (Goffman, 1990; Quinn and Chaudoir, 2009; Vance, et al., 2008). Avoidant behaviour is also a common coping strategy for men generally and makes men more likely to avoid accessing professional help or seeking social support (Cohen, Evans, Stolols and Krantz, 1986). Stress coping strategies, such as avoidance, can often be triggered by events or anticipated scenarios that are not directly related to a source of stress. Psychologists describe this response as 'over-generalization' (Cohen et al., 1986). Over-generalization is defined as a stress coping response applied to situations that are not stressors. Over-generalisation often has the effect of diminishing an individual's quality of life. Cohen et al describe over-generalisation as one of the 'costs of coping', the other costs being cumulative fatigue effects and coping side effects (Cohen et al., 1986:8]. It is important to understand that these coping costs can arise as secondary effects of successful coping, where an individual apparently adjusts well to the effects of stress (Cohen et al., 1986).

Social isolation

Social isolation for PWHIV can arise from multiple factors. The relocation, bereavement, reduced financial means and illness that can accompany ageing are often linked to increased social isolation (MacDonald, et al., 2013; Slater et al., 2012; Vance et al. 2008). Social isolation is also a typical outcome from avoidant coping strategies (Quinn and Chaudoir, 2009; Vance et al. 2008). The experiences of discrimination mixed with an avoidant response to the stress of stigma makes social isolation a common experience for many PWHIV. Earnshaw, Quinn and Park observe that

> *People living with concealable stigmatized identities who experience stigma are more likely to socially isolate themselves, and this social isolation is associated with decreased social support.* (Earnshaw, et al, 2012:80)

Social support is an important tool to reduce the impact of stigma. Insufficient social support can exacerbate the effects of stigma, provoking further avoidant behaviours (Quinn and Chaudoir, 2009). In this way, social isolation, stigma and avoidance can overlap and interact in a 'vicious cycle' of decreasing self-confidence, decreasing social connections, and decreasing access to social support. Many PWHIV are at risk of depression and impaired mental health from the effects of stigma and ageing (Earnshaw and Quinn, 2012; Earnshaw, et al., 2012; Quinn and Chaudoir, 2009; Slater et al., 2012; Vance et al., 2008). Figure 3A below shows this cumulative effect.

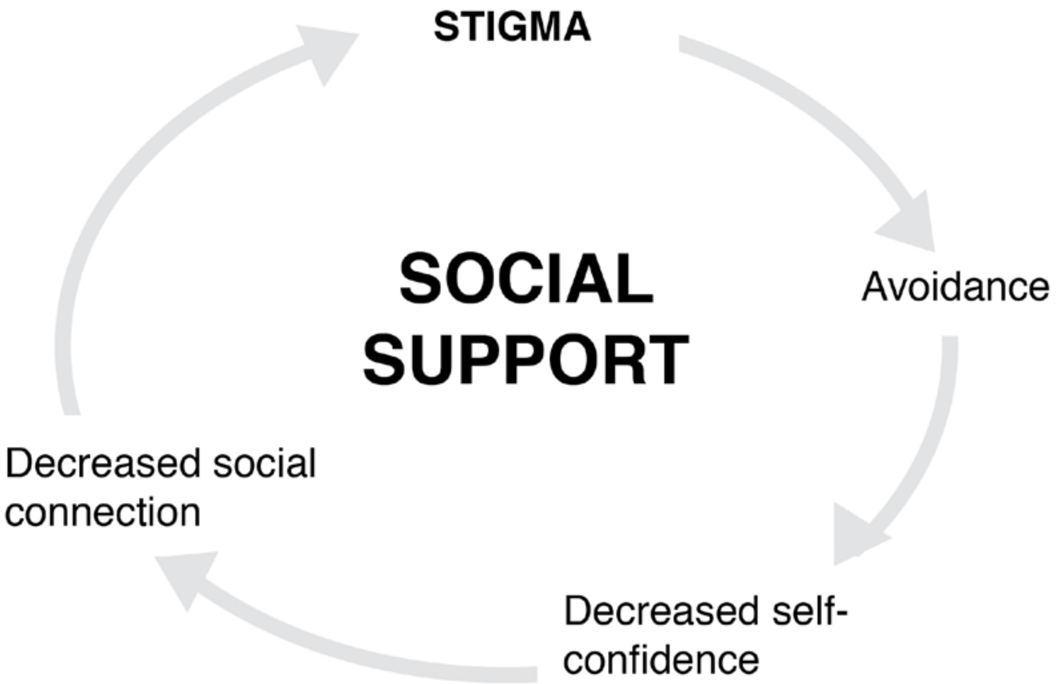

Figure 3-A The effects of stigma on social support

Implications for chronic disease self-management

Strategies for reducing the impact of stigma, and for adopting healthy stress management, overlap in many areas with the successful self-management of chronic disease. Resilience, self-efficacy and good access to healthcare are all essential components to combating stigma, managing stress and managing chronic disease (Earnshaw and Quinn, 2012; Quinn and Chaudoir, 2009; Shively, Smith, Bormann and

Gifford, 2002; Slater et al., 2012; Slavin, 2012; Vance,et al., 2008). The characteristics of resilience and self-efficacy can be captured in the psychological term 'adaptive help seeking'. Adaptive help seeking has been identified as beneficial to men and a key component of accessing professional help (Cohen et al., 1986). Resilience is a psychological process that describes a person's ability to adapt to adversity in a positive way. When coping with stress an individual's cognitive appraisal, their perception, influences the strategy adopted. Resilience is a perception that enables a person to predict that they will be able to resist or recover from a stressful situation (Slavin, 2012; Li and Yang, 2009). Perception is not fixed, it can be influenced by external factors and internal reactions (Li and Yang, 2009). In social cognitive theory self-efficacy is a person's belief in their ability to achieve a desired outcome and have some effect on their environment (Bandura, 1986). Resilience, self-efficacy and social connection often overlap and are recognised as facilitators of good wellbeing and self-management behaviours (Li and Yang, 2009; Quinn and Chaudoir, 2009;

Slavin, 2012). Resilience and self-efficacy can resist avoidance or reduce the costs of avoidant behaviour, while social support is a domain of both resilience and self-efficacy (Addis and Mahalik, 2003).

Access to healthcare is essential for chronic disease self-management and is negatively impacted by stigma (Quinn and Chaudoir, 2009; Shively et al., 2002; Slavin, 2012). Many PWHIV report discriminatory experiences when accessing healthcare, leading to an avoidance of the healthcare system and healthcare providers (Quinn and Chaudoir, 2009; Slavin, 2012). Figure 3-B below shows the potential impact of stigma on chronic disease self-management.

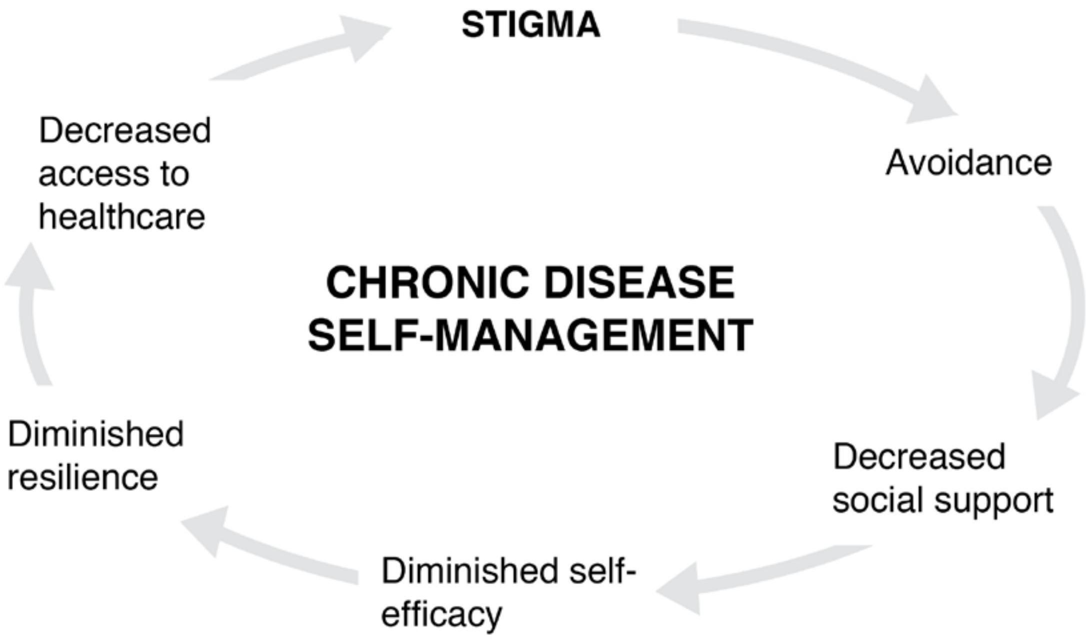

Figure 3-B Impact of stigma on chronic disease self-management

Objective

From this context of stigma, stress-coping, social isolation and chronic disease self-management it is clear that avoidant behaviour plays a strategic role in the impact of stigma on social isolation and chronic disease self-management. Thus we assume that stigma and avoidant behaviour will frame the design for potential HealthMap social media features.

While some may assume that 'off the shelf' social media features are good tools for supporting people experiencing social isolation, our expectation was that for highly stigmatised user groups this is not a safe assumption.

This prompts the questions: what then are the implications from stigma and avoidance on designing social media features? From understanding these implications, what opportunities for future design arise from the HealthMap data?

Stigma, avoidance and social media

It is evident that what constitutes online sociability is dependent on the context and community of users as well as how the social experience is designed (Sieckenius, Souza and Preece, 2004). By addressing sociability first designers are encouraged to focus on the social needs of users before deciding on the software design (Sieckenius et al., 2004:580). Sieckenius de Souza defines sociability as the perceived attributes of Topicality, Reciprocity, Empathy, Trust, Identifiability, Common Ground, Politeness and Privacy (Sieckenius et al., 2004).

These sociability factors are dependent on contextual sensitivity and the particularities of user behaviour. For PWHIV, stigma is a pervasive contextual feature and avoidance is a pervasive particularity of user behaviour. How to design sociability amongst anti-social stressors is the design challenge. The risks of discrimination and stigmatising experiences are not escaped when transferring from offline contexts to online contexts. Online social interactions *often reproduce forms of social stigma encountered in everyday real life, as well as introducing new forms of stigma* (Harrell, 2009:49).

It is no surprise then that we can see users' avoidant behaviour on social media in a number of phenomena. The most obvious is a desire for anonymity and privacy. These can be desirable for a number of reasons unconnected to stigma, yet they remain closely associated with avoidance of disclosure (Fogel and Nehmad, 2009). The urge not to disclose identifying information is common for stigmatized groups in daily life, this urge can be heightened online as the risks of uncontrolled disclosure are greater (Fogel and Nehmad, 2009; Harrell, 2009). Conversely an online context can allow people to feel more confident and less inhibited as anonymity and accessibility enable participants to share in a lower risk environment than face-to-face. The rise of online health fora and other forms of online social support provide myriad examples of this confidence (Chuang and Yang, 2010; Lamberg, 2003; Maitland and Chalmers, 2011; Oh and Lee, 2012, Oostveen, 2011, Sutcliffe, Gonzalez, Binder and Nevarez, 2011; Wang and Fesenmaier, 2003; Woelfer and Hendry, 2012).

Faceted identity

Anonymity is one way of managing 'faceted identities' commonly adopted on social media. Faceted identity stems from the observation that people have many identities in their self-concepts. These self-concepts are built on the number of roles people assume: such as social roles, familial roles and occupational roles (Farnham and Churchill, 2011; Woelfer and Hendry, 2012). People often aim to maintain separation between these roles and take steps to manage the disclosure or blurring of boundaries between roles. Social media that assumes a singularity of identity is inadequate 'as people create connections to others from multiple areas of their lives' (Farnham and Churchill, 2011:359). Addressing this inadequacy is a design challenge. Projects such as The Advanced Identity Representation (AIR) project are specifically seeking to empower users against the effects of stigma via identity management capability

(Harrell, 2009). Woelfer and Hendry seek to employ identity management to balance between fostering pro-social ties and maintaining boundaries between communication spheres (Woelfer and Hendry, 2012).

Stigma, avoidance and online health communities

We looked at a number of examples of online health communities (OHCs) to understand what could potentially benefit HealthMap users. In making this comparison it was important to consider that one primary design target user for HealthMap is men over the age of 40 who have sex with men. The similarities and differences between user groups had a significant bearing on how much we inferred for HealthMap. Research indicates that single working men are the most cautious about managing faceted identity and the least comfortable sharing on social networks (Farnham and Churchill, 2011). Older men are known to be at risk of declining social networks (Alaoui, Lewkowicz and Seffah, 2012; Sankar and Nevedal, 2011; Vance et al., 2008). Women are often more disposed to adopting social stress-coping strategies and they are generally the majority participants in health online communities. (Mo Mo, Malik and Coulson, 2009). Predicting propensity to use social media is hampered by a lack of research into social media non-participation, but a generalisation can be made that people's social media use mirrors their offline social behaviour (Hargittai, 2008).

Supporting this generalization are the studies showing people with higher risk-taking attitudes are more likely to create social media profiles and that similar social technology experiences can be empowering for non-stigmatized users while disempowering for stigmatized users (Fogel and Nehmad, 2009; Oostveen, 2011). This generalization is also borne out by an HIV-specific online support study that found frequent users were more likely to be young females (Mo Mo et al., 2009). Sutcliffe et al observe *...that social affordances may have an indirect relationship with users' aims, motivations, and behavior...' indicating '...subtle relationships between theory, design, and use of SMTs...* (Social Media Technologies) (Sutcliffe, et al., 2011:1062).

While online support groups can clearly appeal to stigmatized groups who avoid face-to-face interactions, (Cooper, 2001), OHCs have not penetrated widely into the lives of people living with chronic disease or HIV. A 2010 survey of people living with chronic disease in California reported a 1.8% use of online support groups (Owen et al., 2010:442). Assuming that avoidant behaviour is a constant, finding a successful approach to designing online social support for PWHIV poses a significant challenge.

Recent work in the design of 'object-centred' social networks suggests a possibly useful approach. Ploderer, Smith, Pearce and Borland describe using digital content, ‘objects’ as stimuli to support varying degrees of indirect and direct online social interaction. They describe their design as aimed at ‘ambivalent socialisers’, that is, people experiencing stigma in regards to behaviour change. (Ploderer, Smith, Pearce and Borland, 2015).

Health information seeking

The picture painted from research into health information seeking gives much more grounds for optimism. In a 2013 Australian survey 50.7% of PWHIV nominated the Internet as providing important sources of information about HIV treatment and about living with HIV (Grierson, Pitts and Koelmeyer, 2013). Since the earliest days of the AIDS epidemic, many HIV positive people have taken an active role in health advocacy and medical research. Many long-diagnosed PWHIV have experienced HIV activism, HIV peer support and had long associations with HIV research centres. In the past this led many individuals to actively engage with their healthcare providers and actively seek diverse information on the clinical and social aspects of HIV (Grierson et al., 2013). In terms of HIV self-management, many PWHIV are highly literate health consumers. However, while literacy around HIV treatment may be high, the future of ageing as an HIV positive person on antiretroviral treatment (ART) remains largely uncharted territory. There is a growing need for information to inform management of co-morbidities, ‘premature’ ageing, and access to care support services (Crock, L., Burk, N., Frecker, J., Morata, O., & Hall, J.,(2013) The Royal District Nursing Service HIV Program in a changing epidemic: an action evaluation, unpublished report, see Appendix B). The HIV Futures 7 Report reveals almost a third of PWHIV perceive a lack of information makes some decision making difficult (Grierson et al., 2013).

The significance of information seeking in the lives of PWHIV presents information demand as a potential design opportunity when planning features to support social interaction. The role of avoidant behaviour in information seeking and the socially affective elements of information behaviour will be discussed further.

Research Method

Overview

As action researchers our reflection was grounded in the data generated during our immersion as HealthMap designers. For this paper our guiding reflective question was: What does the data say with regards to the suitability of social media applications for HealthMap users?

First, we reflected on the design insights and working assumptions developed during the HealthMap design immersion with regards to social media.

Second we consulted literature across stigma, HIV stigma, stress coping strategies, ageing with HIV and chronic disease self-management. This literature was presented in the earlier sections of the paper.

Third we analysed the HealthMap qualitative data for the impact of stigma in regards to social connections, health support and social media technology. The qualitative data were thirty-three transcripts of semi-structured interviews with PWHIV. Quotes relating to social isolation, social media, HIV positive community organizations, stigma and seeking support for health were extracted from eighteen of the transcripts. We used rapid, lean, affinity mapping to identify patterns of behaviour and attitudes around the relevant topics.

The results from the data were compared with findings from the relevant literature to develop further insights and to suggest implications for design.

In this section we explain the HealthMap design phases (see Figure 3-C) and then describe our methods for reflective analysis of the design immersion and of the data.

The HealthMap design phases

Phase 1

In Phase 1, the design team comprised: a social researcher with many years experience in HIV research, a hospital-based HIV treatment provider / clinical researcher, and an occupational therapy PhD candidate with special interest in HIV and chronic disease self-management. This domain expertise combined represents over 40 years of research and work with people with HIV.

During this initial phase of the project, the team conducted a number of research activities to generate data in order to inform design. These data included: a report from Concept Mapping workshops conducted with PWHIV and Key Informants (KI, e.g. peer support workers, practice nurses), transcripts from semi-structured interviews with 30 PWHIV and 14 KIs, and a systematic review of technology-based interventions supporting chronic disease self-management. Project documents such as the original NHMRC grant application were also made available to designers.

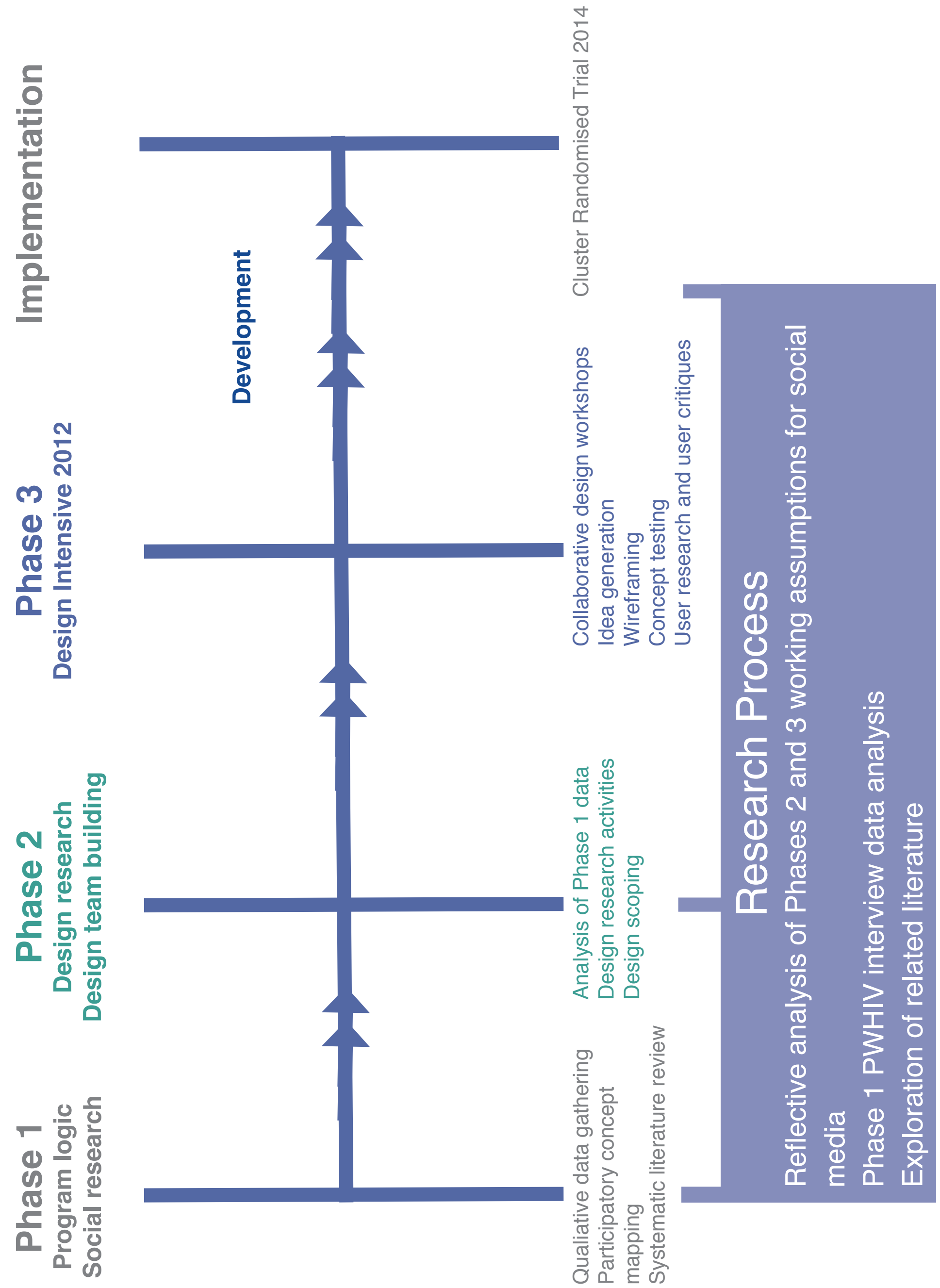

Figure 3-C The HealthMap design phases

The PWHIV interview data addressed questions such as: the impact of HIV, interactions with healthcare providers, use of technology, approaches to self-management of health and wellbeing and psychosocial factors.

Phase 2

In addition to the HIV researchers, the HealthMap design team included three design researchers/practitioners with varying levels of involvement from high-level strategic advice to detailed design research and development.

During Phase 2 the data generated in Phase 1 was analysed and new data generated to identify potential design touchpoints. Early design scoping was achieved through collaborative design workshops to create experience maps, empathy maps, and PWHIV personas and from a technology-use survey of PWHIV distributed through HIV treatment clinics. Designers also conducted their own analysis through affinity mapping and journey mapping.

Phase 3

Phase 3 was a Design Intensive to develop the HealthMap design principles and initial project concepts. The RCT evaluation points acted as aims in shaping the design and gave direction when exploring data. Team sketching workshops were conducted for idea generation and concept critique and refinement.

Direct participation from PWHIV early in the Design Intensive was problematic because of time constraints and ethics approval constraints. In the later stages further user interviews were conducted with PWHIV and HIV treatment providers for data gathering and wireframe concept critiquing.

Implementation

The HealthMap intervention will be evaluated in a two-year cluster-randomised control trial that commenced July 2014.

Reflective analysis

For this paper two main sources of data were explored. They were (i) the working assumptions that developed during the design immersion (ii) the qualitative data collected for the Phase 1 HealthMap design. Figure 3-D below shows this process.

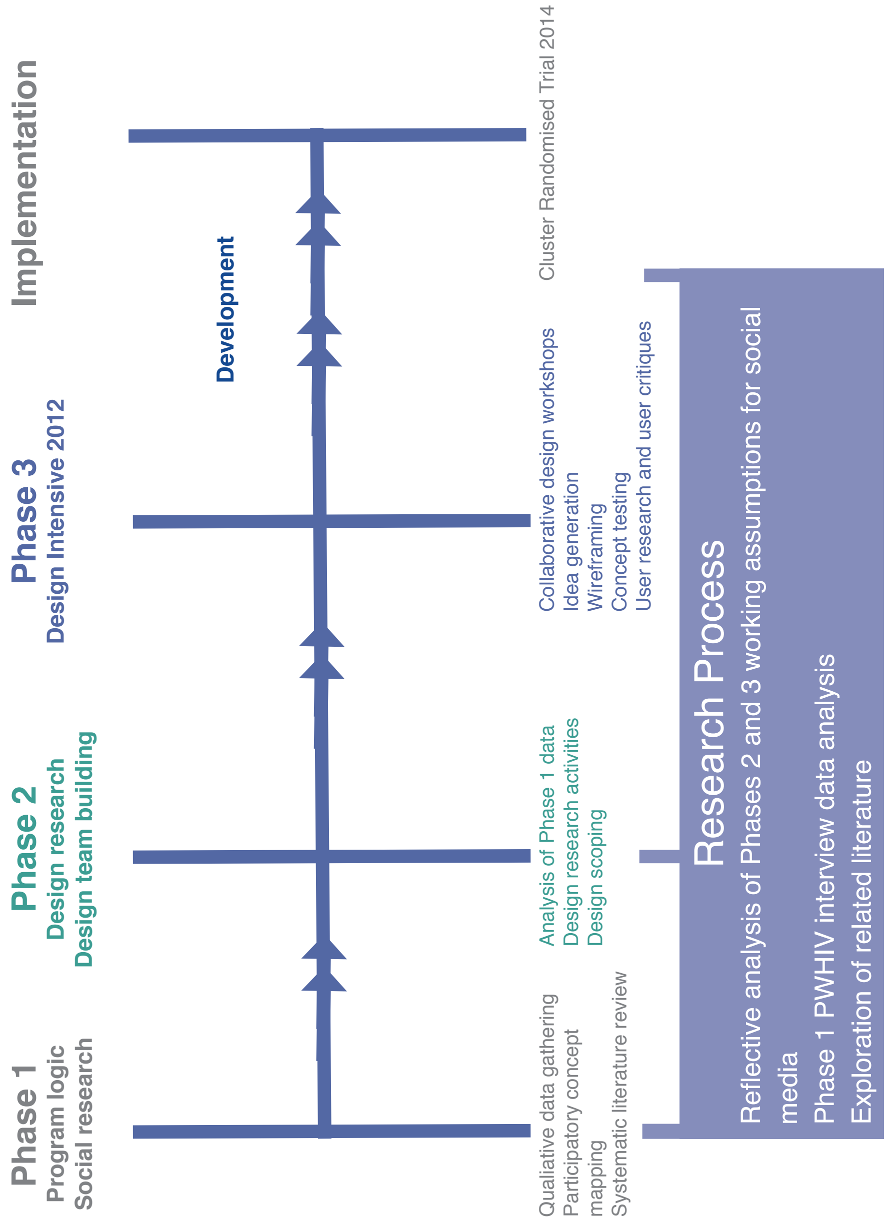

Figure 3-D Research process

Working assumptions during design immersion

The HealthMap designers' revised their assumptions regarding the efficacy of social media for health support and self-management. They developed a shared knowledge with the HIV domain experts and gained insight into the barriers against social media engagement for PWHIV.

Many early design suggestions for potential engagement with existing social media applications were rejected by the HIV researchers as not suitable. Exposure to the qualitative data was the means by which designers grew to understand the difficulties with social media for many PWHIV and in particular the avoidant behaviour it elicited.

These difficulties included discriminatory experiences, concern over data privacy and perceptions that social media sites were not benevolent environments.

The Phase 2 and 3 collaborative workshops allowed the designers and HIV researchers to explore, test and agree on a variety of assumptions regarding patients' lived experiences. These included social isolation and adoption or rejection of social media. This process of assumptions agreement was through collaboratively building patient personas. The two working assumptions for the HealthMap design were: (i) that both physical and psycho-social barriers to exercise, healthy eating and smoking cessation would need to be addressed, and (ii) that there was no scope to design social media features initially but the proliferation of social media might provide some opportunity in the future.

Phase 1 interview data

Phase 1 semi-structured interviews with 33 people living with HIV were conducted by the HealthMap social researcher. Participants were recruited predominantly through HIV treatment providers located in metropolitan and regional areas of Victoria and New South Wales. Interview excerpts were analysed to identify observations, needs and 'pain points' for each topic. Using a rapid, lean design methodology notes were made on colour-coded sticky notes and affinity maps were made to search for patterns and themes. These results were used to prompt direction for the literature search and to form the research objectives.

RESULTS

Working assumptions analysis

Social isolation is a common experience for PWHIV and impacts on wellbeing and self-efficacy, however it was not clear what the appropriate application of social features might be within HealthMap.

During Phase 1 it became clear that many PWHIV experience varying degrees of social isolation and loss of social connections through causes such as ill health, bereavement, relocation, relationship breakdowns and lack of connection with HIV support organizations. The links between this loss of social connection and complex stigmas was clear from our data during the collection and analysis of Phase 1 data.

From our data immersion we developed a working assumption that stigma and other complexities made off the shelf social media platforms, such as Facebook, unlikely to succeed for the HealthMap intervention. This was supported by our Phases

2/3 Technology Use Survey that showed that although the majority of respondents had smartphones and computer access to the internet they were not frequent users of social media. These working assumptions were compiled through the team's collaborative exploration of insights, from the qualitative data and the survey results.

The HealthMap technology-use survey showed almost 70% of respondents owned a smartphone and over 90% had access to computers and but the majority either never or infrequently accessed social media. (Table 3A)

For HealthMap the design priorities evolved to broaden and enrich the PWHIV's existing interactions with healthcare providers, which were largely trusted and longstanding relationships. These were likely to offer fewer barriers to engagement than simply trying to stimulate new social behaviours. Additional social support is selectively offered In HealthMap through health coaches and through an invitation to moderated online peer chat sessions.

From these data the assumption that 'off the shelf' social media features are unsuitable for HealthMap users appears to be sound.

Qualitative data analysis

Stigma

From our data there is strong evidence that stigma plays a significant role in the lives of people living with HIV. For HealthMap patients stigma is more accurately described as 'stigmas'. There are multiple sources of stigma and attitudes to disclosure cannot be attributed to just one source.

The excerpts below give some examples of the types of stigmas experienced:

Excerpt 3 Types of stigma

1) So have you been seeing the same dentist?

> *I have but ... I've got to tell him that I am HIV positive, whereas he should be using total universal care and treating every single patient he has as HIV positive and it's not fair, and I feel like it's like coming out every single time*

So you have to disclose every time you go?

> *Yes ... every six months I dread going to the dentist, so I actually put off the dentist – it's actually* [the most] *infrequent health profession I see, and it's because of that experience…*

> 2) *But I also find sometimes I do need support, but my family, ... I can't remember when I've heard the word AIDS or HIV come out of their mouths, it's sort of, it's there, but it's not discussed, and they don't even really ask, they never ask how I'm going or how are the numbers or, they just assume, I don't know why, like if you had cancer surely people would be asking all the time, but HIV seems to still be a topic which people are very wary of getting into.*

Lack of connection to organisations supporting PWHIV

A common theme in our data was a lack of connection to organisations supporting PWHIV. Some PWHIV had never accessed them, some had around the time of initial diagnosis but not continued, some had been closely involved with support organisations in the 80s and 90s but did not maintain the connection and some had low level or sporadic connections. Those most likely to be connected were facing challenges functioning in daily life and in need of quite high levels of support. This fitted with a perception by many PWHIV that HIV support organisations were for people not managing daily life or as a last resort if one faced practical difficulties. Not wishing to identify with people 'not coping' was one factor in the feeling that HIV support organisations were not for them. There was also a perception that HIV support organizations had become more impersonal since the time when they had been volunteer-led.

Excerpt 4 Lack of connection to organisations supporting PWHIV

3) Have you accessed the services of PLC [Positive Living Cenre] or VAC [Victorian AIDS Council]?

> *I have gone to PLC and I have used the...kitchen and the whole bit. But if you are someone who, ... if you are someone who is earning decent money in whatever profession you are and happens to be positive, if you go to the PLC ... you don't necessarily get a feeling that it's the right place for you to be.... I have sent a couple of people there and I have gotten comments back, ' I found it really off putting'. ... it's just not a place where professionals will go in and feel comfortable and want to hang out and stuff because it's a little bit of a hangout for people who are not working.*

What about VAC, did you try any of their services?

Yeah I went to VAC ... and saw a counsellor initially and that was fantastic. But I found VAC a bit clinical.

4) *then ACON took it over. And the minute that happened it slowly got eroded, you know they closed down, they moved it, they said the building wasn't safe so they moved into the ACON building. People don't like going there because of what they do or don't do in there and they closed down the larder. It really does disenfranchise people, yeah they just, and they just don't seem to care, yeah.*

Support seeking - avoidance

Most PWHIV interviewed had very limited sources of support for their health, often only including their HIV treatment provider. Reasons for not seeking support were varied and often had an explicit or implicit connection to stigma. Support seeking was often viewed as a disclosure of something undesirable (for example inability to function, HIV status, financial need) and therefore avoided.

Excerpt 5 Feelings of disclosure around support seeking

5) *My main problem or concern right now is that my family are all in regional town, ... I rarely see them. I am living on my own. And as I grow older I have nobody at home and if something goes wrong God knows what's going to happen...I don't know frankly what's going to happen to me when I get to a stage where I can't look after myself.*

Is that something that you have discussed with your family ever?

No... they have their own problems to deal with. They don't want their ageing dad on their back as well.

And what about your friendship network? Do you have a lot of friends?

Not a great deal.

6) *Well look every one, everyone I know knows about it but when it comes to support the only person I really talk to about it is my doctor. Because the other people I know, I have, yesterday I went out with a friend of mine who is HIV positive and we just grumbled about the same thing, you know, he has the same problems too, you know...And yeah, yeah. I have friends who are heterosexual and not positive and I don't talk to them about it because they wouldn't understand...*

Support Seeking – accessing information

A number of interviewees expressed a desire for access to broad HIV information relevant to their health, wellbeing and to planning for the future.

Excerpt 6 Need for access to information

7) We have talked about technology. Can you think about any particular benefits of that, of technology especially?

> *Being able to ... look for information on a faceless value means that you don't have to tell people you know, what you have got…So this anonymity that comes with it, you know. And that's so beneficial, like it's paramount.*

Can you think of any drawbacks?

> *No. No like I suppose it's less personal to certain extents, but that's not what I am looking for…The more ... the easier the access is to information the better it is for everybody.*

8) What kinds of things would help you? What kind of apps or… internet based kind of services would…

> *You know, what are your basic services? Where are key places in that state to go for support, for mental health support period, just say mental health support? You know, ... These are the places to go where you know you can actually go to a place where someone is non judgemental of the situation you are in but is there to help you for whatever reason… These are places, you know, etc, that are not necessarily ... a haven but they are not going to judge you.*

Social media

Attitudes to social media were diverse, and seemed to reflect demographic patterns. Some interviewees had no interest in online social media. Many had very compartmentalised approaches to social media, accessing facebook, email and online fora for very specific purposes, often not HIV-related. Many reported negative experiences when participating in online social applications, Facebook and online dating/chat sites were given as examples of discrimination and rejection upon disclosure of their HIV status. Others reported witnessing discriminatory attitudes while 'browsing' which did not encourage them to participate.

Excerpt 7 Ambivalence to social media

9) Do you do any dating or cruising, picking up on it?

> *Look the sites are there and I have tried. But everyone is so … there is this thing you know like what do you look like? …. I got a Facebook stalker.. They went to a lot of trouble to set up a false profile with a picture…And I thought who is this?...I thought oh they must have went to school with me. And then it slowly started. And then 'Name the Homo', we don't want your sort at the thing school reunion… I went and saw the Federal Police about it…*

10) You don't use any of the social networking?

> *I have done, but no, no, nothing but bloody trouble. I don't do Facebook, I refuse. You know, after my experiences on Gaydar or whatever these things are, not where I want to go, you know, I was naïve enough to say well who knows who you're going to meet, but I wasn't looking for what they were looking for you know. It was hideous. No.*

So you don't do any of that?

> *No…I have done, I have tried it, you know, had a look and no, it's not for me.*

OK

> *You find out the hard way.*

Literature analysis

In consulting the literature addressing stigma, HIV stigma, support seeking and stress coping, we note that HIV stigma is pervasive, multilayered and leads to social isolation. We also note the stress coping strategy of avoidance as a pervasive behaviour through the effects of over-generalisation; though this is subject to a number of influences at any given point and is not static. We recognize the key role that resilience and self-efficacy play in combating the effects of stigma and the role that social support can play in building resilience and self-efficacy. At this point in time social media and online health communities are not widely utilized sources of social support for health by PWHIV, especially by those who are longer-term diagnosed (Kalichman, et al., 2006).

In addition to social support, access to relevant health information is valued by PWHIV and is also an important tool for building self-efficacy (Earnshaw and Quinn, 2012; Pope, Eaton and Kalichman, 2005). Like online social contexts, online information behaviour, (beyond just information seeking) has been shown to mirror peoples' existing behaviours (Godbold, 2006). This situation presents designers with an awareness of design constraints and with a range of design opportunities. Constraints appear in the continued presence of avoidant behaviour. When seeking information online people can avoid what they perceive to be dissonant with what they wish to find, they can avoid information from sources they perceive as unreliable and they can actively destroy information (Case, Andrews, Johnson and Allard, 2005; Godbold, 2006; Wilson, 1999). For PWHIV the internet can present an overwhelming volume of information from varying sources. Some HIV information can be medically unreliable and not evidence-based. Ascertaining quality of information can be a persistent challenge and barrier to accessing support.

Opportunities are presented through the information seekers' intrinsic motivation to 'bridge a gap' in personal knowledge, through the inherently social exchange of information sharing and information endorsement, and through potential semantic features that support the perception of empathy and social support (Bojārs, Breslin, Peristeras and Tummarello, 2008; Clemens and Cushing, 2010; Godbold, 2006; Wilson, 1999). Engeström observes how successful social media are typically built around 'objects' or activities that mediate social interaction between strangers (Engeström, 2005; Ploderer et al., 2015). In this way, information seeking may act as a meaningful activity that overcomes the existing avoidant behaviour. Informational support has been credited with greater impact on perceived empathy than social support (Nambisan, 2011). From the domain of HIV research, informational support has been equated with emotional support and described as having a positive impact on quality of life (Quinn and Chaudoir, 2009; Slater et al., 2012; Veinot, 2009). The question of how trust is built in OHCs reinforces the potential for information seeking as a socially affective experience. Also allowing people time to adjust their involvement is essential to building trust (Veinot, 2009). Fan demonstrates how online health community (OHC) characteristics such as perceived similarity and informational quality can foster a perception of benevolence and empathy even in the absence of direct communication between users (Fan, Smith, Lederman and Chang, 2010).

Discussion

The HealthMap data concur with the findings from the literature reviewed. They clearly show a prevalence of avoidant behaviors among PWHIV and reveal a range of stigma arising from: HIV, sexuality, ageing, drug use, loss of fitness, loss of function, body dismorphia, cognitive impairment, sexuality, ethnicity, mental health, unemployment, financial need and loss of social status. In our data there was a perceived lack of access to support, which existed for both the socially isolated and the socially connected. There was also a perceived lack of accurate and relevant information to support planning, decision-making and access to care and a concurrent desire to access relevant information.

Design Tensions

From our data and from our review of related literature on stigma and stress-coping strategies we have developed an understanding of the tension that stigma inherently brings when designing for social support. This is presented as Designing in the face of stigma: a design tension’. (figure 3-E)

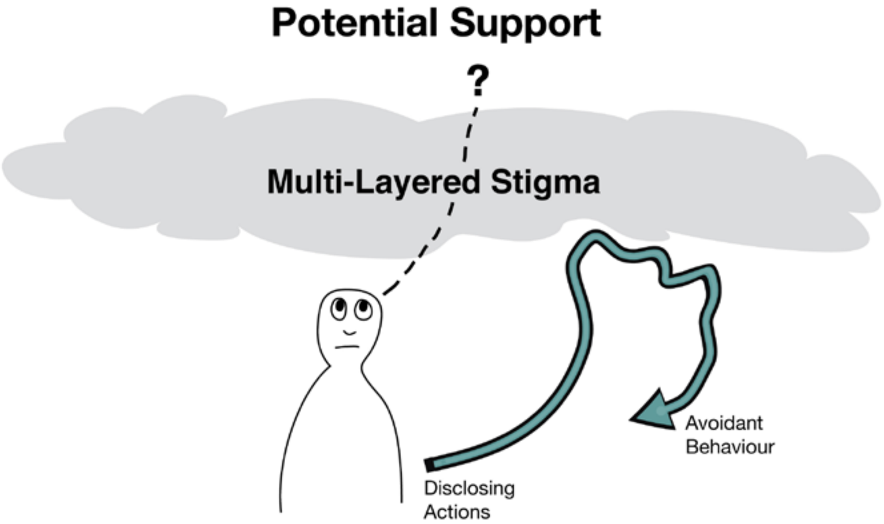

Figure 3-E Designing in the face of stigma: a design tension

This strategy illustrates the barriers to accessing potential support due to the effects of stigma and avoidant behaviour. Stigma and avoidance remain as constants, with the effect that any anticipated access to support is at the same time inherently an act of disclosure, possibly triggering an avoidant reaction. We suggest that attempting to design to ameliorate the direct effects of stigma is not likely to succeed, due to the complexity and multi-faceted nature of HIV stigma. Instead we propose designing to accommodate avoidant behaviour, in a sense supporting avoidant behaviour, but adding the motivating factor of a meaningful activity to potentially override an initial avoidant response. The possible impact of a meaningful activity is shown the ' Finding meaningful support in the face of stigma: a design strategy '(Figure 3-F).

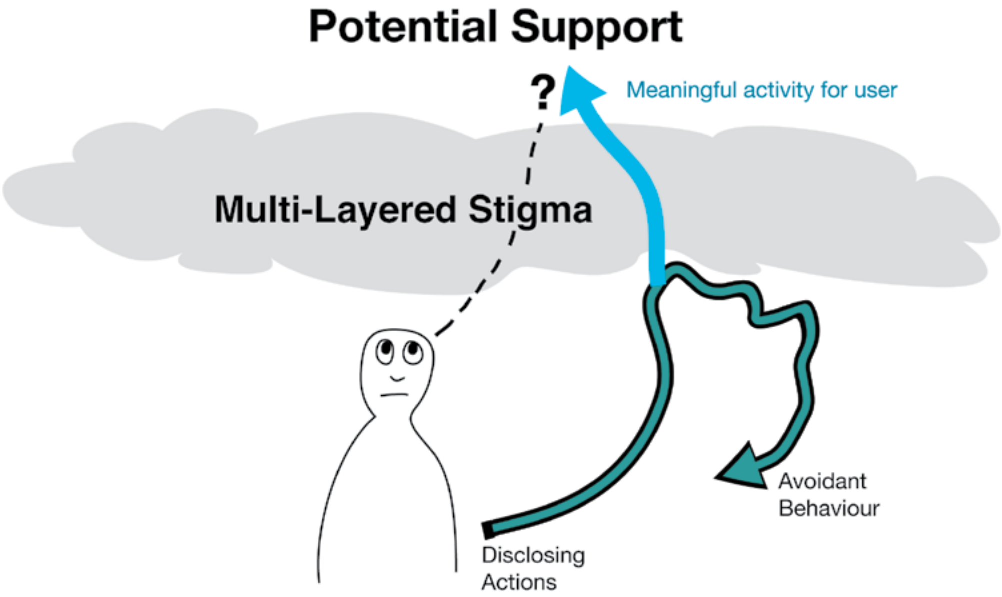

Figure 3-F Finding meaningful support in the face of stigma: a design tension strategy

Accommodating avoidant behaviour

How to accommodate avoidant behaviour is a design challenge for further research. We suggest that designs that enable the user to moderate their levels of engagement and exposure within a platform could support fluctuations in willingness to interact. A design that allows users to 'dip their toe in and out of the water', to disengage and re-engage over time will possibly support users when they feel avoidant and when they feel motivated to enter the platform. Being able to 'dip in and out' could also support trust-building over time.

From the relevant literature and the HealthMap data we know that sensitive identity management, allowing users to control levels of anonymity and disclosure, will play a key role in maintaining an individual's confidence in a platform.

Meaningful activity

In order for an activity to be meaningful to the user it must be derived from the user's own priorities, needs and desires. This predicates the need for any design to take a user-centred, research-led approach. Many design methods exist for eliciting and identifying end-user goals: the fields of User-Centred Design, Participatory Design, Service Design and community-based design research are all methodologies that offer best practices for co-design with highly sensitive user groups (Clements-Nolle and Bachrach, 2010).

For HealthMap the most commonly identified meaningful activity was access to relevant information regarding ageing on HIV treatment. Several interview participants expressed the desire for a 'one stop shop' where broad information could be accessed to offer support when experiencing difficulties and to enable forward planning. There are a number of areas HealthMap can explore to design a socially affective experience when providing information. Rather than direct social features, such as discussion groups and allowing comments, more indirect features can allow a perception of shared experience, benevolence and empathy. 'Object-centred sociality' deliberately includes 'like' buttons, 'favourite' stars, number of views counters and comments fields to provide 'social traces'. These suggest a shared space with people having similar experiences (Ploderer et al., 2015). There is also the opportunity for sociability through allowing users to suggest or contribute information. Reliability, accuracy and relevant of information would all require a content strategy that includes careful curation and moderation of any user contributions. Existing digital information collaborative features such as social bookmarking and user-defined category tags (folksonomies) provide interesting opportunities for socially affective information seeking and sharing (Bojārs et al., 2008; Golovchinsky, Qvarfordt, and Pickens, 2009),

Conclusions

Through reflecting on the three areas of: (i) HealthMap design assumptions, (ii) HealthMap qualitative data and (iii) the literature on HIV stigma, stress coping, social support, chronic disease self-management and online health communities we conclude that 'off the shelf' social media features are not suitable for PWHIV experiencing social isolation. The basis for our conclusion is captured in the strategy'Designing in the face of stigma' a design tension which displays the pervasive impact of complex HIV stigmas in the lives of PWHIV, its role in preventing PWHIV from accessing support and the role of avoidant behaviour as a stress coping strategy.

Another contribution of this paper is to articulate the persistent, and legitimate, presence of stigma in the lives of PWHIV that requires design solutions accommodating avoidant behaviour while at the same time supporting attempts to access support. In this way designs need to allow for fluctuating attitudes towards participation within an individual user, allowing the user to 'dip their toe in and out of the water' of the online social platform. We identify sensitive management of faceted identity as a key component to maintaining user engagement across fluctuating attitudes and an area that requires further research.

We further contribute a design strategy employing a user-defined ‘meaningful activity’. This allows a design approach that can deliver socially affective user experience, even for those commonly employing avoidant behaviour. This proposed design strategy is demonstrated in the ‘Finding meaningful support in the face of stigma’: design strategy This strategy , adds meaningful activity to the ‘Designing in the face of stigma’ design tension. The aim of the strategy is to disrupt the support seeking/avoidant behaviour pattern and invite the user to take a different approach.

For HealthMap the meaningful activity identified through research was information seeking. Therefore we recommend testing design for collaborative information features to enable access to support and potentially alleviate the effects of social isolation for PWHIV. We also recommend testing design for social ‘trace sensing’ features for existing HealthMap content.

Limitations

As this is a reflective paper the strategies proposed are untested. We recommend further design work and research to evaluate how the design strategy can support health technology design projects.

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References

Addis, M. E., & Mahalik, J. R. (2003). Men, Masculinity, and the Contexts of Help Seeking. *American Psychologist*, *58*(1), 5–14. doi:10.1037/0003-066X.58.1.5

Alaoui, M., Lewkowicz, M., & Seffah, A. (2012). Increasing Elderly Social Relationships Through TV-Based Services. In *Proceedings of the 2nd ACM SIGHIT International Health Informatics Symposium* (pp. 13–20). Miami, Florida, USA: ACM. doi:10.1145/2110363.2110369

Bandura, A. (1986). The Explanatory and Predictive Scope of Self-Efficacy Theory. *Journal of Social and Clinical Psychology*. New York, NY, USA: Guildford Publications Inc. doi:10.1521/jscp.1986.4.3.359

Bojārs, U., Breslin, J. G., Peristeras, V., & Tummarello, G. (2008). Interlinking the social web with semantics. *IEEE Intelligent Systems*, 23(June), 29–40. doi:10.1109/MIS.2008.50

Case, D. O., Andrews, J. E., Johnson, D. J., & Allard, S. L. (2005). Avoiding versus seeking : the relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts. *Journal of the Medical Library Association : JMLA 93*(3). Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1175801/

Chenard, C. (2007). The impact of stigma on the self-care behaviors of HIV-positive gay men striving for normalcy. *The Journal of the Association of Nurses in AIDS Care : JANAC*, *18*(3), 23–32. doi:10.1016/j.jana.2007.03.005

Chuang, K. Y., & Yang, C. C. (2010). Helping you to help me: Exploring supportive interaction in online health community. *Proceedings of the American Society for Information Science and Technology*, *47*(1), 1–10. doi:10.1002/meet.14504701140

Clemens, R. G., & Cushing, A. L. (2010). Beyond everyday life: Information seeking behavior in deeply meaningful and profoundly personal contexts. *Proceedings of the American Society for Information Science and Technology*, *47*(1), 1–10. doi:10.1002/meet.14504701228

Clements-Nolle, K., & Bachrach, A. M. (2010). Community-Based Participatory Research for Health: From Process to Outcomes. In M. Minkler & M. Wallerstein (Eds.), *Community-Based Particpatory Research* (2nd ed., pp. 175–186). John Wiley & Sons LTD. ISBN 978-04-709-3249-0

Cohen, S., Evans, G. W., Stolols, D., & Krantz, D. S. (1986). *Behaviour, health and environmental stress* (pp. 1–23). Springer US. ebook ISBN 978-1-4757-9380-2 doi:10.1007/978-1-4757-9380-2_1

Cooper, G. A. (2001). *Online Assistance For Problem Gamblers : An Examination Of Participant Characteristics* (Doctoral dissertation). University of Toronto. Retrieved from http://www.cghub.org/Cooper_Dissertation_2001.pdf

Earnshaw, V. A, & Quinn, D. M. (2012). The impact of stigma in healthcare on people living with chronic illnesses. *Journal of Health Psychology, 17(2)*, 157–68. doi:10.1177/1359105311414952

Earnshaw, V. A, Quinn, D. M., & Park, C. L. (2012). Anticipated stigma and quality of life among people living with chronic illnesses. *Chronic Illness, 8(2)*, 79–88. doi:10.1177/1742395311429393

Fan, H., Smith, S. P., & Lederman, R. (2010). Why People Trust in Online Health Communities : An Integrated Approach. In *21st Australasian Conference on Information Systems*. Brisbane. Retrieved from: http://ssrn.com/abstract=1775303

Farnham, S. D., & Churchill, E. F. (2011). Faceted Identity , Faceted Lives : Social and Technical Issues with Being Yourself Online. *Information Systems Journal*, 359–368. doi:10.1145/1958824.1958880

Fogel, J., & Nehmad, E. (2009). Internet social network communities: Risk taking, trust, and privacy concerns. *Computers in Human Behavior*, *25*(1), 153–160. doi:10.1016/j.chb.2008.08.006

Godbold, N. (2006). Beyond information seeking: towards a general model of information behaviour. *Information Research-an International Electronic Journal*, *11*(4). Retrieved from http://informationr.net/ir/11-4/paper269.html

Goffman, E. (1990). *Stigma: notes on the management of spoiled identity* (2nd ed.). London: Penguin. ISBN 978-0140124750

Golovchinsky, G., Qvarfordt, P., & Pickens, J. (2009). Collaborative information seeking. *Computer, 42*(3), 47–51. doi:10.1109/MC.2009.73

Grierson, J., Pitts, M., & Koelmeyer, R. (2013). *HIV Futures Seven: The Health and Wellbeing of HIV Positive People in Australia* (Monograph). Melbourne: The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia. Retrieved from http://pozhet.org.au/wp-content/uploads/2013/11/HIV-Futures-Seven-Report.pdf

Hargittai, E. (2008). Whose Space ? Differences Among Users and Non-Users of Social Network Sites, *Journal of Computer-Mediated Communication 13*(1), 276–297. doi:10.1111/j.1083-6101.2007.00396.x

Harrell, D. F. (2009). Computational and Cognitive Infrastructures of Stigma : Empowering Identity in Social Computing and Gaming. In *Proceedings of the seventh ACM conference on Creativity and Cognition* (pp. 49–58). Berkeley, California, USA: ACM. doi:10.1145/1640233.1640244

Kalichman, S. C., Cain, D., Cherry, C., Pope, H., Eaton, L., & Kalichman, M. O. (2005). Internet use among people living with HIV/AIDS: coping and health-related correlates. *AIDS Patient Care and STDs, 19*(7), 439–448. doi:10.1089/apc.2005.19.439

Kalichman, S. C., Cherry, C., Cain, D., Weinhardt, L. S., Benotsch, E., Pope, H., & Kalichman, M. (2006). Health information on the Internet and people living with HIV/AIDS: information evaluation and coping styles. *Health Psychology : Official Journal of the Division of Health Psychology, American Psychological Association*, *25*(2), 205–10. doi:10.1037/0278-6133.25.2.205

Lamberg, L. (2003). Online empathy for mood disorders: patients turn to internet support groups. *JAMA : The Journal of the American Medical Association*. doi:10.1001/jama.289.23.3073

Lazarus, R., & Folkman, S. (1984). *Stress, appraisal and coping* (1st ed.). New York: Springer New York.

Li, M., & Yang, Y. (2009). Determinants of problem solving, social support seeking, and avoidance: A path analytic model. *International Journal of Stress Management*. doi:10.1037/a0016844

Mahajan, A. P., Sayles, J. N., Patel, V. A., Remien, R. H., Sawires, S. R., Ortiz, D. J., … Coates, T. J. (2008). Stigma in the HIV / AIDS epidemic : a review of the literature and recommendations for the way forward. *AIDS*, *22*(2), 67–79.

Maitland, J., & Chalmers, M. (2011). Designing for peer involvement in weight management. *Proceedings of the 2011 Annual Conference on Human Factors in Computing Systems - CHI '11*, 315. doi:10.1145/1978942.1978988

McDonald, K., Elliott, J., & Saugeres, L. (2013). Ageing with HIV in Victoria: Findings from a qualitative study, *HIV Australia 11*(2), 13. Retrieved from http://search.informit.com.au/documentSummary;dn=564861079707209;res=IELHEA

Mo, P. K. H., Malik, S. H., & Coulson, N. S. (2009). Gender differences in computer-mediated communication: a systematic literature review of online health-related support groups. *Patient Education and Counseling*, *75*(1), 16–24. doi:10.1016/j.pec.2008.08.029

Nambisan, P. (2011). Information seeking and social support in online health communities: impact on patients' perceived empathy. *Journal of the American Medical Informatics Association : JAMIA*, *18*, 298–304. doi:10.1136/amiajnl-2010-000058

Oh, H. J., & Lee, B. (2012). The effect of computer-mediated social support in online communities on patient empowerment and doctor-patient communication. *Health Communication*, *27*(1), 30–41. doi:10.1080/10410236.2011.567449

Oostveen, A. (2011). The Internet as an Empowering Technology for Stigmatized Groups : a Case Study of Weight Loss Bloggers. In *Proceedings of the 25th BCS Conference on Human-Computer Interaction* (pp. 114–119). British Computer Society Swinton, UK. Retrieved from http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2003129

Owen, J. E., Boxley, L., Goldstein, M. S., Lee, J. H., Breen, N., & Rowland, J. H. (2010). Use of Health-Related Online Support Groups: Population Data from the California Health Interview Survey Complementary and Alternative Medicine Study. *Journal of Computer-Mediated Communication*, *15*(3), 427–446. doi:10.1111/j.1083-6101.2010.01501.x

Ploderer, B., Smith, W., Pearce, J. O. N., & Borland, R. O. N. (2014). An Object-Centred Approach to Encourage Online Participation in the Context of Behaviour Change. *Computer Supported Cooperative Work*, *1*(26), 1–27. doi:10.1007/s10606-014-9212-3

Quinn, D. M., & Chaudoir, S. R. (2009). Living with a concealable stigmatized identity: the impact of anticipated stigma, centrality, salience, and cultural stigma on psychological distress and health. *Journal of Personality and Social Psychology*, *97*(4), 634–51. doi:10.1037/a0015815

Sankar, A., Nevedal, A., Neufeld, S., Berry, R., & Luborsky, M. (2011). What do we know about older adults and HIV? A review of social and behavioral literature. *AIDS Care*, *23*(10), 1187–207. doi:10.1080/09540121.2011.564115

Shively, M., Smith, T. L., Bormann, J., & Gifford, A. L. (2002). Evaluating Self-Efficacy for HIV Disease Management Skills. *AIDS and Behavior*, *6*(4), 371–379. doi:1090-7165/1200-0371/0

Sieckenius, C., Souza, D., & Preece, J. (2004). A framework for analyzing and understanding online communities. *Interacting with Computers*, *16*, 579–610. doi:10.1016/j.intcom.2003.12.006

Slater, L. Z., Moneyham, L., Vance, D. E., Raper, J. L., Mugavero, M. J., & Childs, G. (2012). Support, Stigma, Health, Coping, and Quality of Life in Older Gay Men With HIV. *The Journal of the Association of Nurses in AIDS Care : JANAC*, 1–12. doi:10.1016/j.jana.2012.02.006

Slavin, S. (2012) Results from the stigma audit: A survey on HIV stigma in Australia [online]. *HIV Australia, 10*(1), 27-28. ISSN: 1446-0319. Retrieved from http://search.informit.com.au/documentSummary;dn=642100431762582;res=IELHEA

Sutcliffe, A. G., Gonzalez, V., Binder, J., & Nevarez, G. (2011). Social Mediating Technologies: Social Affordances and Functionalities. *International Journal of Human-Computer Interaction, 27*(11), 1037–1065. doi:10.1080/10447318.2011.555318

Vance, D. E., Moneyham, L., Fordham, P., & Struzick, T. C. (2008). A model of suicidal ideation in adults aging with HIV. *The Journal of the Association of Nurses in AIDS Care : JANAC*, *19*(5), 375–84. doi:10.1016/j.jana.2008.04.011

Veinot, T. C. (2009). Interactive Acquisition and Sharing : Understanding the Dynamics of HIV / AIDS Information Networks. *Journal of the American Society for Information Science and Technology*, *60*(July), 2313–2332. doi:10.1002/asi.21151

Wang, Y., & Fesenmaier, D. R. (2003). Assessing Motivation of Contribution in Online Communities An Empirical Investigation of an Online Travel Community. *Electronic Markets*, *13*, 33–45. doi:10.1080/1019678032000052934

Wilson, T. D. (1999). Models in Information Behaviour Research. *The Journal of Documentation, 55*(3), 249–270. Retrieved from http://ptarpp2.uitm.edu.my/silibus/model.pdf

Woelfer, J., & Hendry, D. (2012). Homeless young people on social network sites. *Proceedings of the 2012 ACM Annual Conference on Human Factors in Computing Systems - CHI '12*, 2825. doi:10.1145/2207676.2208686

6 Conclusions and future work

6.1 Overview

The literature review of case studies from the healthcare domain portrays an emerging design field that is still maturing and attempting to develop sound methodologies for co-designing with the multi-disciplinary, multiple stakeholders who could constitute ‘users’ in a healthcare service project.

There is a clear need for designers to enter the domain of healthcare and, over time, establish a shared understanding with patients and other healthcare stakeholders around a commonly held value of ‘good’ design (Bate and Robert, 2006).

Both of these tasks are complicated by the pervasive domain features of complexity and unfamiliarity. Complexity persists as a barrier to innovation and implementation of healthcare services and technology (Bowen, Dearden, Wolstenholme, and Cobb, 2011; Cottam amd Leadbeater, 2004; Hasvold and Scholl, 2011; Jones, 2013). While unfamiliarity can confront design practitioners and design researchers as a barrier to gaining a tacit understanding of the healthcare context in which they seek to collaboratively ’ act, make and tell’ visions for design (Bowen et al., 2013; Chen, Cheng, Tang, Siek, and Bardram, 2014; Sanders, Ave, Brandt, and Binder, 2010).

Yet complexity and unfamiliarity can present rich opportunities for ‘fresh’ approaches to healthcare innovation and enabling a more human-centred experience for those seeking to support health and healing.

In order to contribute to a potential Community of Practice (COP) for health technology design, this thesis used an action research approach to examine the relationship between unfamiliarity with the healthcare domain of HIV research and design practice. This was through reflexive analysis and evaluation of the HealthMap design phases from the perspective of authentic design practice. (Bowen, Dearden, and Dexter, 2014; Wenger, McDermott, and Snyder, 2002; Wenger, 1998).

The action research enquiry began with the question: What can be learned from the HealthMap design project that offers insight to designers unfamiliar with healthcare as a domain for design?’ This overarching question led to a number of framing questions: i) How can we begin to map the healthcare cultural landscape? ii) What contributes to the effective use of design personas in a healthcare design project? iii) How can we envisage social media features for the highly stigmatised HIV positive population?

This thesis presented: the background to the HealthMap Study design work and my role as a design practitioner; the action research employed to explore and understand the particularities of the HealthMap project that were relevant to health technology design practice; and the results of the reflexive investigation as three journal papers.

The research findings led to a number of outcomes, which I group into two sections. Section 6.2 is the 'micro' outcomes, that is, the implications for design practice within the unfamiliar domain of HIV research as presented in the three papers: i) Pointy versus Soft: Towards a Design Language for Chronic Disease Self–Management in Healthcare; ii) A Collaborative Rapid Persona-Building Workshop: Creating Design Personas with Health Researchers and iii) 'Dipping a toe in the water': addressing the effects of stigma and avoidance when designing social media features for people with HIV

Section 6.3 is the 'macro' outcomes, that is, implications for a broad understanding of the entry of design practitioners into the unfamiliar territory of healthcare and implications for an emerging community of practice for healthcare design.

The following sections will introduce the conclusions and Section 6.5 will propose directions for future work.

6.2 Micro outcomes

The findings of this thesis directly address designing for the highly specialised and complex domain of HIV research, and, by extension, potentially healthcare as a design domain. The findings focus on methodological refinement for designers entering an unfamiliar healthcare context and on techniques for co-design work with health researchers.

6.2.1 Pointy versus Soft: designing and managing for pervasive tensions within the healthcare landscape

Paper 1 in Section 5 introduces the metaphorical concept of 'Pointy versus Soft' contextual influences for healthcare design. 'Pointy' and 'Soft' describe pervasive 'landmarks' present within healthcare systems. The paper identifies persistent 'pointy' characteristics as: a) systemic time scarcity, b) interoperability, and c) metrics as a requirement and d) the persistent 'soft' characteristic of stigma. These are posited as permanent characteristics of the 'landscape' of healthcare. By identifying these features of the healthcare landscape designers may devise strategies to successfully navigate divergent, and sometimes contradictory, project demands.

The reflexive analysis identified a number of outcomes from the co-creation and collaborative adoption of ‘Pointy versus Soft’ during the HealthMap design phases: i) it played a pivotal role in bridging the boundaries between design practice, medical research and social research through co-creation of a plain, accessible, mutually agreed lexicon, ii) it successfully explored and captured complex contextual influences and articulated them in an accessible and systematic way, iii) it enabled a design strategy for reflexive analysis of contextual features to ‘tease apart’ interwoven and sometimes conflicting factors which supported clear strategic design guidance and actionable insights, iv) it provided the HealthMap design team with a design language to apply to on-going design work, both generative and evaluative.

6.2.2 Eliciting requirements and engaging health researchers: collaborative rapid persona-building

The HealthMap collaborative rapid persona-building workshop is an example of efficient and comprehensive incorporation of numerous data and contextual considerations into early design scoping. At the same time it initiated health researchers into co-design processes and design thinking; thereby supporting cross-disciplinary understanding and the legitimacy of design practice within a health research project.

The collaborative persona-building employed dialogical tools to draw on tacit domain knowledge in the co-construction of design personas. This technique provided an efficient and comprehensive vehicle for reaching an agreed understanding around the details and experiences that directly affect PWHIV with regards to their ability to manage the chronic diseases of ageing.

The workshop also allowed the team to collaborate on setting the design scope and early design goals, creating shared values around how the design was envisioned to support patients and establishing a collaborative and productive team dynamic.

As industry and research practice move towards low fidelity ‘lean’ and ‘agile’ methodologies we suggest collaborative rapid persona-building as an appropriate process for user research analysis and design collaboration. As healthcare systems seek to harness broad socio-technological ecosystems in delivering healthcare, and as we seek to support patient and healthcare staff engagement, this is a potentially reliable process to identify and address potential barriers and opportunities for design.

6.2.3 Designing for the effects of stigma

Many people with HIV experience growing social isolation as they age and as their health needs become more complex.

Through reflecting on the three areas of: HealthMap design assumptions, HealthMap qualitative data and the literature on HIV stigma, stress coping, social support, chronic disease self-management and online health communities we conclude that ‘off the shelf’ social media features are not suitable for PWHIV experiencing social isolation. The basis for our conclusion is captured in ’Designing in the face of stigma’ a design tension’ which displays the pervasive impact of complex HIV stigmas in the lives of PWHIV, its role in preventing PWHIV from accessing support and the role of avoidant behaviour as a stress coping strategy (see Figure 6.1 below).

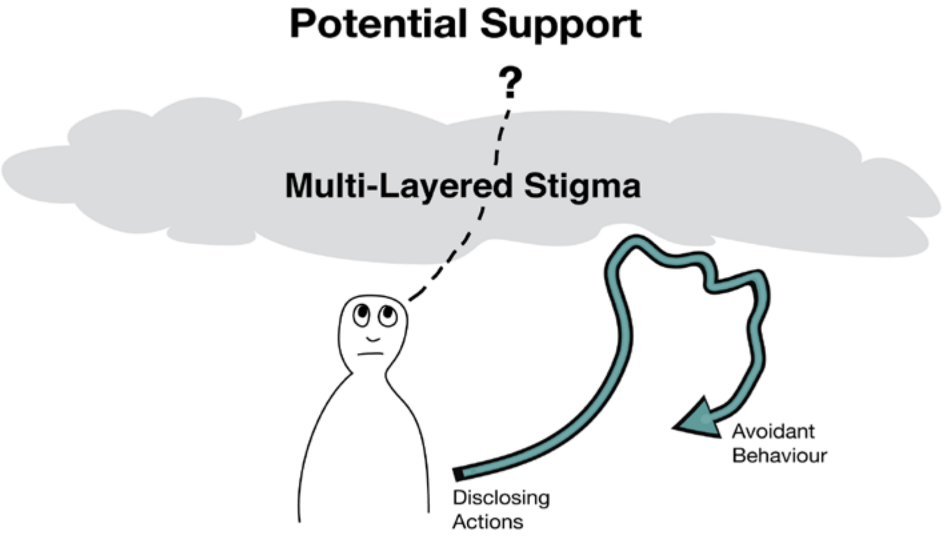

Figure 6.1 Designing in the face of stigma: a design tension

6.2.4 Designing for avoidant behaviour: fluctuating engagement and faceted identity

Another contribution of this thesis is to articulate the possible, and legitimate, presence of avoidance in the lives of many PWHIV. This is a significant characteristic that requires sensitive design responses while at the same time supporting attempts to access support. Consequently, designs need to allow for fluctuating attitudes towards participation within an individual user, allowing the user to ‘dip their toe in and out of the water’ of the online social platform. We identify sensitive management of faceted identity as a key component to maintaining user engagement across fluctuating attitudes and an area that requires further research.

6.2.5 Overcoming an avoidant response: meaningful activity

We further contribute a design strategy employing a user-defined ‘meaningful activity’. This allows a design approach that can deliver socially affective user experience, even for those commonly employing avoidant behaviour. This proposed design strategy is demonstrated in the ‘Finding meaningful support in the face of stigma’: a design strategy , which adds meaningful activity to the ‘Designing in the face of stigma: a design tension’ in order to disrupt the support seeking/avoidant behaviour pattern and invite the user to take a different approach (See Figure 6.2, below).

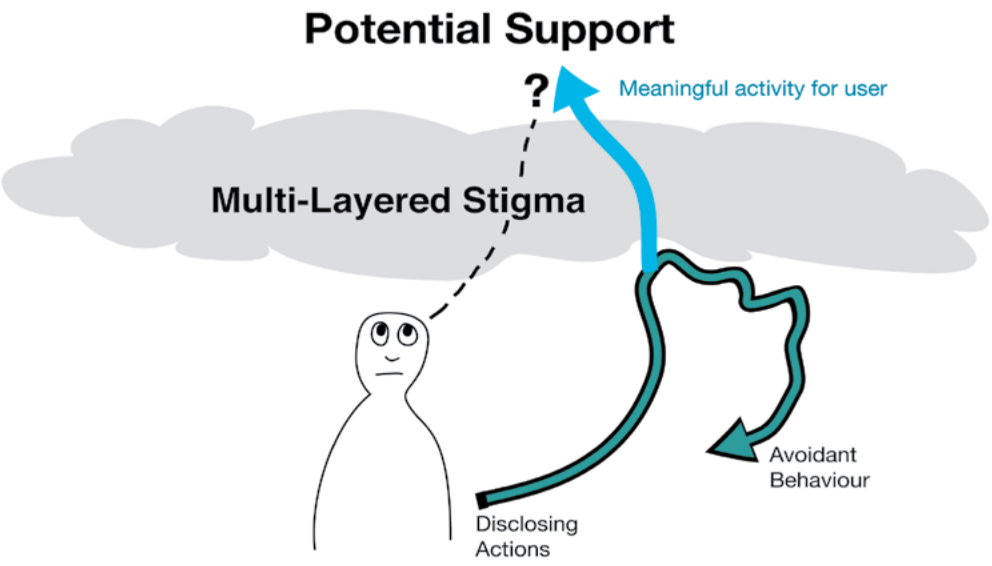

Figure 6.2 Finding meaningful support in the face of stigma: a design strategy

For HealthMap the meaningful activity identified through research was information seeking. Therefore we recommend testing design for collaborative information features to enable access to support and potentially alleviate the effects of social isolation for PWHIV. We also recommend testing design for social ‘trace sensing’ features for existing HealthMap content.

6.3 Macro outcomes

The focus of this thesis is to identify, articulate and share the Interaction Design practice for the HealthMap design. Particularly with regard to: i) the need to address the unfamiliarity of design practitioners with the strong, value-driven, cultural context of healthcare, ii) the need to offer tools for exploring and traversing the boundaries between medically-centred healthcare knowledge and human-centred design – to compile a knowledge base that is meaningful to a multi-disciplinary community of practice for healthcare design and iii) the need to understand more fully the value of design framing and design methodologies in contributing to healthcare innovation, especially the role of intuition and empathic design. (Brereton, 2009; Carlile, 2004; Chen et al., 2014; Ross, 2014; Sanders et al., 2010; Segalowitz and Brereton, 2009; Stolterman, 2008; Wright and McCarthy, 2008)

6.3.1 Bridging gaps

Successful Participatory Design and successful Communities of Practice both rely on the bridging of knowledge gaps between participants. Where participants are from diverse domains, even potentially conflicting domains (such as design and science), the cost of 'gaps' in shared knowledge is potentially high.

Together the Pointy versus Soft design strategy , the Pointy versus Soft design language and the collaborative persona-building process offer tools for co-design that support shared 'sense-making' and shared design activity; thereby facilitating mutual knowledge creation and mutual knowledge management. These are both crucial components for a successful COP and a co-design apporach to User-Centred Design.

A 'Pointy versus Soft' cross-disciplinary design lexicon for healthcare is distinct from the existing medical and engineering based terminology, such as 'safety' and 'functionality' (Bate and Robert, 2007a) . The value of a specific lexicon for 'designerly' thought and activities is recognised in current experience design practice and design research. (Kouprie and Visser, 2009; Nielsen and Storgaard Hansen, 2014; E. Sanders and Stappers, 2008; Spool, 2012)

6.3.2 Managing nuance

These design strategiess and techniques also serve as tools for managing the multifaceted, complex and competing elements of healthcare as a domain for design. Many design researchers use the word 'nuance' to describe the fabric of tacit, explicit, formal and informal factors that impact on the design context and the stakeholder values (Gaver, 2011; Hoshi, 2011; Jacobs, Dreessen, and Pierson, 2008; Kaplan and Harris-Salamone, 2009; Pilemalm and Timpka, 2008; Pruitt, 2003; J. Woelfer and Hendry, 2012; J. P. Woelfer and Hendry, 2010; Wright, Wallace, and McCarthy, 2008). A defining element of the Pointy versus Soft strategy is that it can hold both qualities at the same time. These are sometimes in tension, sometimes complementary and can be dynamic, with the same variable shifting between pointy and soft depending on the perspective. For example, an item of patient education information might need to be authoritative and medically accurate in order to comply with clinical governance (pointy) but also to reassure the patient that the source is trustworthy and dependable (soft). The language in the information might need to be both accessible, simple and short, to allow for cognitive impairment or stress (pointy), and to be inclusive and reassuring, to allow for stigma or anxiety (soft).

Collaborative persona building can be a vehicle for the shared understanding of these nuances to be explored, defined and shaped to fit design goals.

6.3.3 Design strategy

The previous discussion of bridging knowledge gaps, and managing nuance, places the value of these tools squarely within the ‘fuzzy front end’ of design work (Sanders and Stappers, 2008). The majority of the HealthMap data in which these tools are grounded are also from early-mid design phases. However, application of these tools in the early phases can establish a design strategy for service or product development and support later stage evaluation and testing. This on-going relevance is grounded in the collaborative sense-making and shared tacit understanding of what the design language means. When it is employed the whole rationale for its evolution and relevance is understood. Figure 6.3 below gives examples of typical generative and evaluative design activities where there is opportunity to apply and test a ‘Pointy versus Soft’ strategy tool.

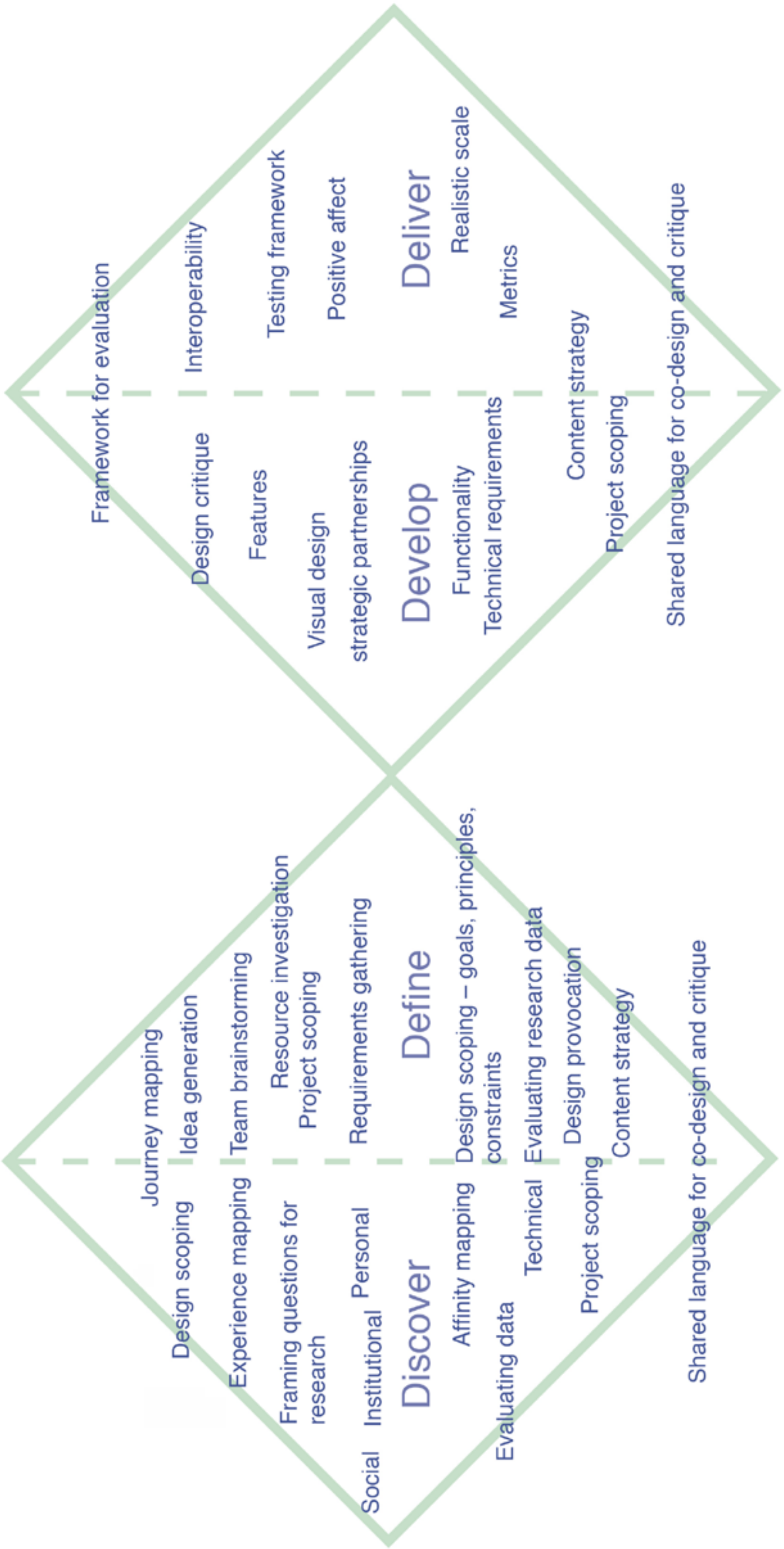

Figure 6.3 Potential design actvities for testing a ‘Pointy versus Soft’ approach

Bowen et al., (2013) and Dearden et al., (2010) both find the NHS Experience-based Design toolkit to provide little guidance or support for the later ‘develop’ and ‘deliver’ phases of design projects. It is possible that the Pointy versus Soft strategy, if collaboratively applied to early design activities, could be a strategic tool for service development and implementation (especially for team members skilled in project management)

From the experience-based/experience-centered design literature and Participatory Design literature it is clear that the question of ‘who?’ and ‘why?’ is much more clearly understood than ‘how?’ The values of patient-centred design, patient empowerment, and Participatory Design all clearly require the inclusion of those affected by a system to play a role in its design (P. Bate and Robert, 2007b; Bowen et al., 2011; Dexter et al., 2010; Jones, 2013; Pilemalm and Timpka, 2008; Postma, Zwartkruis-Pelgrim, Daemen, and Du, 2012; Wolstenholme et al., 2010). The implementation of ‘user-friendly’, pervasive healthcare information technology is considered critical to sustainable and effective healthcare systems in the era of digital ecosystems and ageing populations. However the tools and techniques to effectively include system stakeholders in the design and implementation of health technology and healthcare service design are still emerging. The intention of ‘patient-centred’ service design is not enough to deliver a patient-centred experience (Bate and Robert, 2006).

This thesis presents a number of conceptual and methodological tools for ‘how’ human-centred design might be practised in the healthcare domain.

6.3.4 Empathic design in healthcare

This thesis identifies stigma as a pervasive ‘soft’ terrain feature of people’s experiences in healthcare. It shows how exploring empathic and intuitive designer responses to a highly stigmatised domain can generate strategies that support future service delivery to people experiencing stigmas.

My role on the HealthMap team and the development of my intuitive and empathic design creativity provides an example of the successful blending of creative and evidence-based approaches to envisage new human-centred technology (Postma et al., 2012; Wright and McCarthy, 2008).

6.3.5 Communities of practice / User-Centred Design

Broader implications: toward a community of practice for healthcare design

Successful design techniques for bridging knowledge boundaries within healthcare design supports both User-Centred Design practice and the search for a cross-disciplinary community of practice for 'design for health' (Carlile, 2004; Segalowitz and Brereton, 2009; Simonsen and Robertson, 2012).

A co-created design lexicon aligns with Lave and Wenger's framework for communities of practice: which describes the value of shared construction of a shared understanding and shared repertoire of methods and concepts. This repertoire can act as a resource for further design engagement (Wenger, 1998; Wenger et al., 2002).

Whether a community of practice can be built, and whether a community of practice can appropriate these strategies, can only be demonstrated over time and through channels additional to the presentation of an academic thesis. It is envisioned that by building dialogue through established industry design and design research networks, and informal peer interactions, over time agreed principles and good practice might be identified and disseminated.

6.4 Limitations

As this is a reflexive thesis the processes and strategies proposed are untested and require validation. Further design work and research to evaluate how the design strategiess can support health technology design is required. The outcomes of this one case study may be a result of team dynamics, intrinsic design skills and productive collaboration rather than inherent value in the strategies and processes.

By definition, collaborative design tools are enacted by the participants applying them and they are mediated by those actors. They are also situated in time and the materials employed (Light and Akama, 2012; Ruhl, Richter, Lembke, and Allert, 2014). Rather than providing a set of utilitarian strategiess and techniques, the transferability and relevance of the HealthMap case study may be limited to a catalyst for future design practitioners; acting as a provocation for designers to explore the themes raised and form their own 'version', or new method, appropriate to the participants and project at hand.

6.5 Future Work

The conclusions are that further case-study research to i) illuminate areas of cross-disciplinary collaboration, ii) to support designer familiarity with the healthcare design landscape and iii) to report on the outcomes of applying these design processes within a healthcare context would support practising designers in the day-to-day processes of healthcare design work and support designers engaging in their first healthcare project.

Bibliography

Addis, M. E., & Mahalik, J. R. (2003). Men, Masculinity, and the Contexts of Help Seeking. *American Psychologist, 58(1)*, 5–14. doi:10.1037/0003-066X.58.1.5

Alaoui, M., Lewkowicz, M., & Seffah, A. (2012). Increasing Elderly Social Relationships Through TV-Based Services. In *Proceedings of the 2nd ACM SIGHIT International Health Informatics Symposium* (pp. 13–20). Miami, Florida, USA: ACM. doi:10.1145/2110363.2110369

Bandura, A. (1986). The Explanatory and Predictive Scope of Self-Efficacy Theory. *Journal of Social and Clinical Psychology*. New York, NY, USA: Guildford Publications Inc. doi:10.1521/jscp.1986.4.3.359

Barlow-Busch, R., (2010) Case 11 A Case Study in personas, in Righi, C., James, J. *User-Centered Design Stories: Real-World UCD Case Studies*. Elsevier Science, Burlington, pp. 209-240 ISBN 978-0-12-370608-9

Bate, P., & Robert, G. . (2007). *Bringing user experience to healthcare improvement: The concepts, methods and practices of Experience-based Design* (pp. xi, 207). Oxford, UK: Radcliffe Publishing Ltd. ISBN 978-1-84-619176-3

Bate, P., & Robert, G. (2006). Experience-based design: from redesigning the system around the patient to co-designing services with the patient. *Quality & Safety in Health Care, 15(5)*, 307–10. doi:10.1136/qshc.2005.016527

Bate, P., & Robert, G. (2007a). Toward More User-Centric OD: Lessons From the Field of Experience-Based Design and a Case Study. *The Journal of Applied Behavioral Science, 43(1)*, 41–66. doi:10.1177/0021886306297014

Bate, S. P., & Robert, G. (2002). Knowledge management and communities of practice in the private sector: lessons for modernizing the National Health Service in England and Wales. *Public Administration, 80(4)*, 643–663. doi:10.1111/1467-9299.00322

Berryman, M. S., Haberman, V., & Lynn, B. (2011). User Experience Design in a Surgical Environment. In UX Australia. UX Australia. Retrieved from http://www.slideshare.net/micberryman/ux-design-in-a-surgical-environment

Blomquist, Å., & Arvola, M. (2002). Personas in Action : Ethnography in an Interaction Design Team. In *Proceedings of NordiCHI 10/02* (pp. 197–200). Aarhus, Denmark: ACM. doi 10.1145/572020.572044

Boer, L., Donovan, J., & Buur, J. (2013). Challenging industry conceptions with provotypes. *CoDesign, International Journal of CoDesign in Design and the Arts, (9:2)*, 73–89. doi:10.1080/15710882.2013.788193

Bojars, U., Breslin, J. G., Peristeras, V., Tummarello, G., & Decker, S. (2008). Interlinking the social web with semantics. *IEEE Intelligent Systems*, 23(June), 29–40. doi:10.1109/MIS.2008.50

Bowen, S., Dearden, A., & Dexter, M. (2014). Wearing Two Hats : Reflecting Alongside Authentic Designing. In *Proceedings of DRS 2014*. Umea, Sweden: Design Research Society. Retrieved from http://www.drs2014.org/media/647964/0161-file1.pdf

Bowen, S., Dearden, A., Wolstenholme, D., & Cobb, M. (2011). Different Views : Including Others In Participatory Health Service Innovation. In J. Buur (Ed.), *PINC 2011: Participatory Innovation Conference 2011*. Sonderborg: University of Southern Denmark. Retrieved from http://shura.shu.ac.uk/3536/

Bowen, S., Dearden, A., Wright, P., Wolstenholme, D., & Cobb, M. (2010). Participatory Healthcare Service Design and Innovation. In *Proceedings of the 11th Biennial Participatory Design Conference* (pp. 155–158). Sydney, Australia: ACM. doi:10.1145/1900441.1900464

Bowen, S., McSeveny, K., Lockley, E., Wolstenholme, D., Cobb, M., & Dearden, A. (2013). How was it for you? Experiences of Participatory Design in the UK health service. *CoDesign, 9(4)*, 230–246. doi:10.1080/15710882.2013.846384

Brandt, E., Binder, T., and Sanders, EBN. (2013) Tools and techniques: Ways to engage telling, making and enacting. In Simonsen, J., Robertson, T. Routledge *International Handbook of Participatory Design*, Routledge, New York, e-book, eISBN 978-1-136-26626-3

Brereton, M. (2009). Designing From Somewhere - a located, relational and transformational view of design. In T. Binder, J. Löwgren, & L. Malmborg (Eds.), *(Re)Searching the Digital Bauhaus* (1st ed., p. 371). London: Springer London. doi:10.1007/978-1-84800-350-7

Brereton, M. & Buur, J. (2008) New challenges for design participation in the era of ubiquitous computing, *CoDesign: International Journal of CoCreation in Design and the Arts, (4:2),* 101-113 doi:10.1080/15710880802098099

Brereton, M., Roe, P., Schroeter, R., & Hong, A. L. (2014). Beyond Ethnography : Engagement and Reciprocity as Foundations for Design Research Out Here, 1183–1186. doi 10.1145/2556288.2557374

British Design Council, (n.d.) How Designers Work Retrieved from http://www.designcouncil.org.uk/about-design/how-designers-work/the-design-process/

Buur, J., & Matthews, B. (2008). Participatory innovation: a research agenda. In *Proceedings of the Tenth Anniversary Conference on Participatory Design* (pp. 186–189). Bloomington, Indiana: Indiana University, Indianapolis. Retrieved from http://dl.acm.org/citation.cfm?id=1795234.1795269

Calde, S., Goodwin, K., & Reimann, R. (2002). SHS Orcas: The first integrated information system for long-term healthcare facility management. *Case studies of the CHI2002|AIGA Experience Design FORUM (CHI '02).* ACM, New York, NY. doi: 10.1145/507752.507753

Carlile, P. R. (2004). Science An Integrative Transferring , Translating , and Transforming : Framework for Managing Knowledge Across Boundaries, *Organization Science* 15(5), 555–568. doi:10.1287/orsc.

Case, D. O., Andrews, J. E., Johnson, D. J., & Allard, S. L. (2005). Avoiding versus seeking : the relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts. *Journal of the Medical Library Association : JMLA 93*(3). Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1175801/

Chang, Y., Lim, Y., & Stolterman, E. (2008). Personas: from theory to practices. In *Proceedings of the 5th Nordic conference on Human-Computer Interaction: Building Bridges*, Lund, Sweden (pp. 439–442). New York, NY: ACM. doi: 10.1145/1463160.1463214

Chapman, C. N., & Milham, R. P. (2006). The persona's new clothes: methodological and practical arguments against a popular method. In *Proceedings of the Human Factors and Ergonomics Society 50th Annual Meeting* (pp. 634–636). Retrieved from http://cnchapman.files.wordpress.com/2007/03/chapman-milham-personas-hfes2006-0139-0330.pdf

Chen, Y., Cheng, K., Tang, C., Siek, K. a., & Bardram, J. E. (2014). The invisible work of health providers. Interactions, 21(5), 74–77. doi:10.1145/2645645

Chenard, C. (2007). The impact of stigma on the self-care behaviors of HIV-positive gay men striving for normalcy. *The Journal of the Association of Nurses in AIDS Care : JANAC, 18*(3), 23–32. doi:10.1016/j.jana.2007.03.005

Chuang, K. Y., & Yang, C. C. (2010). Helping you to help me: Exploring supportive interaction in online health community. *Proceedings of the American Society for Information Science and Technology, 47*(1), 1–10. doi:10.1002/meet.14504701140

Clemens, R. G., & Cushing, A. L. (2010). Beyond everyday life: Information seeking behavior in deeply meaningful and profoundly personal contexts. Proceedings of the American Society for Information Science and Technology, 47(1), 1–10. doi:10.1002/meet.14504701228

Clements-Nolle, K., & Bachrach, A. M. (2010). Community-Based Participatory Research for Health: From Process to Outcomes. In M. Minkler & M. Wallerstein (Eds.), *Community-Based Particpatory Research* (2nd ed., pp. 175–186). John Wiley & Sons LTD. ISBN 978-04-709-3249-0

Cohen, S., Evans, G. W., Stolols, D., & Krantz, D. S. (1986). *Behaviour, health and environmental stress* (pp. 1–23). Springer US. ebook ISBN 978-1-4757-9380-2 doi:10.1007/978-1-4757-9380-2_1

Cooper, A. (2004). *The inmates are running the asylum: Why high-tech products drive us crazy and how to restore the sanity*. (2nd ed.) Indiana, IN: Sams Publishing. ISBN 0672326140 06

Cooper, G. A. (2001). *Online Assistance For Problem Gamblers : An Examination Of Participant Characteristics* (Doctoral dissertation). University of Toronto. Retrieved from http://www.cghub.org/Cooper_Dissertation_2001.pdf

Cottam, H., & Leadbeater, C. (2004). Red Paper 01 Health: Co-creating Services. Retrieved from http://www.designcouncil.info/RED/health/REDPaper01.pdf

Dearden, A., Wright, P., Bowen, S., Rahman, F., Cobb, M., & Wolstenholme, D. (2010). User-centred design and pervasive health: A position statement from the User-Centred Healthcare Design project. Proceedings of the 4th International ICST Conference on Pervasive Computing Technologies for Healthcare, 8–11. doi:10.4108/ICST.PERVASIVEHEALTH2010.8837

Dexter, M., Cobb, M., Bowen, S., Dearden, A., Rahman, F., Wolstenholme, D., & Wright, P. (2010). Participatory Design Methodologies Used to Effect Change in a Healthcare Environment. In *Design Research Conference*. Retrieved from http://conferences.wsu.edu/conferences/design/default.aspx

Donovan, J. W. A. (2011). Framing Movements for Gesture Interface Design. Unpublished doctoral dissertation. University of Queensland http://espace.library.uq.edu.au/view/UQ:230249

Earnshaw, V. A, & Quinn, D. M. (2012). The impact of stigma in healthcare on people living with chronic illnesses. *Journal of Health Psychology, 17(2)*, 157–68. doi:10.1177/1359105311414952

Earnshaw, V. A, Quinn, D. M., & Park, C. L. (2012). Anticipated stigma and quality of life among people living with chronic illnesses. *Chronic Illness, 8(2)*, 79–88. doi:10.1177/1742395311429393

Engeström, J. (2005). Why some social network services work and others don't - or: the case for object-centered sociality. Retrieved from http:/ /www. zengestrom. com/ blog/ 2005/ 04/ why-some-social-network-services-work-and-others-dont-or-the-case-for-object-centered-sociality.

Experience as Evidence? – Symposium – 13-14 October 2014. (2014). Retrieved from http://experience-as-evidence.org/

Faily, S., & Flechais, I. (2011) Persona cases: A technique for grounding personas. In *Proc. CHI 2011* (pp. 2267-2270). New York, NY: ACM Press. doi:10.1145/1978942.1979274

Fan, H., Smith, S. P., & Lederman, R. (2010). Why People Trust in Online Health Communities : An Integrated Approach. In *21st Australasian Conference on Information Systems*. Brisbane. Retrieved from: http://ssrn.com/abstract=1775303

Farnham, S. D., & Churchill, E. F. (2011). Faceted Identity , Faceted Lives : Social and Technical Issues with Being Yourself Online. *Information Systems Journal*, 359–368. doi:10.1145/1958824.1958880

Floyd, I. R., Jones, M. C., & Twidale, M. B. (2008). Resolving incommensurable debates: A preliminary identification of persona kinds, attributes, and characteristics. *Artefact*, *2*(1), 12–26. doi:10.1080/17493460802276836

Fogel, J., & Nehmad, E. (2009). Internet social network communities: Risk taking, trust, and privacy concerns. *Computers in Human Behavior*, *25*(1), 153–160. doi:10.1016/j.chb.2008.08.006

Gaver, W. (2011). Making Spaces : How Design Workbooks Work. In *CHI '11 Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 1551–1560). Vancouver, Canada. doi:0.1145/1978942.1979169

Godbold, N. (2006). Beyond information seeking: towards a general model of information behaviour. *Information Research-an International Electronic Journal, 11*(4). Retrieved from http://informationr.net/ir/11-4/paper269.html

Goffman, E. (1990). *Stigma: notes on the management of spoiled identity* (2nd ed.). London: Penguin. ISBN 978-0140124750

Golovchinsky, G., Qvarfordt, P., & Pickens, J. (2009). Collaborative information seeking. *Computer, 42*(3), 47–51. doi:10.1109/MC.2009.73

Gonzales, M., & Riek, L. (2013). Co-designing Patient-centered Health Communication Tools for Cancer Care. *Proceedings of the 7th international conference on Pervasive Computing Technologies for Healthcare and Workshops,* (pp.208-215) Venice, Italy: EAI. doi:10.4108/pervasivehealth.2013.252109

Greenhalgh, T., Robert, G., Macfarlane, F., Bate, P., & Kyriakidou, O. (2004). Diffusion of innovations in service organizations: systematic review and recommendations. *The Milbank Quarterly*, *82*(4), 581–629. doi:10.1111/j.0887-378X.2004.00325.x

Grierson, J., Pitts, M., & Koelmeyer, R. (2013). *HIV Futures Seven: The Health and Wellbeing of HIV Positive People in Australia* (Monograph). Melbourne: The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia. Retrieved from http://pozhet.org.au/wp-content/uploads/2013/11/HIV-Futures-Seven-Report.pdf

Grocott, P., Blackwell, R., Currie, C., Pillay, E., & Robert, G. (2013). Co-producing novel wound care products for Epidermolysis bullosa; an empirical case study of the use of surrogates in the design and prototype development process. *International Wound Journal*, *10*(3), 265–73. doi:10.1111/j.1742-481X.2012.00972.x

Grudin, J., & Pruitt, J. (2002, June 23-25). Personas. Participatory design and product development: An infrastructure for engagement. In T. Binder, J. Gregory, I. Wagner, (Eds.), *Proceedings of the Participatory Design Conference (PDC 02)*, Malmo, Sweden. Palo Alto, CA: CPSR. ISBN 0-9667818-2-1

Hargittai, E. (2008). Whose Space ? Differences Among Users and Non-Users of Social Network Sites, *Journal of Computer-Mediated Communication 13*(1), 276–297. doi:10.1111/j.1083-6101.2007.00396.x

Harrell, D. F. (2009). Computational and cognitive infrastructures of stigma. In *Proceeding of the seventh ACM conference on Creativity and cognition - C&C '09* (p. 49). Berkeley, California, USA: ACM. doi:10.1145/1640233.1640244

Hasvold, P. E., & Scholl, J. (2011). Flexibility in interaction: sociotechnical design of an operating room scheduler. International Journal of Medical Informatics, 80(9), 631–45. doi:10.1016/j.ijmedinf.2011.06.007

Hayes, G. R. (2011). The relationship of action research to human-computer interaction. ACM Transactions on Computer-Human Interaction, 18(3), 1–20. doi:10.1145/1993060.1993065

Heart Foundation, (n.d.). Cardiovascular wellness for people living with HIV. Retrieved 12 November 2013 from http://www.heartfoundation.org.au/SiteCollectionDocuments/Cardiovascular-wellness-for people-living-with-HIV.pdf

Henry, S. L. (2007). Just Ask: integrating Accessibility Throughout Design. Retrieved from http://www.uiaccess.com/accessucd/

Heyer, C., & Brereton, M. (2009). Reflective Agile Iterative Design. In Social Interaction with Mundane Technologies Conference (pp. 20–21). Cambridge. Retrieved from http://www.mundanetechnologies.com/goings-on/workshop/cambridge/papers/HeyerBrereton.pdf

Hoshi, K. (2011). Reframing Dichotomies : Human Experiential Design of Healthcare Technologies. In Human Centred Design of E-Health Technologies (pp. 65–93). doi:10.4018/978-1-60960-177-5.ch004

How Designers Work. (n.d.). British Design Council. Retrieved from http://www.designcouncil.org.uk/about-design/how-designers-work/the-design-process/

Jacobs, A., Dreessen, K., & Pierson, J. (2008). " Thick " personas – Using ethnographic Methods for Persona Development as a Tool for Conveying the Social Science View in Technological Design. Observatorio, 5, 79–97. Retrieved from http://obs.obercom.pt/index.php/obs/article/viewFile/203/171

Jones, P. H. (2013). *Design for Care: Innovating Healthcare Experience*. New York: Rosenfeld Media. ISBN 9781933820231

Julier, G. (2013, March 11). Experience-based design, innovation and the NHS. Social Design Talks on WordPress.com [Web log post]. Retrieved, from http://socialdesigntalks.org/2013/03/11/experience-based-design-innovation-and-the-nhs-report/

Kalichman, S. C., Cain, D., Cherry, C., Pope, H., Eaton, L., & Kalichman, M. O. (2005). Internet use among people living with HIV/AIDS: coping and health-related correlates. *AIDS Patient Care and STDs, 19*(7), 439–448. doi:10.1089/apc.2005.19.439

Kalichman, S. C., Cherry, C., Cain, D., Weinhardt, L. S., Benotsch, E., Pope, H., & Kalichman, M. (2006). Health information on the Internet and people living with HIV/AIDS: information evaluation and coping styles. *Health Psychology : Official Journal of the Division of Health Psychology, American Psychological Association*, *25*(2), 205–10. doi:10.1037/0278-6133.25.2.205

Kälviäinen, M. (2012). Elderly as content providers in their everyday life supporting services, In *Proceedings of the Cumullus Helsinki Conference*. 1–15. Retrieved from http://cumulushelsinki2012.org/cumulushelsinki2012.org/wp-content/uploads/2012/05/Elderly-as-content-providers-in-their-everyday-life-supporting-services.pdf

Kaplan, B., & Harris-Salamone, K. D. (2009). Health IT success and failure: recommendations from literature and an AMIA workshop. *Journal of the American Medical Informatics Association : JAMIA*, *16*(3), 291–9. doi:10.1197/jamia.M2997

Koshy, E., Koshy, V., & Waterman, H. (2011). *Action Research in Healthcare*. London, UK: Sage Publications Ltd. ISBN 978-1-84860-189-5

Kouprie, M., & Visser, F. S. (2009). A framework for empathy in design: Stepping into and out of the user's life. *Journal of Engineering Design*, *20*(5), 437–448. doi:10.1080/09544820902875033

Lab4Living. (n.d.). Lab 4 Living | Cultural, Communication and Computing Research Institute | Sheffield Hallam University. Retrieved from http://www.shu.ac.uk/research/c3ri/projects/lab-4-living

Lamberg, L. (2003). Online empathy for mood disorders: patients turn to internet support groups. *JAMA : The Journal of the American Medical Association*. doi:10.1001/jama.289.23.3073

Lazarus, R., & Folkman, S. (1984). *Stress, appraisal and coping* (1st ed.). New York: Springer New York. ISBN 0826141927

Lerouge, C., Ma, J., Sneha, S., & Tolle, K. (2011). User profiles and personas in the design and development of consumer health technologies. *International Journal of Medical Informatics*, *82(*11),1–18. doi:10.1016/j.ijmedinf.2011.03.006 PMID:21481635

Li, M., & Yang, Y. (2009). Determinants of problem solving, social support seeking, and avoidance: A path analytic model. *International Journal of Stress Management*. doi:10.1037/a0016844

Light, A., & Akama, Y. (2012). The human touch. In PDC '12- Proceedings of the 12th Participatory Design Conference on Research. Roskilde, Denmark. doi:10.1145/2347635.2347645

Locock, L., Robert, G., Boaz, A., Vougioukalou, S., Shuldham, C., Fielden, J., Pearcey, J. (2014). Testing accelerated experience-based co-design: a qualitative study of using a national archive of patient experience narrative interviews to promote rapid patient-centred service improvement. Health Serv Deliv Res, 2(4). doi:10.3310/hsdr02040

Lyng, K. M., & Pedersen, B. S. (2011). Participatory design for computerization of clinical practice guidelines. *Journal of Biomedical Informatics*, *44*(5), 909–18. doi:10.1016/j.jbi.2011.05.005

Mahajan, A. P., Sayles, J. N., Patel, V. A., Remien, R. H., Sawires, S. R., Ortiz, D. J., Coates, T. J. (2008). Stigma in the HIV / AIDS epidemic : a review of the literature and recommendations for the way forward. *AIDS, 22*(2), 67–79. doi:10.1097/01.aids.0000327438.13291.62

Maitland, J., & Chalmers, M. (2011). Designing for peer involvement in weight management. *Proceedings of the 2011 Annual Conference on Human Factors in Computing Systems - CHI '11*, 315. doi:10.1145/1978942.1978988

Martin, D., Mariani, J., & Rouncefield, M. (2009). Practicalities of Participation: Stakeholder Involvement in an Electronic Patient Records Project. In M. Büscher, R. Slack, M. Rouncefield, R. Procter, M. Hartswood, & A. Voss (Eds.), *Configuring User-Designer Relations SE - 7* (pp. 133–155). Springer London. doi:10.1007/978-1-84628-925-5_7

Mattelmäki, T., Brandt, E., & Vaajakallio, K. (2011). On designing open-ended interpretations for collaborative design exploration. *CoDesign*, *7*(2), 79–93. doi :10.1080/15710882.2011.609891

Matthews, T., Judge, T. K., & Whittaker, S. (2012). How do designers and user experience professionals actually perceive and use personas? In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, Austin, Texas *(CHI '12)* (pp. 1219–1228). New York, NY: ACM. doi:10.1145/2207676.2208573

McDonald, K., Elliott, J., & Saugeres, L. (2013). Ageing with HIV in Victoria: Findings from a qualitative study, *HIV Australia 11*(2), 13. Retrieved from http://search.informit.com.au/documentSummary;dn=564861079707209;res=IELHEA

McHattie, L.-S., Cumming, G., & French, T. (2014). Transforming patient experience: health web science meets medicine 2.0. *Medicine 2.0*, *3*(1), e2. doi:10.2196/med20.3128

Miaskiewicz, T., & Kozar, K. a. (2011). Personas and user-centered design: How can personas benefit product design processes? *Design Studies, 32*(5), 417–430. doi:10.1016/j.destud.2011.03.003

Mo, P. K. H., Malik, S. H., & Coulson, N. S. (2009). Gender differences in computer-mediated communication: a systematic literature review of online health-related support groups. *Patient Education and Counseling, 75*(1), 16–24. doi:10.1016/j.pec.2008.08.029

Mockford, C., Staniszewska, S., Griffiths, F., & Herron-Marx, S. (2012). The impact of patient and public involvement on UK NHS health care: a systematic review. *Journal of the International Society for Quality in Health Care / ISQua*, *24*(1), 28–38. doi:10.1093/intqhc/mzr066

Mønsted, T., & Onarheim, B. (2010). Segmentation of users in PD for healthcare. In Proceedings of the 11th Biennial Participatory Design Conference on PDC 10 (pp. 159–162). Sydney, Australia: ACM New York, NY, USA. doi:10.1145/1900441.1900465

Moser, C., Fuchsberger, V., Neureiter, K., Sellner, W., & Tscheligi, M. (2012) Revisiting personas: the making-of for special user groups. In *Proceedings of the Extended Abstracts on Human Factors in Computing Systems (CHI '12)* (pp. 453-468). New York, NY: ACM. doi:10.1145/2212776.2212822

Nambisan, P. (2011). Information seeking and social support in online health communities: impact on patients' perceived empathy. *Journal of the American Medical Informatics Association : JAMIA, 18*, 298–304. doi:10.1136/amiajnl-2010-000058

NHS. (n.d.). Experience Based Design for Clinical Commissioning Groups and the Engagement Cycle. NHS Patient Experience Portal. Retrieved August 15, 2014, from http://patientexperienceportal.org/article/experience-based-design-for-clinical-commissioning-groups-and-the-engagement-cycle

Nielsen, Lene, (2007). Personas – Communication or Process? In Proceedings of the Seventh Danish HCI Research Symposium. IT University of Copenhagen, Copenhagen, November 22, 2007, pp 25-26. Retrieved from http://www.kommunikationsforum.dk/lene-nielsen/blog/personas-communication-or-process

Nielsen, Lene, (2007a). 10 Steps to Personas Based on "Engaging Personas and Narrative Scenarios" by Ph.D. Lene Nielsen. © Snitker & Co. 2007 PDF poster. Retrieved from http://personas.dk/?page_id=196 downloaded 30/3/14

Nielsen, L. (2014). Personas. In M. Soegaard, & R. F. Dam (Eds.), *The Encyclopedia Of Human-Computer Interaction* (2nd ed.). Aarhus, Denmark: The Interaction Design Foundation. Retrieved from http://www.interaction-design.org/encyclopedia/personas.html

Nielsen, L., & Storgaard Hansen, K., (2014). Personas is applicable. I*n Proceedings of the 32nd annual ACM conference on Human factors in computing systems - CHI '14* (pp. 1665–1674). New York, New York, USA: ACM Press. doi:10.1145/2556288.2557080

Nijland, N. (2011). *Grounding ehealth*. (Thesis) University of Twente, Netherlands, ISBN: 978-90-365-3133-7 Retrieved from http://purl.utwente.nl/publications/75576 doi:10.3990/1.9789036531337

Nilsson, L., Borg, C., Hofflander, M., & Eriksén, S. (2010). PD 3.1 to the rescue: challenges for Participatory Design in a health care context. In Proceedings of the 11th Biennial Participatory Design Conference (PDC '10). ACM, New York, NY, USA, 269-270. doi 10.1145/1900441.1900501

Nunes, F., & Silva, P. A. (2010, June 23-25). Human-computer interaction and the older adult: An example using user research and personas. In *Proceedings of the PETRA'10*, Samos, Greece. ACM ISBN 978-1-4503-0071-1/10/06 doi:10.1145/1839294.1839353

Oh, H. J., & Lee, B. (2012). The effect of computer-mediated social support in online communities on patient empowerment and doctor-patient communication. *Health Communication, 27*(1), 30–41. doi:10.1080/10410236.2011.567449

Oostveen, A. (2011). The Internet as an Empowering Technology for Stigmatized Groups : a Case Study of Weight Loss Bloggers. In *Proceedings of the 25th BCS Conference on Human-Computer Interaction* (pp. 114–119). British Computer Society Swinton, UK. Retrieved from http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2003129

Owen, J. E., Boxley, L., Goldstein, M. S., Lee, J. H., Breen, N., & Rowland, J. H. (2010). Use of Health-Related Online Support Groups: Population Data from the California Health Interview Survey Complementary and Alternative Medicine Study. *Journal of Computer-Mediated Communication, 15*(3), 427–446. doi:10.1111/j.1083-6101.2010.01501.x

Petersen, M. G., Hallnäs, L., & Jacob, R. J. K. (2008). Introduction to special issue on the aesthetics of interaction. ACM Transactions on Computer-Human Interaction, 15(3), 1–5. doi:10.1145/1453152.1453153

Pickles, J., Hide, E., & Maher, L. (2008). Experience based design: a practical method of working with patients to redesign services. *Clinical Governance: An International Journal*, *13*(1), 51–58. doi:10.1108/14777270810850634

Pilemalm, S., & Timpka, T. (2008). Third generation Participatory Design in health informatics--making user participation applicable to large-scale information system projects. *Journal of Biomedical Informatics*, *41*(2), 327–39. doi:10.1016/j.jbi.2007.09.004

Ploderer, B., Smith, W., Pearce, J. O. N., & Borland, R. O. N. (2015). An Object-Centred Approach to Encourage Online Participation in the Context of Behaviour Change. *Computer Supported Cooperative Work, 1*(26), 1–27. doi:10.1007/s10606-014-9212-3

Postma, C. E., Zwartkruis-pelgrim, E., Daemen, E., & Du, J. (2012). Challenges of Doing Empathic Design : Experiences from Industry. International Journal of Design, 6(1), 59–70. Retrieved from http://www.ijdesign.org/ojs/index.php/IJDesign/article/view/1008/403

Pruitt, J., & Adlin, T. (2006). *The Persona lifecycle: Keeping people in mind throughout product design*. [EBL version] Elsevier Science. ebook ISBN 9780123814197 Retrieved from http://site.ebrary.com/id/10138281?ppg=3

Pruitt, J., & Grudin, J. (2003) Personas: Practice and theory. In *Proceedings of the 2003 Conference on Designing for User Experiences (DUX '03)* (pp. 1-15). New York, NY: ACM. doi:10.1145/997078.997089

Qu, Y., & Hansen, D. L. (2008). Building Shared Understanding in Collaborative Sensemaking. Position paper presented at the sense-making workshop at the ACM Conference on Human Factors in Computing Systems 2008, Florence, Italy Retrieved from http://scholar.google.com.au/scholar?cluster=11793863688532387146&hl=en&as_sdt=2005&sciodt=0,5

Quinn, D. M., & Chaudoir, S. R. (2009). Living with a concealable stigmatized identity: the impact of anticipated stigma, centrality, salience, and cultural stigma on psychological distress and health. *Journal of Personality and Social Psychology, 97*(4), 634–51. doi:10.1037/a0015815

Reeder, B., & Turner, A. M. (2011). Scenario-based design: A method for connecting information system design with public health operations and emergency management. *Journal of Biomedical Informatics*, *44*(6), 978–988. doi: doi:10.1016/j.jbi.2011.07.004 PMID:21807120

Reidpath, D. D., & Chan, K. Y. (2005). A method for the quantitative analysis of the layering of HIV-related stigma. *AIDS Care*, *17*(4), 425–32. doi:10.1080/09540120412331319769

Rogers, Y. (2004). New Theoretical Approaches for HCI.In Cronin (Ed.) *Annual Review of Information Science and Technology (ARIST), 38*. ASIS&T ISSN 0066-4200 Retrieved from http://www.editlib.org/p/97535/

Ross, L. (2014). FjordKitchen talks: Lorna Ross "Service Design in Health and Health Care." Vimeo. Retrieved from http://vimeo.com/88746452

Ruhl, E., Richter, C., Lembke, J., & Allert, H. (2014). Beyond methods : Co - creation from a practice - oriented perspective A practice - oriented perspective Conceptual framework. In Proceedings of DRS 2014 (pp. 967–979). Retrieved from http://www.drs2014.org/media/745827/drs14_proceedings.pdf

Sanders, E. B. (2002). From User-Centered to Participatory Design Approaches Sanders. In J.Frascara (Ed.), *Design and the Social Sciences*.(pp. 1–8) London, Taylor & Francis. ISBN 0-415-27376-5

Sanders, E. B., Ave, O. P., Brandt, E., & Binder, T. (2010). A Framework for Organizing the Tools and Techniques of Participatory Design. In PDC '10 Proceedings of the Eleventh Anniversary Conference on Participatory Design 2010. Sydney, Australia: ACM New York, NY, USA. doi:978-1-4503-0131-2

Sanders, E., & Stappers, P. J. (2008). Co-creation and the new landscapes of design. *CoDesign*, *4*(1), 5–18. doi:10.1080/15710880701875068

Sankar, A., Nevedal, A., Neufeld, S., Berry, R., & Luborsky, M. (2011). What do we know about older adults and HIV? A review of social and behavioral literature. *AIDS Care, 23*(10), 1187–207. doi:10.1080/09540121.2011.564115

Schön, D. A. (1992). Designing as reflective conversation with the materials of a design situation. *Research in Engineering Design*, *3*(3), 131–147. doi:10.1007/BF01580516

Schulz, T., & Fuglerud, K. S. (2012). Creating Personas with Disabilities. In K. Miesenberger, A. Karshmer, P. Penaz, & W. Zagler (Eds.), *Computers Helping People with Special Needs, 13th International Conference, ICCHP 2012 Proceedings Part II* (pp. 145–152). Linz, Austria: Springer Verlag, Berlin Heidelberg. doi:10.1007/978-3-642-31534-3_22

Segalowitz, M., & Brereton, M. (2009). An examination of the knowledge barriers in Participatory Design and the prospects for embedded research. In *OzCHI '09 Proceedings of the 21st Annual Conference of the Australian Computer-Human Interactin Special Interest Group.* (pp. 337–340) ACM New York, NY, USA. doi:10.1145/1738826.1738890

Shedroff, N. (2001). Experience Design (1st ed.). Thousand Oaks: New Riders Publishing. ISBN 0735710783

Shively, M., Smith, T. L., Bormann, J., & Gifford, A. L. (2002). Evaluating Self-Efficacy for HIV Disease Management Skills. *AIDS and Behavior, 6*(4), 371–379. doi:1090-7165/1200-0371/0

Sieckenius, C., Souza, D., & Preece, J. (2004). A framework for analyzing and understanding online communities. *Interacting with Computers, 16*, 579–610. doi:10.1016/j.intcom.2003.12.006

Simonsen, J., Robertson, T., (2012) *Routledge International Handbook of Participatory Design*. Taylor and Francis, Hoboken, e-book, ISBN 978-0-203-10854-3

Sinha, R. (2003). Persona development for information-rich domains. In *CHI '03 Extended Abstracts on Human Factors in Computing Systems (CHI EA '03)* (pp. 830–831). New York, NY: ACM. doi:10.1145/765891.766017

Slater, L. Z., Moneyham, L., Vance, D. E., Raper, J. L., Mugavero, M. J., & Childs, G. (2012). Support, Stigma, Health, Coping, and Quality of Life in Older Gay Men With HIV. *The Journal of the Association of Nurses in AIDS Care : JANAC 24*(1),1–12. doi:10.1016/j.jana.2012.02.006

Slavin, S. (2012) Results from the stigma audit: A survey on HIV stigma in Australia [online]. *HIV Australia, 10*(1), 27-28. ISSN: 1446-0319. Retrieved from http://search.informit.com.au/documentSummary;dn=642100431762582;res=IELHEA

Spool, J. M. (2012, May 16). From Critique, A Language Emerges. User Interface Engineering: Brain Sparks. [Web log post] Retrieved from http://www.uie.com/brainsparks/2012/05/16/from-critique-a-language-emerges/

Stolterman, E. (2008). The Nature of Design Practice and Implications for Interaction Design Research. *International Journal of Design*, *2*(1), 55–66. Retrieved from http://www.ijdesign.org/ojs/index.php/IJDesign/article/view/240/148

Sutcliffe, A. G. (2010). Designing for User Engagement. In J. M. Carroll & E. M. Frymoyer (Eds.), Synthesis Lectures on Human-Centered Informatics #5 (p. 55). Morgan & Claypool Publishers. doi:10.2200/S00210ED1V01Y200910HCI005

Sutcliffe, A. G., Gonzalez, V., Binder, J., & Nevarez, G. (2011). Social Mediating Technologies: Social Affordances and Functionalities. *International Journal of Human-Computer Interaction, 27*(11), 1037–1065. doi:10.1080/10447318.2011.555318

Sutcliffe, A., Thew, S., De Bruijn, O., Buchan, I., Jarvis, P., McNaught, J., & Procter, R. (2010). User engagement by User-Centred Design in e-Health. Philosophical Transactions. Series A, Mathematical, Physical, and Engineering Sciences, 368(1926), 4209–24. doi:10.1098/rsta.2010.0141

Swann, C. (2002) Action Research and the Practice of Design *Design Issues.* 2002 (p. 49–61) MIT Press Journals. doi: 10.1162/07479360252756287

Tsianakas, V., Robert, G., Maben, J., Richardson, A., Dale, C., Griffin, M., & Wiseman, T. (2012). Implementing patient-centred cancer care: using experience-based co-design to improve patient experience in breast and lung cancer services. *Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer*, *20*(11), 2639–47. doi:10.1007/s00520-012-1470-3

Van der Linden, J., Waights, V., Rogers, Y., & Taylor, C. (2012). A blended design approach for pervasive healthcare: bringing together users, experts and technology. *Health Informatics Journal*, *18*(3), 212–8. doi:10.1177/1460458212442934

Van Velsen, L., Wentzel, J., & Van Gemert-Pijnen, J. E. (2013). Designing eHealth that matters via a multidisciplinary requirements development approach. *JMIR Research Protocols,* 2(1), e21. doi:10.2196/resprot.2547 PMID:23796508

Vance, D. E., Moneyham, L., Fordham, P., & Struzick, T. C. (2008). A model of suicidal ideation in adults aging with HIV. *The Journal of the Association of Nurses in AIDS Care : JANAC, 19*(5), 375–84. doi:10.1016/j.jana.2008.04.011

Veinot, T. C. (2009). Interactive Acquisition and Sharing : Understanding the Dynamics of HIV / AIDS Information Networks. *Journal of the American Society for Information Science and Technology, 60(*July), 2313–2332. doi:10.1002/asi.21151

Veinot, T. C., Campbell, T. R., Kruger, D. J., & Grodzinski, A. (2013). A question of trust: user-centered design requirements for an informatics intervention to promote the sexual health of African-American youth. Jourrnal of the American Medical Information Association, 20(4), 758–65. doi:10.1136/amiajnl-2012-001361

Velsen, L. v., Gemert-Pijnen, L. v., Nijland, N., Beaujean, D. v., & Steenbergen, J. v. (2012). Personas: The linking pin in holistic design for ehealth, c. In *Proceedings of the Fourth International Conference on eHealth, Telemedicine, and Social Medicine (eTELEMED 2012)* (pp. 128–133). ISBN: 978-1-61208-179-3

Vines, J., Clarke, R., Wright, P., Mccarthy, J., & Olivier, P. (2013). Configuring Participation : On How We Involve People In Design Republic of Ireland. In CHI, 2013 (pp. 429–438). Paris: ACM New York, NY, USA. doi:978-1-4503-1899-0

Visser, F. S., Stappers, P. J., van der Lugt, R., & Sanders, E. B.-N. (2005). Contextmapping: experiences from practice. CoDesign, 1(2), 119–149. doi:10.1080/15710880500135987

Wang, Y., & Fesenmaier, D. R. (2003). Assessing Motivation of Contribution in Online Communities An Empirical Investigation of an Online Travel Community. *Electronic Markets, 13*, 33–45. doi:10.1080/1019678032000052934

Wärnestål, P., Svedberg, P., & Nygren, J. (2014). Co-constructing child personas for health - Promoting services with vulnerable children. In *Proceedings of the CHI 2014*, April 26 - May 01, Toronto, ON, Canada. ACM. . doi:10.1145/2556288.2557115

Weng, C., McDonald, D. W., Sparks, D., McCoy, J., & Gennari, J. H. (2007). Participatory design of a collaborative clinical trial protocol writing system. International Journal of Medical Informatics, 76 Suppl 1, S245–51. doi:10.1016/j.ijmedinf.2006.05.035

Wenger, E. (1998). *Communities of practice: learning, meaning and identity* (1st ed., p. 318). Cambridge: Cambridge University Press. ISBN 978-0-521-66363-2

Wilson, T. D. (1999). Models in Information Behaviour Research. *The Journal of Documentation, 55*(3), 249–270. Retrieved from http://ptarpp2.uitm.edu.my/silibus/model.pdf

Winschiers-theophilus, H., Chivuno-kuria, S., Bidwell, N. J., Box, P. O., & Blake, E. (2010). Being Participated - A Community Approach. In PDC '10 Proceedings of the Eleventh Anniversary Conference on Participatory Design 2010. Sydney, Australia. doi:978-1-4503-0131-2/10/0011

Wöckl, B., Yildizoglu, U., Buber, I., Aparicio, B., Ernst, D., & Tscheligi, M. (2012). Basic senior personas: A representative design tool covering the spectrum of European older adults. In *Proceedings of the ASSETS'12*, October 22-24, Boulder, CO (pp.25–32). ACM doi:10.1145/2384916.2384922

Woelfer, J., & Hendry, D. (2012). Homeless young people on social network sites. *Proceedings of the 2012 ACM Annual Conference on Human Factors in Computing Systems - CHI '12,* 2825. doi:10.1145/2207676.2208686

Wolstenholme, D., Cobb, M., Wright, P., Bowen, S., Dearden, A., Binder, T., & Brandt, E. (2010). Participatory Design and the " Health and Social care Institution": An Interactive workshop at the 2010 PDC Conference. In PDC '10 Proceedings of the Eleventh Anniversary Conference on Participatory Design 2010 (pp. 275–276). Sydney, Australia: ACM New York, NY, USA. doi:10.1145/1900441.1900505

Wright, P., & McCarthy, J. (2008). Empathy and experience in HCI. In *Proceeding of the Twenty-Sixth Annual CHI Conference on Human Factors in Computing Systems - CHI '08*, 637. doi:10.1145/1357054.1357156

Wright, P., & McCarthy, J. (2010). *Experience-Centered Design: Designers, Users, and Communities in Dialogue. Synthesis Lectures on Human-Centered Informatics* (Vol. 3, pp. 1–123). doi:10.2200/S00229ED1V01Y201003HCI009

Wright, P., Wallace, J., & McCarthy, J. (2008). Aesthetics and experience-centered design. *ACM Transactions on Computer-Human Interaction*, *15*(4), 1–21. doi:10.1145/1460355.1460360

Appendices

Appendix A

Assumptions mapping document for reflection-on-practice. See following pages.

30 April 2013

HEALTHMAP DESIGN CONTEXT

How did we navigate a path through the context?

What was the given?

What processes led to unearthing these assumptions?....How did the realisations dawn? … (identifying gaps in knowledge, eg GP care for PLHIV)

A community of practice exists around PLHIV > designers needed to plug into these tacit understandings…

How were assumptions challenged?

What are the KEY assumptions? – what can be learned by examining these?

- Limited time for Design Research, fieldwork not feasible
- Need to listen to PLHIV interviews, see what we can get
- Design will need long-term sustainability and preferably be scalable across the HC system.

Context	Assumptions	Tests
Who are PLHIV? • 80% gay male. • 39% smokers. • Most PLHIV live in major metropolitan areas. PLHIV living in regional areas often access HIV treatment in large cities. • Virtually all PLHIV have a routine scheduled blood test and Dr consultation to discuss the results (3-4/year) • Many 50+ PLHIV have had the same HIV treatment provider for 10-25 years • Many 50+ PLHIV trust their HIV Dr deeply and discuss questions with them • PLHIV are concerned about: empowerment and autonomy, age-specific services, frank lifestyle advice, better treatment and research, human rights (*results of concept mapping workshops* conducted in 2010) • 50+ PLHIV often lived through acute AIDS epidemic. • 50+ PLHIV can be very familiar with sources of reliable HIV information and are able to discern high quality from poor quality health advice. • 50+ PLHIV often experienced loss of close friends and partners. • 50+ PLHIV have often experienced episodes of severe illness and long hospitalisation. • 50+ PLHIV have often lost their careers, savings and assets • 50+ PLHIV have often been exposed to drug use. • 50+ PLHIV can be long-diagnosed or recently diagnosed. • Most PLHIV have experienced discrimination, often when accessing healthcare and at work. • Many PLHIV have health-related concerns that they don't discuss with any healthcare provider. • For 50+ gay PLHIV there is associated discrimination around ageing.	• HM will have to engage male users. • The routine scheduled Dr consultation cannot be left-out of HM • HM will have to be as 'stigma free' as possible • HM will have to be 100% medically reliable > limited and vetted presence of alternative therapies • HM will need to support agency and self-efficacy for PLHIV. • HM will need to design for physical and psycho-social barriers to exercise	

• Most 50+ PLHIV have HIV controlled and stable through treatment. • Most 50+ PLHIV experience co-morbidities. • Most 50+ PLHIV experience some form of chronic pain or impairment. • Most 50+ PLHIV have experienced treatment side effects. • Most 50+ PLHIV have had some interaction with HIV support organisations. • Many 50+ PLHIV have a shrinking or very small network of social contacts (some have none). • Many 50+ PLHIV have had negative experiences in online social interactions. • PLHIVs want a 'one stop shop' for Health and Wellbeing advice and support.		
Role of RCT 1. The effect of interactive self-care plans and self-management support on CVD risk and other chronic condition outcomes in PLHIV. 2.Evaluate patient and health care provider experiences and acceptability of interactive selfcare plans and self-management support. 3. Evaluate intervention cost-effectiveness and effect on health service utilisation Primary Design Goal for HealthMap is to implement the intervention and satisfy the outcomes of the RCT. REQUIREMENTS 1. Evaluation of CVD risk – has it been reduced? a. Cholesterol levels b. Blood Pressure c. Smoking 2. Evaluation against secondary outcomes – have they been improved? a. Mental health b. Wellbeing c. Self-efficacy	1. Most effective intervention for Chol and BP is medication > HM needs to increase treatment uptake > need to design path to increased treatment 2. Smoking has similarly high impact on CVD risk > HM needs to target Smoking Cessation 3. Most CVD risk response is seen in the 50+ population > in order to demonstrate maximum effectiveness HM needs to target the 50+	Do we need to reinvent the wheel and have a bespoke HM smoking cessation component? Can we plug into, direct users to, existing programs? • Qual Data re: SmCess experiences • Literature review of SmCess programs • Design Team visit to Quit Victoria • Designer meeting with existing SmCess designer 4. Secondary outcomes will need to be demonstrated (i.e. measureable) 5. Secondary outcomes will need formal evaluation 6. Secondary outcomes will need to demonstrate formal theoretical basis 7. What are the known issues around CDSM as they relate to mental health, wellbeing, self-efficacy? • Qual Data regarding these issues • CDSM program meetings with HM Team ○ Arthritis, Diabetes, Medibank Private, CDSM platform for GPs (CDSMnet) Literature Review
• **Role of Healthcare System**	1. Existing HIV treatment provider too important not to include in HM	1. CDSM program meetings with HM Team

30 April 2013

- CONTEXT
- HIV treatment provider often long-standing relationship with 50+ PLHIV.
  - (safe to assume a level of trust – Practice Nurses report disclosures that are not shared with Drs)
- 50% of PLHIV get HIV treatment from hospital-based/sexual health clinic based providers.
- 50% from specialist HIV (S100) GPs.
- PLHIV attend HIV blood test results consultations 3-4/year.
- PLHIV often use hospital pharmacies for access to free/cheap treatment drugs.
- Most HIV treatment providers also address sexual health issues and co-morbidity issues.
- Most hospital/ SH Clinic-based Providers would like PLHIV to have extra GP care.
- Many PLHIV use other healthcare providers for non-HIV related issues.
- Many clinics employ specialist Practice Nurses to address wellbeing, lifestyle and adherence issues.
- Communication between different Providers is problematic, an endemic problem for the HC System as a whole.
- Many providers are frustrated by broken communication and spend time chasing up communication.
- HIV management is shifting from a primary care model to a chronic disease care model.
- GPs receive extra Medicare funding for producing a Chronic Disease Self Management Plan for patients diagnosed with a Chronic Condition. This funding can be accessed every 3 months, though the bulk of money available is for the 12 monthly Plan.
- The healthcare system has often been a source of discrimination and disempowerment for PLHIV.
- All collected data is highly sensitive with medical record status.
- Data security top priority = deal breaker
- GPs very sensitive to interoperability issues.
- Providers (especially GPs) very sensitive to impact on consultation time
- Must be compatible with Clinic / Hospital IT systems
- Provider data entry NOT acceptable
- Design Research needs Ethics Approval
  - Medical Ethics Boards not familiar with Design jargon or practices (e.g. 'Users' = injecting drug users)
- Providers educate patients through a variety of methods:

design

2. Because stigma and the threat of discrimination are highly significant for PLHIV HM needs to be a specific HIV+ 'friendly' service, for the most part plugging into existing non-HIV CDSM programs is not appropriate.
3. Being 'HIV+ friendly' does not mean being explicitly an HIV+ service (needs discretion, sensitivity)
4. It cannot be assumed that all healthcare providers know a patient's HIV status.
5. Providers see communication problems as a major barrier to holistic care (and therefore to Chronic Disease management). Therefore designing to support healthcare communication could be a **hook**.
6. Designing to produce a Chronic Disease Management Plan could be a **hook**.
7. We need to either reduce GP consultation time (unlikely) or add enough value to make using HM worth their while.
8. GPs value:
   a. improved communication,
   b. improved time management,
   c. improved patient engagement.
9. Need to get a clearer picture of how wellbeing and lifestyle needs can be successfully incorporated into a Healthcare context.
10. Need to investigate Health Coaches. (outcome from CDSM program meetings)
11. As early as possible need to 'map' Design activities and prepare Ethics applications. Make these as wide as possible. Try not to use too much Design jargon, but make sure include descriptions of possible activities.
12. An automated referral service could be a hook for GPs and SH Clinic Providers

   a. Arthritis, Diabetes, Medibank Private, CDSM platform for GPs (CDSMnet)
2. Interviews with GPs
3. Interviews with hospital-based providers
4. Interviews with Practice Nurses
5. Wireframe concept critiques with GPs
6. Wireframe concept critiques with Hospital-based providers
7. Technology survey re: accessing health information

○ In-consultation websites ○ Mobile phone apps ○ Health promotion leaflets ○ Recommended website addresses • HIV Providers can often need to refer to specialists and allied health providers • SH Clinic Practice Nurses often maintain a database of recommended allied healthcare providers		
IT Systems Development in HealthCare • Security (risk management) is key • Interoperability is key • For HM real time responses are key	1. This is an enterprise IT system 2. For any Provider-side interactions interoperability is KEY 3. Needs to 'talk' to Hospital / Clinic IT systems (EMR) + Practice Management 4. Needs to 'talk' to GP Practice systems (EMR) + Practice Management 5. This has to be mobile compatible 6. Can't store data on mobile devices 7. Needs to write to EMR, how will/can it extract?	
Behaviour Change models and practices		
Ubiquitous Technology Proliferation of Health Apps. Access to online health information. Proliferation of Social Media.	1. HM will need to be a mobile platform 2. Social media could be a tool for social isolation.	1. Survey PLHIV for technology use
	3.	2.

Appendix B

Executive summary of unpublished report from Liz Crock, Royal District Nursing Service HIV program. Cited p.138. See following pages.

‘They make me feel worthy’

‘RDNS was there for me when no family was’

‘I can talk about things I cannot talk with family or friends’

‘When I finish tablets, they come. If I am sick, they come’

‘ "invaluable" emotional support, especially for those who live alone, living longer’.

‘They helped me when I was homeless’

Project Team: Liz Crock, Nalla Burk,
Judy Frecker, Oscar Morata, John Hall

The Royal District Nursing Service HIV Program in a changing epidemic: an action evaluation

Final report

Elizabeth Crock 17th September 2013

Disclaimer

The work in this project was undertaken in partial fulfilment of the requirements of The University of Melbourne for the degree of Master of Public Health. The views expressed are those of the author and may not reflect the views of The University of Melbourne, School of Population Health or of the Royal District Nursing Service Limited.

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Acronyms & abbreviations

Acquired Immune Deficiency Syndrome	AIDS
Antiretroviral therapy	ART
Clinical Nurse Consultant	CNC
Gay, Lesbian, Bisexual, Transgender, Intersex, Queer	GLBTIQ or LGBTI
Human Immunodeficiency Virus	HIV
Men who have Sex with Men	MSM
RDNS Homeless Person’s Program	HPP
Royal District Nursing Service	RDNS
Royal District Nursing Service HIV Team/Program	HIV Team/HIV Program
Victorian AIDS Council/Gay Men’s Health Centre	VAC

EXECUTIVE SUMMARY

Background

The HIV Program at Royal District Nursing Service (RDNS) provides home– and community–based nursing care, support, education, counselling and health promotion to People Living with HIV (PLHIV) in Melbourne, Victoria[1]. Whilst most PLHIV in Australia are living well, many RDNS HIV clients face poor health outcomes, complex social problems, stigma and discrimination, and experience barriers to access to services, despite the availability of effective treatments. Furthermore, emerging issues including co–morbidities, 'premature' ageing and changing demographics in PLHIV pose challenges for community–based nurses in maintaining skills and knowledge, especially in a 'low prevalence' HIV epidemic. Evaluation of the RDNS HIV Program was critical to inform its development.

Aim

The aim of this project was to evaluate the RDNS HIV Program in relation to HIV clients' current and projected needs, to develop and improve the program and plan for future service provision. Specifically, it aimed to identify and describe HIV clients' needs, considering: the current model of care, the Australian HIV epidemic dynamics and service use. Second, it examined workforce development needs through evaluating district nurses' educational preparation regarding HIV (including issues around ageing, co–morbidities, cultural and diversity competence, ethics and law). Third, it examined HIV Program data in view of the Program's human resources, sustainability and responsiveness to changing needs.

Methodology

This was a formative evaluation based on action research principles. A mixed methods approach was taken, utilising quantitative data from 10 years of RDNS HIV Program reports, 86 HIV client and 372 RDNS staff questionnaires, and qualitative data from 15 key informant interviews and the surveys. Surveys were conducted over a 6 –week period in March–April 2013. Data was entered into Survey Monkey® and analysed with its built–in tools and through Excel©. Qualitative data was thematically analysed.

KEY FINDINGS

Client profile and needs – HIV Program Data

Client demographics

HIV clients receiving care from RDNS are a very diverse group, and have a range of co–morbidities that render their care in the community complex. Findings of this evaluation suggest that clients of the RDNS HIV Program are, on average, 10 years older than PLHIV generally in Australia. There are increasing numbers of women and people from refugee backgrounds, along with a significant proportion of long–term survivors. Many experience mental health problems and cognitive impairment and have substantial needs for HIV nursing expertise and community support.

Human resource use

HIV–related human resource use (nursing hours) has increased markedly over the past 10 years, peaking in 2009. Additional HIV nursing roles were implemented in 2003 at two high case load sites which have increased the Program's capacity. Several sites have high case–loads with inequitable HIV specialist resource allocation.

Evidence of increasing demand on human resources, and subsequent greater educational needs of staff, is supported by the literature, HIV Program data, client and staff surveys, qualitative data from interviews with key informants and staff comments.

Client survey

Service description

A diverse and representative sample of 86 clients was achieved, including nearly 40% from culturally and linguistically diverse backgrounds and over 8% indigenous clients.

The HIV Program provides a holistic service targeted to individual needs. The program broadly encompasses care coordination, medication management, psychosocial support, health promotion, health education and mental health support. Clients' comments added richness to the Program description:

Practical support

> *'Personal care attendant visits me weekly to help me arrange my clothing, paperwork. I am totally blind' (*65 year old gay man, long term survivor).

> *'It is good because helped me get better and kept explaining things when I didn't remember, and help me remember my appointments, when I didn't understand letters (*32 year old Sudanese woman).

Moral support

> *'Make me feel worthy. All you nurses, doesn't matter who, have made me feel worthy, it's true' (*48 year old gay man, long term survivor).
>
> *'I can talk about things I cannot talk with family or friends'.*

Information, health education

> *'Help me understand my health problems. Talk through things'.*
>
> *'She made information about my illness easier to understand'.*

Client satisfaction

Client satisfaction was evaluated in the domains of communication and accessibility, and quality of care (knowledge and skills, continuity of care, support, ethical practice, frequency and duration of visits, responsiveness and reliability, and cultural competence). Clients were also asked what they valued most about the service.

Clients expressed a high degree of satisfaction with the service. The model of care provided by the HIV Program is highly valued by clients and other HIV sector service providers:

> *'Of all the support services, RDNS is the most useful and dedicated and does the most useful work'* (HIV+ heterosexual man).
>
> *'Empathy, compassion and personalization – this is not a "one–size–fits–all" approach and I really appreciate that'.*

Accessibility and communication

Client were mostly satisfied with accessibility to RDNS, agreeing that finding information about RDNS and making an appointment was easy, although fewer agreed that after hours support was easy to access.

100% said they could understand nurses' responses when they asked questions, one noting:

> *'Better than I can understand my doctors at times'.*

Visit duration and frequency

Most were satisfied that nurses visited for an appropriate length of time or as often as was required (98%). One commented *'not long enough'.*

Quality of care

Knowledge and skills

86% said RDNS nurses skills in HIV were of a high standard 'all the time'.

> *'My RDN (sic) is someone knowledgeable who I can talk to about multiple chronic illnesses (Nurse has more time than my HIV specialist). It's comforting to have a regular visit... Get advice re illness and treatment. Never felt judged by RDN'.*
>
> *'Some nurses do not seem to know as much about HIV but they are still good'.*

Continuity of care

Clients agreed that they 'mostly' received care from staff who were known to them (continuity of care).

> *'They explain everything I need to do. They know me well and I know them well. I have confidence'.*

Ethics

Ethical principles, values and practices such as trust, commitment to confidentiality, respect, and advocacy within health services are very important to HIV clients. Nearly all said nurses were sensitive to their situation and respected their confidentiality.

> *'[They] don't judge me, everyone else judges me'* (49 year old gay man, long term survivor).
>
> *'Treat me and my husband with respect'* (53 year old woman, newly diagnosed).
>
> *'Felt confident that confidentiality would be maintained'.*

Cultural competence/sensitivity

Cultural competence or cultural safety in the HIV sector is essential for the care of people from culturally and linguistically diverse backgrounds as well as GLBTI.

Clients reported getting services in the language they wanted (98%) and 100% of those for whom this was relevant said they felt nurses 'respected their culture'. Two commented that they did not want an interpreter. Two said:

> *'I would like services in Italian'.*
>
> *'Respect my culture – they help me a lot'.*

98% said nurses were accepting of their life and health care choices.

Need and expectations for support

82% of respondents said the 'care provided meets their needs' all the time, and 84% said 'care meets their expectations' all the time, indicating high congruence between what clients think they need and what they expect of the service. Many commented on the supportive nature of nursing visits:

> *'I know I need input. I recognise I am not self–sufficient. I have problems procrastinating and RDNS helps me with my mental blocks'* (Gay man, long term survivor).
>
> *'My wife and I are on our own with near no support. Each visit with our nurse was like a friend or family coming into our home. This was a huge support for my wife'* (57 year old heterosexual man, newly diagnosed).

Responsiveness and reliability, complaints

A majority were satisfied with RDNS' responsiveness:

> *'They come to see me when I need it, even when I have been in crisis accommodation'* (young male, homeless, newly diagnosed).
>
> *'Because of this, in September 2011, the nurse saved my life'* (52 year old gay man, long term survivor).
>
> *'Value is exceptional. Have not experienced such a great level of support. Always on hand. Trust'.*
>
> *'When I finish tablets, they come. If I am sick, they come'* (41 year old Ethiopian woman, refugee, newly diagnosed).

Few felt if they made a complaint to RDNS, it would be ignored.

What clients value most

Clients spoke of many elements of care that they valued highly. They valued the relationship they developed with nurses, confidence that their privacy and confidentiality would be maintained, regularity of visits, and being able to talk about issues that they could not discuss with others. The importance of RDNS helping them stay in their own home was also mentioned:

> *'African people, they talk [about people in their community with HIV], me not like talking to them [about HIV]. Me happy [with RDNS nurses]. I not like African people [knowing about her HIV]' (*41 year old African woman).
>
> *'I most value the sensitive nature in which they thoughtfully manage my needs'.*
>
> *'The relationship developed over short period of time – very comfortable with nurse'.*
>
> *'The nurses make me feel at ease and more acepting (sic) of the condition, easy to talk and understand'.*
>
> *'They are there for you. They help you mentally and emotionally'.*
> *'RDNS allows me to stay at home, which makes me very happy'.*

Future needs

Clients’ views on their needs in the next 5 to 10 years

Clients expressed most concern about HIV specialist nursing service provision being available to them, ‘friends dying’; ‘dying of AIDS’, ‘being forced to leave my home’; ‘HIV– and non HIV–related illnesses’, ‘pain’, ‘having to go to a nursing home’ and ‘finances’. Many were concerned about ‘being able to get the health care I need’. Anxiety and sadness were concerns for many:

> *‘Sadness has always been there’ (*49 year old gay man, long term survivor).
>
> *‘My youth is gone. I worry about companionship and being with services and people who are non–judgmental as I age’* (76 year old gay man).

Over a third hoped to return to work/study or independence.

> *‘I would like to be a contributing member of my society/community. I would need help and assistance in all areas. I am lonely and desperate, how can I get more help?’* (53 year old Asian man, newly diagnosed).

Clients’ future priorities for care from RDNS included assistance to stay in their own homes, staying out of hospital, understanding their health conditions, and advice on care they might need. Preparing an Advance Care Plan was rated important by many. Few saw becoming independent of RDNS as important, seeing the care as a component of helping them maximise their independence:

> *‘Helping me achieve independence for as long as possible’.*

This comment suggests that ongoing involvement of RDNS (and other services) does not necessarily represent a loss of independence for some, but a way to achieve longer–lasting independence

Key informants' views

Interviews with HIV sector workers and HIV specialists (nursing and medical) identified ageing, co–morbidities, increasing diversity more (women and children, refugees), public health issues related to drug use and unsafe behaviours, increasing numbers of newly diagnosed people, the risk of a potential epidemic amongst injecting drug users, and social isolation as key issues for the future that would impact upon RDNS’ service.

> *‘We know that with premature ageing, either caused by the disease or by the drugs or by a combination thereof, we’re going to see more*

> *people requiring increased community and then residential or high level care'* (HIV Specialist Nurse, external agency).
>
> *'[…] clients who have got schizophrenia, who have got HIV who are out in the community they are a public health risk because they are unable to negotiate or their delusional system won't allow them to negotiate safety…I think that we will do a lot more close liaison [with RDNS] and working with co–clients in that I am seeing a lot more disabilities, intellectual disabilities…' (*Senior Public Health Nurse).

Strengths

Key informants identified the HIV Team's role in advocacy, community development initiatives (such as a nutrition program), education role and high quality service response as key strengths of the HIV program.

Service gaps

The key informant interviews identified lack of continuity of care, inadequate HIV specialist nursing support, need for better care coordination across services, and the need for mental health expertise as 'occasional' gaps in the service.

> *'there's been a handful of people I've seen recently where I have thought, that they DO need ONE nurse at home, because of the types of problems they have, so I think there's a group that need the consistency […]I suspect that maybe you're not always resourced to do that' (*HIV Specialist Physician).

Mainstreaming

'Mainstreaming' was raised by key informants as a potential future concern. HIV sector workers, especially those who are HIV positive themselves, are wary about calls for mainstreaming:

> *'I actually choose services that are HIV savvy, I won't go outside of that' (*Peer support worker, HIV agency, HIV+ woman).
>
> *'It would bother me if it was mainstreamed [into RDNS] because you've got a whole bunch of people who aren't educated and you don't know what their response is going to be. If they're educated, we don't have that issue, we can go to one of you guys and it's all OK, we have that confidence in you and we don't have to speak up. If there's any discrimination that goes on (laughs) you guys DEAL with it. You bear the brunt of it FOR us'* (Peer support worker, HIV agency, HIV+ve woman).

Staff survey – Workforce development needs

Knowledge and skills

RDNS staff report significant knowledge deficits in all areas of HIV care, but especially those most pertinent to this client group – needs of specific populations/vulnerable groups (such as gay men, refugees), HIV prevention (post exposure prophylaxis), medical management (antiretrovirals, medication toxicities, co–morbidities), legal and ethical issues (‘right to know’ a diagnosis, privacy, disclosure, discrimination), mental health and psychosocial needs. Disturbingly, many report ambivalence about Standard Precautions, the foundation stone of safe clinical nursing practice in terms of infection prevention.

Attitudes

Staff are generally willing to provide care to PLHIV, though fewer are comfortable in doing so, most citing inadequate knowledge.

Limited exposure to HIV clients in their area, complexity of HIV clients’ issues, lack of knowledge, concern over clients’ mental health drug use or behaviours and inability to provide continuity of care were seen as potential concerns in caring for PLHIV.

A number of staff, principally managers, expressed lack of understanding of and support for the HIV Program, suggesting that having specialist staff ‘de–skills’ other staff, and that clients should be (or already are) treated ‘the same’ as all others, effectively ‘mainstreamed’ into RDNS.

> *‘Having an HIV Resource nurse takes opportunities away from primary nurses – they then become deskilled’.*
>
> *‘HIV clients should be seen and treated as every other client not discriminated or made to appear “special”’.*

There is incongruence between the views of field staff, most of whom report low levels of skills and knowledge yet are interested to learn more and partake in care of PLHIV, some managers suggesting that they have been ‘deskilled’ and that care should be ‘mainstreamed’, and key informants who describe PLHIV’s concerns about disclosure and poor treatment in health services. Field staff acknowledge the supportive role of the HIV Team and the need for expertise.

Key informants in the sector note that stigma and discrimination are still prevalent and it is this, in particular, that affects PLHIV’s access to and experiences within services:

> *‘…stigma, less so discrimination, but stigma, profoundly affects the lives of every single person living with HIV. There is no one I know with HIV who has not experienced some form of stigma that makes them feel bad, unworthy, ashamed and then of course all that stuff that that raises for them.[…] (*Senior Manager, HIV agency, HIV+ gay man).

Practice

A significant proportion of staff is concerned about contracting HIV in the workplace, even in 'no risk' situations. For example, 68 respondents (21.6%) were concerned about contracting HIV from 'drinking from a cup in a client's home'. Unease about whether pregnant staff should visit HIV clients was expressed. A significant number of staff, including managers, support the use of computer 'alerts' regarding HIV clients, justifying the practice in terms of infection prevention. Nearly 20% said they would 'use special measures with HIV clients that they would not use with other clients', and over 18% said they 'would use gloves during every aspect of client care (including history–taking)'.

> *'I would make alert HIV positive. This may not be required but I would err on the side of precaution with pregnancy'.*

A majority of staff (72%) said they felt they had a duty to disclose an HIV client's status to another nurse; 14% were unsure. 7% said they would disclose a client's HIV status to a council worker; 12% were unsure.

Many others commented simply that they use standard precautions at all times:

> *'It's not the clients we already know about, it's the unknown clients, universal precautions are there to protect all' (*DN Specialist).

Other comments indicate careful and nuanced thinking around this issue.

Stigma and discrimination

Some practices mentioned above amount to active discrimination (the use of 'alerts' regarding HIV status; excessive infection control precautions); others (such as generic intake policies and inflexible work practices) can result in indirect or passive discrimination if they pose a systematic barrier to access to some groups. Specific HIV Program practices, ('assertive outreach' approach, use of an unmarked car/no uniform to protect privacy, holistic model of care led by specialists) aiming to reduce barriers to access to care and promote quality care were not supported consistently. The Program itself is seen by some as unnecessary:

> *'The stigma associated with this disease is kept alive by assuming that a "special" team of nurses are required to look after these people. I do not believe we need a team for these people'* (Clinical Nurse Consultant).
>
> *'Cars & uniforms, I don't see where what people drive or wear as important, it needs to be promoted as "normal" to the client, if the clients have an issue can they access a clinic, LMO or pharmacist?* (Management role).

> *'[…] management feel they require too many resources to accommodate need'* (District Nurse Grade 2).

Such views, increasingly widespread across the organization, undermine the integrity of the HIV Program. Policies or practices that recognize and support HIV Program clients due to specific sensitivities related to the diagnosis and its psychosocial implications, are at risk of being dismantled or ignored because they are not understood and do not align with broader organizational practices.

Program development, service improvement

Many clients expressed the view that no change was needed to the service. Some made practical suggestions such as reminder calls before visits, and 'more resources'.

Key informants suggested that an HIV Program requires a supportive structure and flexibility to deal with HIV clients' specific needs including concerns about disclosure of their status, mental health and cognitive problems. Peer support and professional supervision for HIV Team staff was recommended. Mental health expertise was seen as essential for the HIV Team by one respondent.

Two HIV sector managers expressed views about the 'vulnerability' of the HIV Program, suggesting it be removed from RDNS and auspiced by a community–based organisation such as VAC who has its own medical and nursing services:

> *'My concern is that it's a vulnerable animal, an endangered species if you like. […] we've got this good working relationship with RDNS, it's a world first unique model of integrated care and I think it's not valued enough perhaps within RDNS itself. I think it needs to be front and centre' (*Senior Manager, HIV organisation).
>
> *'I think there would be merit if the RDNS HIV Consultancy Team was integrated into an HIV specific service such as VAC as its work is at risk of being diminished within RDNS bureaucracies or ultimately disappearing'* (Senior Manager, HIV organisation).

Nevertheless, these respondents also saw the future as requiring greater collaboration and partnerships between organisations.

Expansion of the service through Telehealth, especially for rural PLHIV, was suggested.

Sustainability

Gaps in the RDNS HIV Program service perceived by HIV sector workers related to lack of continuity of care and inadequate number of HIV–educated nurses. Sustainability problems are identified by HIV Program staff relating to reduction in resources dedicated to nursing education, workloads and cumbersome management structures.

To build capacity within the HIV Program and to allow for succession planning, HIV Team staff propose replacement of staff leave with appropriately trained staff ‘reliever(s)’. This would also help prevent loss to follow up of vulnerable clients who are difficult to engage with services and require specific expertise, for example, those with complex social or mental health problems and are newly diagnosed. It is this group who are most at risk of poor health outcomes that can also lead to public health risks.

Leadership and management

An efficient and effective management structure and dynamic leadership is essential to Program sustainability and development. In March, 2012, the HIV Team developed a discussion paper on the management of the HIV Team which outlined difficulties with its management structures – inconsistent lines of reporting, lack of support for a cohesive team approach affecting productivity and quality of care and a lack of resources tied to Program planning, growth and development [2].

Effective leadership structures in HIV care have been recognised as essential to strengthening social justice and human rights in all aspects of HIV response[3]. Good leadership structures help ensure the voices and needs of all affected (especially those most disenfranchised) are recognised and reflected – this helps protect the interests of vulnerable groups and promotes equitable distribution of services[3]. The development of a Senior Clinical Nurse Advisor (HIV) or Team Leader/Coordinator for the HIV Program is proposed to enable ongoing Program development, evaluation, seek funding opportunities and so on. Program development requires a long–term commitment from RDNS to its HIV Program.

Conclusions and Recommendations

This study provides evidence for the specific needs of RDNS HIV Program clients, and a detailed description of the role of the HIV Team in the care in the community. It provides a contribution to the literature regarding a cohort not previously described. Knowledge gaps and sustainability concerns have been identified within the agency that must be addressed to enable quality care and to plan for the future.

The role of HIV specialist nurses in the community is central to bridging the gaps between clinics, other specialist services and generic community services, especially in low HIV prevalence settings such as Australia[4]. They help facilitate transition from hospital to home and establish communication and networking between hospital and community teams. They work with family, carers and other community health workers for the benefit of PLHIV and their assessments in the home can identify issues affecting adherence, welfare and well–being that may not have been identified before[4]. They educate the community as well as other services about HIV and provide holistic care[4]. This project demonstrates that the RDNS cohort requires special attention, expertise and resources for the Program to have a sustainable workforce, develop and meet the needs of PLHIV into the future.

The HIV Program must grow to respond to emerging issues. Utilisation of this evaluation is enhanced through the articulation of practical and realistic recommendations.

Immediate and longer–term recommendations are made for HIV Program Support and staff education based on the findings. Organisation–wide professional development is recommended. Feasibility of expansion of the service into rural areas should be investigated.

The following recommendations are made for RDNS for the development of the HIV Program. These align with the priorities of the 6th National HIV Strategy[5] including emerging issues (ageing, co–morbidities) focusing on priority populations, models of care and workforce development, and the Victorian HIV Strategy[6].

HIV Program Evaluation Recommendations

Organisational	**Next 12 months**	**1–3 years**
Capacity building	1. Implement role of Senior Clinical Nurse Advisor (.5 EFT) to enable Program development and better resource utilisation (see Draft Position description in Appendix 9). 2. Adjust HIV Resource Nurse hours as detailed in footnote[1]. *Consider HIV Resource Nurses to cross site boundaries.* 3. Implement backfilling of HIV Team staff for any more than one week with ‘permanent reliever’ position - For succession–planning, skill development and to build capacity in engaging marginalised clients, reducing barriers to access. 4. Recognise and streamline relationship between HARP RDNS/HIV and RDNS HIV Program to facilitate seamless referral and integration of services, efficient resource use, documentation and accurate data collection for improved Program reporting and planning.	5. Review management of HIV Team with a view to reducing number of line managers to one. 6. Model HIV Program on Homeless Person’s Program and consider partnership with HPP to foster Program development, research, staff support, education, shared resources, capacity building. (e.g. outreach to high and low HIV case load GPs, co – locations at other services). 7. Reconsider funding of mental health nursing role within the HIV Team; support for mental health training for HIV Team staff. 8. Implement Professional supervision for HIV Team staff. *Consider expansion of RDNS HIV service into rural areas (with a view to Telehealth consultations with CNCs, local Resource nurses and clients).*
Workforce development	9. Reinstate RDNS HIV Program into staff orientation program. - HIV prevention information made explicit in the context of Standard Precautions and information provided on staff safety and pregnant staff visiting HIV clients to demystify misconceptions and fear.	10. RDNS participate in ‘Rainbow Tick’ campaign and ‘How2’[7, 8] through Gay and Lesbian Health Victoria to enhance cultural competency. *Consider reinstating dedicated HIV educator position or incorporate into Senior Clinical Nurse Advisor role.*

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1 Heidelberg – increase from 16 hours to 32 hours per week; Moreland – increase to 40 hours per week; Essendon – new position, 24 hours per week. Re–assess hours at Caulfield and Altona.

Policy and procedures	11. Policy review – recommit to relevant, specific HIV policies in consultation with HIV Team advice (intake, assessment and care plan, referral). • Promote across RDNS to foster recognition and understanding of the impact of stigma, fear and prejudice for those infected/affected by HIV to this day that results in barriers to access to services. 12. Review and provide education on RDNS policy on computer ‘alerts’ to prevent discrimination and further stigmatisation.	
Marketing and branding	13. Provide banner to be used at community events (including Rainbow Tick approval once achieved), to promote RDNS as HIV and GLBTIQ–friendly.	14. Improve marketing and profile of the RDNS HIV Program internally and externally, through dedicated webpage. • Review brochures at regular intervals with HIV Team
Partnership Strengthening	15. Review and recommit to Partnership Agreement with Victorian AIDS Council/Gay Men’s Health Centre HIV Services with HIV Team and identify and formalise other HIV sector Partnerships. 16. Invite representative of PLHIV organisation(s) to participate in RDNS consumer reference group.	

HIV Team	**Next 12 months**	**1–3 years**
Workforce development	1. Utilise evaluation data in reviewing internal and external education – in particular, for sessions on HIV and ageing, psychosocial issues, prevention, specific populations, legal and ethical issues, stigma and fear, health literacy, engagement and retention in HIV care. *Collaborate with Diversity Team, Quality Manager, Education department, Safety, Health and Environment.*	2. Implement regular educational 'road shows' to sites 3. Revise and update RDNS HIV Manual for RDNS staff – 'Caring in the Community' and carers' booklet, 'Positive Caring' to promote the HIV Program model of care and education role.
Policy and procedure	4. Policy review – recommit to relevant, specific HIV policies (intake, assessment and care plan, referral) (see also 11 above).	5. Develop HIV assessment tool and nursing care plan. 6. Revise HIV staff position descriptions utilising national competency standards to promote understanding and recognition of roles[9].
Model of care	7. Further develop HIV holistic model of care, document. 8. Presentations and promotion of model of care.	
Partnership Strengthening	9. Review and recommit to Partnership Agreement with Victorian AIDS Council/Gay Men's Health Centre HIV Services and identify and formalise other HIV sector Partnerships (see 15 above).	
Research and evaluation		10. Develop research and evaluation plan, conference presentations, publications (pending support of and implementation of Senior Clinical Nurse Advisor or similar role).

Appendix C

2015 revised draft of Paper 1

‘Pointy versus Soft’: Towards A Design Languae for Chronic Disease Self-Management in Healthcare - Reflections on the HIV HealthMap Study

‘Pointy versus Soft’: Towards A Design Language for Chronic Disease Self–Management in Healthcare – Reflections on the HIV HealthMap Study

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Abstract

Design practitioners on healthcare information technology projects often come from non-medical backgrounds and find healthcare an unfamiliar and complex context for design work. This can introduce barriers to collaboration, but also offer innovative solutions to healthcare challenges.

We report on the HealthMap Study to support people with HIV in self-management of cardiovascular disease risk. The HealthMap designers worked in a multi-disciplinary design team with HIV researchers. This paper introduces the HealthMap design metaphor of ‘Pointy versus Soft’: a helpful framing tool for capturing design relevant contextual features and to support design dialogue within healthcare.

The ‘Pointy versus Soft’ framework can be employed as a cross-disciplinary design lexicon for both generative and evaluative design practices. For HealthMap, the construction and application of ‘Pointy versus Soft provided i) a coherent design vernacular to support design practice, ii) a framework for cross-disciplinary dialogue bridging knowledge boundaries and building cross-disciplinary tacit design knowledge, iii) an evaluative tool that identified key contextual elements impacting on design and requiring early strategic attention.

‘Pointy versus Soft’ potentially supports healthcare design knowledge management and contributes to an emerging community of practice for healthcare design. We aim to contribute to a potential ‘community of practice’ of designers engaged in healthcare design projects.

Keywords

H5. Information interfaces and presentation; H5.3 Group and Organization Interfaces; Participatory Design; Collaboration; eHealth; Co-design; Knowledge Barriers; Chronic Disease Self-Management

1 Background

This case study describes implications for the entry of design practice into healthcare for chronic disease self-management (CDSM). It discusses the HealthMap Study, an Australian National Health and Medical Research Council funded information technology intervention. The aim of HealthMap is to reduce chronic disease risk factors for People living with HIV (PWHIV) by creating interactive self-management plans. The project is led by the Alfred Hospital / Monash University, Department of Infectious Diseases. It is evaluated in a cluster-randomized control trial (RCT) over two years, commencing 2015. Smoking is the highest risk factor for developing chronic disease with a prevalence of smoking of 42% among PWHIV (Heart Foundation, n.d).

A chronic disease management approach includes support for self-management, service coordination and integration. Thus information and communication systems will play a crucial role in chronic disease management (Internal document ID No. 1012459, HealthMap grant application).

1.1 The role of design practice in healthcare: co-design

Healthcare systems all over the world are littered with information technology programs that are under utilized, poorly integrated, or abandoned (Bate and Robert 2002; Mockford et al. 2012). As Kaplan and Salamone report, “Despite best practice research that identified success factors for health information technology projects, a majority, in some sense, still fail. Similar problems plague a variety of different kinds of applications, and have done so for many years.” (Kaplan and Harris-Salamone 2009, p.291)

The persistent challenges in implementing healthcare information technology have meant that health IT projects have looked beyond traditional engineering paradigms to a broader, multidisciplinary approach that includes design practice. In particular the role of co-design, where design methodologies are employed by multidisciplinary stakeholders (ideally including all system users, including patients), is seen as a key strategy for avoiding the errors of past technology design failure (Bate and Robert 2006; Gonzales and Riek 2013; Pickles, et al. 2008; Tsianakas et al. 2012). Co-design, (often facilitated by design practitioners) is a central tenet of a Participatory Design (PD) approach and how to conduct successful PD within a healthcare context is an ongoing research agenda for designers engaged on healthcare projects (Berryman et al. 2011; Jones 2013; Ross 2014; Sanders 2002; Sanders and Stappers 2008; Simonsen and Robertson 2012).

1.2 Healthcare: a complex context for design

At the same time the burden of increased chronic diseases means governments all over the world face rising healthcare system demands, with ageing populations and the spread of lifestyle influenced diseases. The User-Centred Healthcare Design (UCHD) project in the UK suggests that “new models of healthcare that re-define the institutional and social context of care are required if we are to meet the challenge of chronic illness.” UCHD describes designing for pervasive healthcare as “a focus on individuals, their experiences, practices and social relationships, in order to understand how these effect their self-management.” (Dearden et al. 2010, p.8)

As a context for design, health and healthcare have particularities that present complex problems encompassing the personal and intimate, the social, the physical and the institutional. It also inherently requires designing an experience across time and space. These complexities and sensitivities present a natural need for design that is human-centred, participatory and experience led. The value of design processes in healthcare innovation have been recognized for many years, with the British NHS development of the ‘Experience-Based Design’ toolkit a striking example of institutional adoption of design methodologies (Pickles et al. 2008; Dearden et al. 2010; Bate and Robert 2007; Bowen et al. 2010; NHS 2014; Julier 2013).

Despite the strong drivers towards experience-based and co-design practices, successful healthcare technology ecosystems success is often sporadic and significant gaps remain between desired outcomes and common experiences in developing healthcare technology (Pilemalm and Timpka 2008; Jones 2013; Mockford et al. 2012).

There is ongoing dialogue amongst design researchers/practitioners and healthcare providers that seeks to articulate healthcare as a design domain. They propose principles and practices to establish a body of understanding and expertise in developing successful health experiences and sustainable health supporting systems (Pickles et al. 2008; Berryman et al. 2011; Jones 2013; Ross 2014; Dearden et al. 2010; Bowen et al. 2010; Bowen et al. 2011; McHattie et al. 2014; Wright and McCarthy 2010). The work of the UK based ‘Lab4Living’, a multidisciplinary research centre combining art and design research with health and social care research, is one example of designers and health researchers exploring the relationship between design, health and wellbeing (Lab4Living 2015).

1.3 HealthMap : designing for chronic disease self-management

As a design project the HealthMap Study is placed exactly in this space. It involves a patient group with complex medical and psychosocial needs, who are ageing, who experience enormous stigma from a variety of sources and who are permanently engaged with the healthcare system. HealthMap’s potential is to support the day-to-day wellbeing of people living with chronic disease while facilitating a meaningful and efficiently delivered engagement with the healthcare system.

The following sections will introduce the HealthMap design phases over time, indicating the types of activities and artefacts generated within each phase (Figure 1), and then introduce the HealthMap design team members.

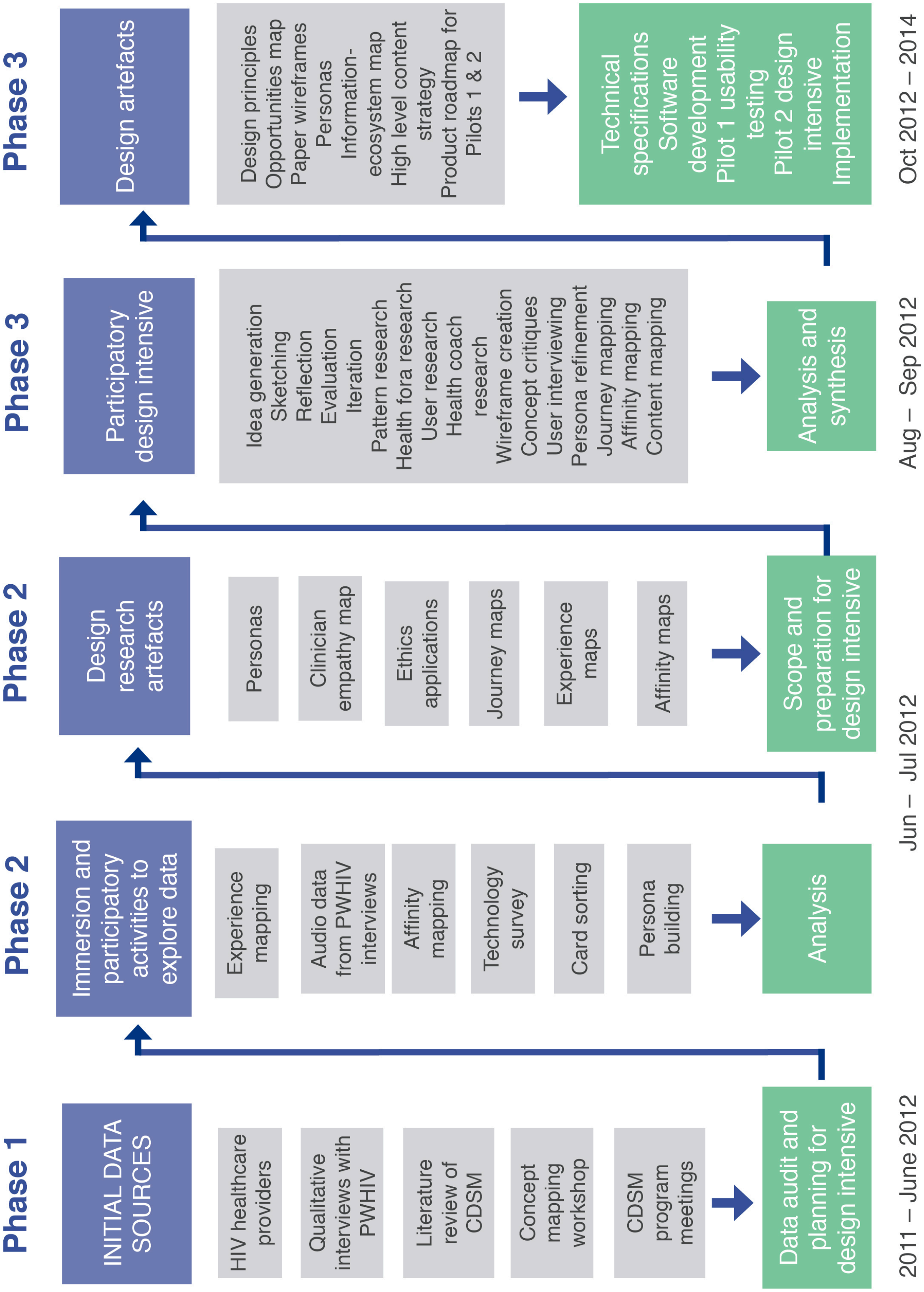

Figure 1 HealthMap design phases

1.4 HealthMap design team

Initially the HealthMap team comprised: a social researcher with many years experience in HIV research, a hospital-based HIV treatment provider / clinical researcher (who was the project lead) and an occupational therapy postgraduate researcher with special interest in HIV and chronic disease self-management. This domain expertise combined represents over 40 years of research and work with PWHIV. The research team consulted with Designer 1, who provided high-level design strategy advice but was not co-located with the team. Designer 1 is a design researcher specializing in Participatory Design and Interaction Design and was known to the clinical researcher. These team members conducted the activities in Phase 1 (see Figure 1). Designer 2 is a User Experience Design practitioner employed at the beginning of Phase 2. Her role was to collaborate with the HealthMap team to conduct design research, scoping exercises and project management in preparation for the 6-week design intensive in Phase 3 and to participate in ongoing design work.

Designer 3 is an Interaction Designer with over ten years experience designing for healthcare. HealthMap is his first HIV project. He works on HealthMap remotely, but was co-located for the Phases 3 and 4 design intensives.

In addition HealthMap has chief investigators and associate investigators who receive reports and make project decisions.

2 Objective

Given the challenges facing healthcare technology design, and the challenges facing institutional healthcare globally, the work in designing HealthMap using a collaborative, human-centred model, can demonstrate a design contribution to knowledge development and to building expertise for an emerging community of practice for healthcare service design.

By reflexively analysing the HealthMap co-design experiences we offer a case study to contribute transferable knowledge and actionable insights relevant to other design work for chronic disease self-management and potentially for wider healthcare service design.

2.1 Healthcare as a context for design

Managing chronic disease needs an integrated service interface between people's experiences of life, suffering and human relationships and the socio-technical system of healthcare. Jones calls for a new methodology of service design that can address these complex practices and institutional contexts (Jones 2013).

Following recommendations to describe contextual features that impact on healthcare design (Jones 2013; Greenhalgh et al. 2004), we describe some of the medical and institutional influences on the HealthMap design and suggest contextual generalities (landmarks) that might be common when designing for healthcare. We describe these landmarks to help build a body of knowledge and design framework for healthcare technology designers.

While these contextual landmarks might appear easily anticipated, it is still useful to have them articulated within design strategy. Their very ubiquity runs the risk that they are overlooked and taken for granted, rather than approached strategically from the earliest stages of a design project.

2.2 A vernacular design framework for healthcare – towards a healthcare design lexicon

In analysing the HealthMap contextual factors we employ the 'Pointy versus Soft' design framework developed by the multidisciplinary HealthMap team. This framework had several functions across the design lifecycle. We describe the evolution and the functions of the 'Pointy versus Soft' framework as an example in successful cross-disciplinary dialogue and design knowledge co-creation.

In order to support cross-disciplinary dialogue knowledge, barriers between diverse domains of expertise must be overcome (Carlile 2004; Segalowitz and Brereton 2009). Segalowitz and Brereton describe the negative impact of knowledge barriers between different domains of expertise on Participatory Design projects (Segalowitz and Brereton 2009). Design projects in healthcare contexts are particularly prone to knowledge barriers as the highly specialized nature of medical institutions and the contrasting approaches of traditional medicine (scientific) and traditional design (intuitive and creative) all have an impact on how design teams members make sense of design problems and how they envisage design solutions (Sanders and Stappers 2008; Bowen et al. 2011; Stolterman 2008). By analysing the creation of the ‘Pointy versus Soft’ framework within HealthMap we offer i) a framing tool for adoption in other healthcare design projects, and ii) a potential design ‘lexicon’ specific to an emerging field of healthcare design.

3 Methodology

3.1 Action Research

In analysing the HealthMap design processes we have taken a reflexive Action Research (AR) approach, employing critical reflection both during design work and as a retrospective, systematic ‘reflection-on-design’ (Bowen et al. 2014). We referred to collected design artefacts and project data (Bowen et al. 2014; Schon 1992). AR is an appropriate approach for collecting, exploring and analysing data for collaborative, problem-focused and practice-based design research questions (Koshy et al. 2011).

3.1.1 Action Research data

The main focus of the HealthMap design team was to create a working platform to deliver the NHMRC defined project requirements. The subsequent reflexive AR processes are grounded in the data collected during the technology project development and through reflexive analysis of design artefacts, workshop audio recordings and with reference to relevant literature. Tables 1 and 2 give an overview of the data used for the reflexive analysis:

Table.1 Action Research data from design phases 1 – 2

DESIGN ARTEFACT	DESIGN PHASES 1 – 2 DATA
Technology Survey of PWHIV	
	access to devices
	access to health information
	access to social media
	SMS use
	cardiovascular disease risk factors
Notes from meetings with existing technology-based CDSM programs	
	Diabetes
	Arthritis
	smoking cessation
	GP management plans
	health insurance clients
	affinity diagrams
Design workshop artefacts	
	PWHIV Experience Map
	HIV clinician empathy map
	collaborative persona-building workshop audio recordings
PWHIV qualitative data – semi- structured interview questions – recordings and transcripts	
	impact of HIV
	interactions with healthcare providers
	use of technology

Table 2 Action Research data from design phase 3

DESIGN ARTEFACT	**DESIGN PHASE 3 DATA**
Design workshop artefacts	
	patient personas collaborative idea generation workshop sketches collaborative idea generation workshop audio recordings collaborative brainstorming workshop sketches collaborative brainstorming workshop audio recordings content brainstorming workshop audio recordings content brainstorming workshop notes
PWHIV interviews	
	user interviews – concept critique audio recordings user interviews – concept critique notes
HIV treatment provider interviews	
	user interviews – concept critique audio recordings user interviews – concept critique notes
Health coach interviews	
	Health coach interview audio recordings Health coach interview notes
Paper-based artefacts	
	user journey maps user interface sketches health coach interviews
Digital artefacts	
	online health coaching research affinity diagram photos design pattern research static concept diagrams static wireframes

These data were reviewed with a view to identifying important project milestones and to identify patterns and themes.

3.2 Data analysis

Rapid and lean design techniques were used for data analysis, employing the same techniques employed for the HealthMap design processes (such as note-taking, sketching and affinity diagramming). A number of framing questions were used to guide the exploration and organization of data into themes and to identify significant factors influencing design. Examples of these questions are given below (Figures 2-3).

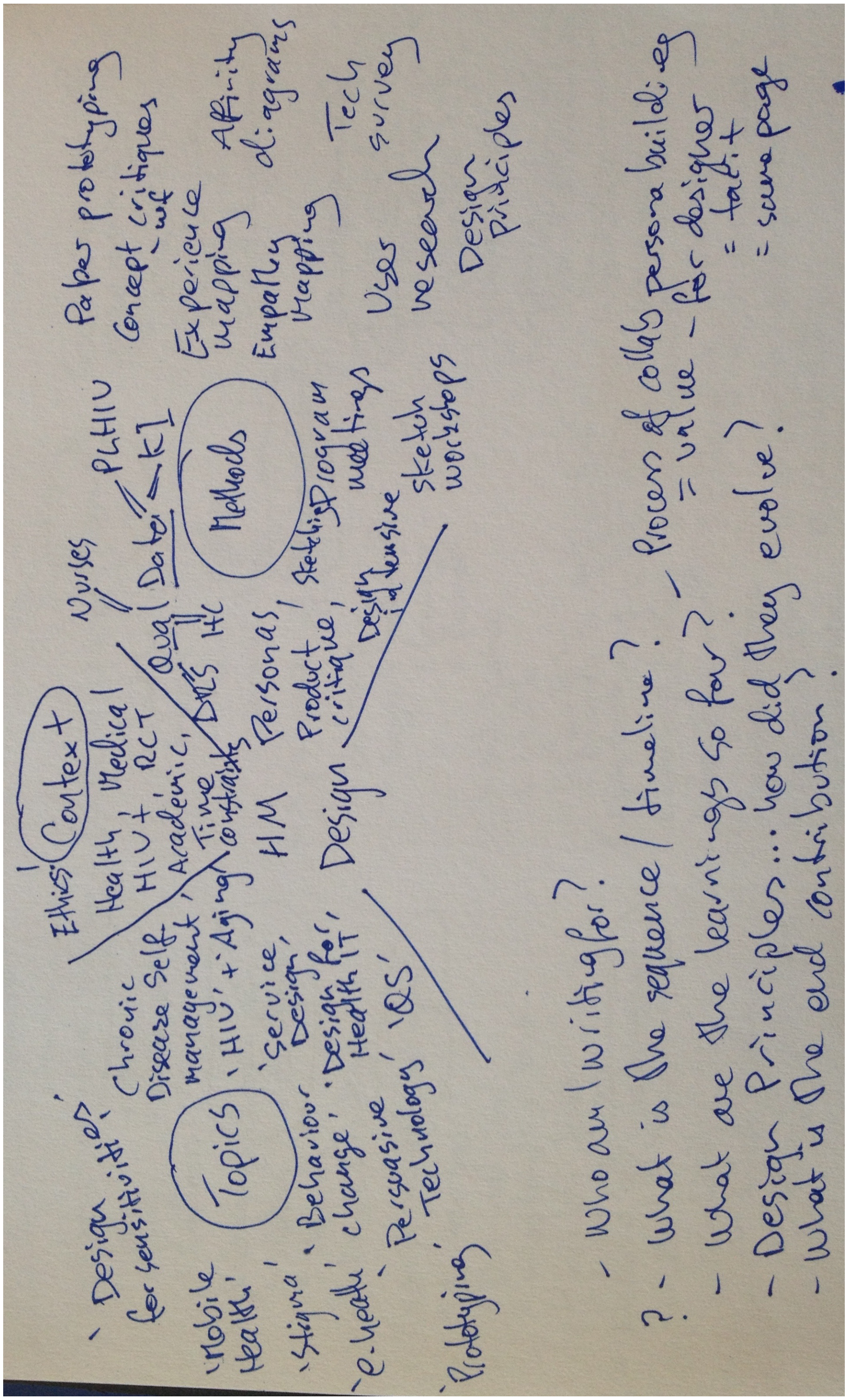

Figure 2 Notes from data exploration

We used framing questions such as ‘How did the HealthMap design principles evolve?’ and ‘What are the learnings so far?’ to chronologically review the design activities timeline. We used the technique of mapping the design team working assumptions from the earliest phase 1 activities until the beginning of phase 4. An extract of a working assumptions map is below (Figure 3).

Primary Design Goal for HealthMap is to implement the intervention and satisfy the requirements of the RCT.

RCT Requirements:

1. Evaluation of CVD risk – has it been reduced?
    a. Cholesterol levels
    b. Blood Pressure
    c. Smoking
2. Evaluation against secondary outcomes – have they been improved?
    a. Mental health
    b. Wellbeing
    c. Self-efficacy

Context

Role of RCT

1. The effect of interactive self-care plans and self-management support on CVD risk and other chronic condition outcomes in PLHIV.
2. Evaluate patient and health care provider experiences and acceptability of interactive selfcare plans and self-management support.
3. Evaluate intervention cost-effectiveness and effect on health service utilisation

Assumptions

1. Most effective intervention for Chol and BP is medication > HM needs to increase treatment uptake > need to design path to increased treatment
2. Smoking has similarly high impact on CVD risk > HM needs to target Smoking Cessation
3. Most CVD risk response is seen in the 50+ population > in order to demonstrate maximum effectiveness HM needs to target the 50+
4. Secondary outcomes will need to be demonstrated (i.e. measureable)
5. Secondary outcomes will need formal evaluation
6. Secondary outcomes will need to demonstrate formal theoretical basis
7. What are the known issues around CDSM as they relate to mental health, wellbeing, self-efficacy?
8. How important are the ‘Stages of Change’ for HM design?
9. Can we plug into existing CDSM programs?

Investigations

Do we need to reinvent the wheel and have a bespoke HM smoking cessation component? Can we plug into, direct users to, existing programs?

- Qual Data re: SmCess experiences
- Literature review of SmCess programs
- Design Team visit to Quit Victoria
- Designer meeting with existing SmCess designer
- Qual Data regarding these issues
- CDSM program meetings with HM Team
    - Arthritis, Diabetes, Medibank Private, CDSM platform for GPs (CDSMnet)
- Literature Review
- Researching online patient support applications/progams (e.g. patientslikeme.com)

Investigation Results (*re RCT working assumptions*)

Smoking Cessation (SmCess)

- Many PLHIV smokers have had contact with smoking cessation programs but the contact was fractured, inconsistent > would be open to follow up
- Evidence for technology based SmCess services is mixed. Some evidence for well designed SMS-based services.
- Personal goals and motivations will keep PLHIV persisting with SmCess attempts
- Some older PLHIV are not motivated re: SmCess because of past addiction history.
- Some PLHIV do not count SmCess as a priority.

Figure 3 Example of assumptions mapping – RCT impact on design

This shows the reflection on the role of the cluster-randomized control trial in shaping the HealthMap design. It notes the factors from the RCT that directly guided design requirements. It then summarises contextual factors relevant to RCT evaluation points, the working assumptions arising from the evaluation points and the investigations conducted to test those working assumptions.

3.2.1 Focused reflection – the role of the service-envisioning workshop

Our reflexive data analysis identified the significant role of a service-envisioning co-design workshop that took place during design phase 3, facilitated by Designer 3. This section will briefly describe the workshop activities. The outcomes from analysing the workshop audio data, design artefacts and impact of the workshop on HealthMap design work will be discussed in the following ‘Results’ section.

3.2.2 Service Envisioning Workshop activities: ‘Pointy’versus‘Soft’

This section describes a participatory service-envisioning workshop that took place a couple of weeks into the phase 3 of the HealthMap design lifecycle. The workshop began with an exploratory exercise using two randomly chosen objects with opposing attributes to provoke creativity and discussion. The two objects were: a bicycle repair tool (Figure 4) and a soft, green, stuffed toy representing a neurone (Figure 5). Boer, Donovan, and Buur discuss the value of embodying tensions to support collaborative analysis and design explorations among stakeholders (Boer et al. 2013). In this respect, we were fortunate in that although the objects for the exploratory exercise were chosen at random, by virtue of their contrasting qualities they seemed to call forth discussion of tensions within the design context and differing perceptions among workshop participants.

The workshop moved from collaborative team discussion around the two objects and how their characteristics related to patients’ experiences of health and healthcare to a series of guided sketching and critique exercises. The sketching generated high-level ideas for services and technology screens that were then selected for the ‘best’ ideas. These best ideas were used to instigate a further sketching workshop the following day.

Figure 4 Bike repair tool - ‘Pointy’

Figure 5 Toy neuron - ‘Soft’

3.2.3 Exploratory reflection – literature and discussions

Parallel to our formal reflexive data analysis we consulted relevant literature from the design research and health design research fields. This informed our understanding of how the HealthMap design processes and outcomes related to other case studies.

We also engaged with Interaction Design research colleagues through seminar presentations and informal dialogue as well as informal dialogue with industry-based User Experience Designers and with reference to user experience industry media.

4 Results

The exploratory reflection raised the role of context, specifically HIV treatment and the lived experiences of people with HIV, as foundational both to the HealthMap design work and discussion of the HealthMap design research. That is, it became clear that without articulating and describing important contextual elements much of what underpinned the HealthMap design decisions would be unclear to other designers.

The service-envisioning co-design workshop discussions provoked by the bike repair tool and the soft toy soon adopted the metaphorical framework of ‘pointy’ versus ‘soft’. ‘Pointy’ referred to functionality: task oriented, measurable, predictable, medical aspects of PWHIV experiences and ‘soft’ referred to the experiential: psychosocial, wellbeing, quality of life aspects of PWHIV. This ‘soft’ value aligned with a premise of User-Centred Design, which is that ‘softness’ (affective elements and quality of experience), can be crucial to successful human interactions with technology (Qu and Hansen 2008; Wright et al 2008b).

We therefore saw a convergence between the important role of the ‘Pointy versus Soft’ workshop in capturing contextual elements for the HealthMap design and the ongoing need to articulate contextual elements for clarity in design discussion.

The results of this action research reflexive inquiry focusing on the service-envisioning co-design workshop have identified outcomes at several levels. The macro level outcomes are: a co-created cross-disciplinary design language, a descriptive framework for contextual factors influencing design, an analytical framework for contextual factors influencing design, and an ongoing design lexicon for the HealthMap design and development team. The more detailed ‘micro’ level outcomes were identified though the application of the ‘Pointy versus Soft’ framework to the action research analysis. Both ‘macro’ and ‘micro’ outcomes are discussed below.

4.1 Macro level outcomes

4.1.1 A HealthMap design language

The service-envisioning workshop found the ‘Pointy versus Soft’ metaphor a useful framework for service idea generation. However, on reflection, much was gained from the process of collaboratively building a shared lexicon to capture the many elements from the medical and personal spheres of patient and provider experiences. This dialogical co-construction of a shared understanding facilitated cross-disciplinary ‘sense-making’ (Qu and Hansen 2008). The workshop activities allowed the ‘Pointy versus Soft’ terms to be suggested, explored, defined and employed to develop a cohesive, tacit agreement on their usefulness in describing the many contextual and experiential factors workshop participants sought to discuss.

The conversation was able to depart from the medical, the academic and the anecdotal into a simple vernacular to succinctly and accurately capture complex contextual factors that were significant for design work and necessary for ongoing design planning and design critique.

The co-creation of this language for design (separate from the domains of health research and social research) essentially bridged the knowledge boundaries between the multiple disciplines represented in the HealthMap team and facilitated mutual understanding, collaborative idea generation and constructive criticism. Carlile’s framework for knowledge management across domain boundaries is helpful in understanding these dynamics (Carlile 2004). The dialogical exploration and co-construction of a design language can be described as ‘bridge-building’ between the knowledge boundaries that exist between diverse domains of expertise. Developing strategies and skills for knowledge boundary ‘bridge building’ is a persistent requirement for Participatory Design practitioners in healthcare (Segalowitz and Brereton 2009).

The ‘pointy’ and ‘soft’ terms are still used by HealthMap team members as a useful ‘short-hand’ language to discuss design opportunities, constraints and contextual factors.

4.1.2 The Pointy versus Soft framework: a tool for understanding context

Many design projects seek to make explicit contextual and experiential factors that influence human behavior, shape socio-technical systems and ultimately impact on the success of program implementation. While design practice techniques exist for understanding contextual influences, contexts that are particularly complex, or particularly unfamiliar, can prove very challenging for traditional user-centred design practitioners (Sanders and Stappers 2008; Stolterman 2008; Rogers 2004). Healthcare is a demonstrably complex context for design projects. This complexity is further compounded by the technological ecosystems that can provide a ubiquitous healthcare engagement.

Any tool that supports a simple and practical exploration of complex contextual factors is potentially highly valuable to healthcare design practice. The usefulness of ‘Pointy’ and ‘Soft’ as a design language is not just in the simplicity and aptness of the terms, it is in their flexibility when exploring complex, multi-faceted contextual factors. Pointy and Soft have the ability to accommodate many nuances that pervade healthcare as a context for design. The ‘Yin and Yang’ section below gives an example of this flexibility.

4.1.2.1 The Yin and Yang of ‘Pointy’

Sometimes the same ‘pointy’ aspect of healthcare can provide both design opportunities and barriers. The parallel design opportunity and design constraint of healthcare providers pressed for time is an example. While it is difficult to successfully disrupt patterns of workflow, and to risk adding to a consultation workload, if there is opportunity to add efficiency, or to add so much extra value that the pressure on time is seen as worthwhile, this raises the possibility for provider adoption.

Two HIV treatment provider values identified during HealthMap design research were continuity of data and patient motivation. These were both designed for and tested during the concept critiques. While continuity of data is a complex challenge, and will be partially addressed, improved patient motivation was enough of a priority for providers to accommodate a certain level of disruption to their workflow. If patients are enthusiastic towards an application then many providers will support its adoption, assuming adoption is reasonably straightforward. Thus the ‘soft’ factor of patient motivation relates to the ‘pointy’ factor of provider time-scarcity as a potential opportunity for design. It also reinforces the priority of patient-motivation beyond a ‘soft’ consideration to a strategic ‘pointy’ value.

4.1.3 The Pointy versus Soft framework: a tool for evaluation

The ‘Pointy versus Soft’ framework was used as a reflexive action research tool for design practice evaluation. It supported a reflexive analysis of both contextual features and the HealthMap design process. This allowed us to ‘tease apart’ interwoven and sometimes conflicting factors which impacted the HealthMap design work.

Having identified significant contextual factors we were able to explore their impact on design and propose future design strategy for HealthMap and potentially wider healthcare design projects. In this way the Pointy versus Soft framework supported clear strategic design guidance and actionable insights for further design work.

The ‘Micro level outcomes’ section below presents the results of this ‘Pointy versus Soft’ analysis.

4.2 Micro level outcomes

Based on the ‘Pointy versus Soft’ evaluation of the HealthMap design project we describe how ‘soft’ and ‘pointy’ factors influenced HealthMap design processes and suggest how they might be generalizable as landmarks when designing for the healthcare system.

4.2.1 HealthMap Pointy Influences

The ‘pointy’ influences identified were: metrics, interoperability, and systemic time scarcity. These contextual landmarks for design are discussed below.

4.2.1.1 Metrics

The evaluation of HealthMap study is the cluster RCT commenced in 2015. This automatically requires that quantitative data be delivered from the HealthMap design. It also dictates what those data will be, such as cholesterol levels and blood pressure, thus the designers are tasked with envisioning a system that can deliver those data.

Many designers work for clients who want to measure their return on investment, however, for health technology a medical approach to evaluation is common. Understanding the project evaluation points and thinking about how to deliver meaningful data is an early design task.

Not all health care technology is subjected to an RCT, yet projects need to support stakeholders’ reporting requirements. Awareness of data points and delivering early reporting can be a pathway to meeting these requirements.

Bowen, et al., discuss the limitations of the NHS ‘Experience Based Design’ guidelines in providing for adequate evaluation, observing that evaluation is prioritized but under developed. We suggest that early understanding of stakeholders’ evaluation is useful for the design planning and for the designers’ own evaluation (Bowen et al. 2013).

4.2.1.2 Interoperability

Healthcare systems all over the world are littered with information technology programs that are under-utilized, poorly integrated or abandoned. Kaplan and Harris-Salamone report that the majority of health IT projects fail to some extent (Kaplan and Harris-Salamone 2009). Much of this failure has been attributed to the inability of technology platforms and applications to operate together. In the era of pervasive health the need for interoperability still exists at the micro level of software and devices, but it also expands to the macro level of the changing contexts of health: from the institutional to the personal and mobile.

For the HealthMap design phase 3, scoping the necessary level of interoperability was an important constraint and shaped many design decisions. It led to early guidance on feasibility and exploration of ways to overcome barriers, which, in turn, encouraged a design approach to the strategy for piloting and implementation. These constraints ran from identifying medical practice EMR software requirements to surveying patient access to technology and technology-based information and social interaction. In HealthMap’s design research with healthcare providers there was evidence of great sensitivity to the threat of poor interoperability. Often providers cited examples of useful tools that lay idle because they could not be integrated into existing systems. Bowen et al., define this macro and micro interoperability as: “providing an ecology of systems and services that relate to the person as embodied in ever changing contexts.” (Bowen et al. 2011, p.158).

4.2.1.3 Systemic Time Scarcity

We have alluded to the inherent time constraints in designing for healthcare provider/patient interaction. This paucity of time pervades the whole medical landscape and impacts every stage of the PD process. Accessing users for research activities, for collaborative exercises, or critique and testing is a challenge to PD. Understanding these chronic constraints and strategies to overcome them is an important tool for designing in healthcare. Time unavailability and ethics approval delays both become ‘design problems’ in themselves that require planning for creative and adaptable solutions. The HealthMap team’s ability to identify and respond to healthcare provider availability was key to our participatory approach. Situated in a medical teaching school, close to an Infectious Diseases Unit and specialist HIV General Practices allowed us to make use of lunch-time and ad hoc user availability. Raising project awareness with staff and hierarchy was also important to support ongoing design research and collaboration. Dearden et al., describe similar challenges in accessing staff and the negative impact on staff workload from time spent in design participation (Dearden et al. 2010). In healthcare, patient needs are a constant and inflexible demand. For the healthcare service designer, access to staff as participants is a critical challenge to be faced as early as possible.

4.2.2 HealthMap ‘Soft’ Influences

One pervasive ‘soft’ influence on HealthMap design was stigma. Stigma is from the ‘soft’ domains of the psychosocial and quality of life.

4.2.2.1 Discrimination and Stigma

For PWHIV, stigma can be so pervasive and so bound up with experiences accessing medical care and health information, that it cannot be separated from health design considerations. It is a ‘soft terrain’ feature that intertwines with the medical and institutional, thus sensitivity to stigma must be considered foundational to any design work for PWHIV.

Mahajan et al., point out that stigma continues to present barriers to disease prevention and accessing care and treatment for HIV (Mahajan et al. 2008). For PWHIV, these barriers persist into all aspects of health and wellbeing. Yet many people living with chronic disease also share these experiences of stigma, and the associated barriers to care, to some degree. Earnshaw and Quinn, describe the experiences of stigma, especially in the context of healthcare, for people living with a variety of chronic diseases (Earnshaw and Quinn 2012). In addition to HIV and chronic disease, ageing brings its own experiences of stigma. Slater et al., point out how ageing PWHIV “must also deal with multiple stigmas related to their sexual orientation, HIV status, and age.” (Slater et al. 2012, p.9) Reidpath and Chan describe this as the layering of stigmas that can affect a patient’s access to healthcare and support (Reidpath and Chan 2005). We would suggest that any healthcare-based service needs to become aware of the specificities of stigma affecting their particular user group(s) as a design priority. Although people with other diseases and medical needs do not necessarily experience the level of stigma experienced by HIV-positive patients, there will be a set of vulnerabilities and sensitivities particular to each medical condition. In a sense, each condition can have an accompanying set of its own commonly experienced sensitivities. Understanding these particularities and the ‘culture’ unique to that set of patients is a crucial ‘soft’ design requirement and an important area for designers to research at the earliest opportunity. Gathering a body of data to inform the intuitive practices of design is a crucial step for patient-centred design efforts.

For health IT designers, gaining awareness of specific sensitivities will involve design research that requires ethics approvals. In Australia many health projects are embedded in academic funding models. While design researchers encounter these protocols as a matter of course, there is still unfamiliarity in human ethics committees with design vernacular and design practices. Thinking about what are the most low-risk and easily executed design activities and data treatment is an important additional early task for ‘soft’ health technology design.

5 Discussion

In designing the HealthMap chronic disease self-management platform for PWHIV a cross-disciplinary design framework of ‘Pointy versus Soft’ was implemented. This framework emerged from a collaborative service-envisioning workshop and served several useful functions: i) it played a pivotal role in bridging the boundaries between design practice, medical research and social research through co-creation of a plain, accessible, mutually agreed lexicon, ii) it successfully explored and captured complex contextual influences and articulated them in an accessible and systematic way, iii) it enabled a framework for reflective analysis of contextual features to ‘tease apart’ interwoven and sometimes conflicting factors which supported clear strategic design guidance and actionable insights, iv) it provided the HealthMap design team with a design language to apply to ongoing design work, both generative and evaluative.

We suggest that early identification of the ‘soft’ and ‘pointy’ influences on a particular project with an appropriate pragmatic design strategy to address them will support realistic design scoping and decisions. Furthermore, this method enables project designers to approach service implementation from a contextually aware position.

By applying the ‘Pointy versus Soft’ framework as an action research evaluative tool we identified the following three characteristics of the ‘pointy’ medical and institutional contextual ‘landmarks’ and a pervasive ‘soft terrain’ feature. These are characteristics of a persistent context for healthcare design:

5.1 Metrics as a requirement

In healthcare design many projects must address evaluation points (Jones 2013; Lyng and Pedersen 2011). Indentifying, understanding and designing for project evaluation points is an early design task to address. This early prioritization will help to create useful data to satisfy evaluation.

5.2 Interoperability – from the micro to the macro

Acknowledging the barriers to interoperability in the whole ecosystem of a service is key to discovering the opportunities for feasibility and possible implementation (Jones 2013; Dearden et al. 2010). Exploration of interoperability problems and decisions around strategic partnerships needs to occur in the early stages of a project lifecycle in order to scope a design that has any chance of real adoption.

5.3 Systemic time scarcity

In healthcare designers often suffer from a lack of time availability with project stakeholders and patients. Designers need to plan strategies that are time efficient and flexible in order to utilize the short notice and small amounts of user availability that are presented. Planning, and seeking approval for, informal, opportunistic and nimble engagement with users will be a valuable early investment in supporting a PD process (Jones 2013; Dearden et al. 2010; Bowen et al. 2013; Grocott et al. 2013).

5.4 ‘Soft’terrain: stigma as a pervasive experience

Most people living with chronic disease experience stigma (Earnshaw and Quinn 2012; Earnshaw, et al. 2012). Patient enthusiasm for any healthcare service is predicated on a sensitive engagement that supports feelings of vulnerability and reduced confidence. Designing for the health or wellbeing of a person living with chronic disease requires design that addresses how stigma may influence engagement. Designing for patients in any context means designing for particular sensitivities and requires an explicit, strategic set of design priorities and a deeply empathic, tacit understanding that permeates the design lifecycle (Jones 2013; Wright and McCarthy 2010).

6 Conclusions

In summary, we introduce the metaphor of ‘pointy’ landmarks and ‘soft’ terrain as a design framework to describe the healthcare context and as a design vernacular for healthcare. By reviewing the HealthMap case study, we suggest that this framework can begin to help designers anticipate and recognize important pointy landmarks and soft terrain features relevant to their projects. Once these landmarks have been identified the appropriate approaches to navigate, and exploit, these touchpoints presents an opportunity for design strategy. We invite further framework expansion and descriptions of features that may comprise persistent healthcare contextual landmarks.

6.1 Broader implications: toward a community of practice for healthcare design

The ‘Pointy versus Soft’ cross-disciplinary design lexicon for healthcare is distinct from the existing medical and engineering based terminology, such as ‘safety’ and ‘functionality’ (Bate and Robert 2007b). The value of a specific lexicon for ‘designerly’ thought and activities is recognised in current design practice (Spool 2012). Successful design techniques for bridging knowledge boundaries within healthcare design support both PD practice and the search for a cross-disciplinary community of practice for ‘design for health’ (Simonsen and Robertson 2012; Carlile 2004; Segalowitz and Brereton 2009).

A co-created design lexicon aligns with Lave and Wenger’s framework for communities of practice: which describes the value of shared construction of a shared understanding and shared repertoire of methods and concepts. This repertoire can act as a resource for further design engagement (Wenger 1998).

Limitations

As this is a reflexive paper from one case study the ‘Pointy versus Soft’ framework and design lexicon are untested in other healthcare projects. The value of ‘Pointy versus Soft’ to the HealthMap design may be a result of team dynamics and productive collaboration rather than inherent value in the framework.

We recommend further design work and research to evaluate how the ‘Pointy versus Soft’ framework and design vernacular can support health technology design strategy.

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Abbreviations

AR: action research

CDSM: chronic disease self-management

EMR: electronic medical record

HCI: human computer interaction

HIV: Human Immunodeficiency Virus

NHMRC: National Health and Medical Research Council

PWHIV: people with HIV

RCT: randomised control trial

UCHD: user-centred healthcare design

References

Bate, Paul and Glenn Robert, (2002) "Knowledge Management and Communities of Practice in the Private Sector: Lessons for Modernizing the National Health Service in England and Wales." *Public Administration* vol.80, no.4, pp.643–663. doi:10.1111/1467-9299.00322.

Bate, Paul and Glenn Robert, (2006). "Experience-Based Design: From Redesigning the System around the Patient to Co-Designing Services with the Patient." *Quality & Safety in Health Care* vol.15, no.5, pp.307–310. doi:10.1136/qshc.2005.016527.

Bate, Paul and Glenn Robert, (2007a) "Toward More User-Centric OD: Lessons From the Field of Experience-Based Design and a Case Study." *The Journal of Applied Behavioral Science* vol.43, no.1, pp.41-66. doi:10.1177/0021886306297014.

Bate, Paul and Glenn Robert, (2007b) *Bringing user experience to healthcare improvement: The concepts, methods and practices of experience-based design*. Oxford, UK: Radcliffe Publishing Ltd; 2007. p.207 ISBN: 9781846191763

Berryman, Michelle., Vicki Haberman, and Brian Lynn (2011) "User Experience Design in a Surgical Environment." *IDSA* 25 August 2011. Eco Visualisaton LLC. [Web log post] http://www.webcitation.org/6XqXfYjGQ.

Boer, Laurens, Jared Donovan, and Jacob Buur (2013) "Challenging Industry Conceptions with Provotypes." *CoDesign, International Journal of CoDesign in Design and the Arts* vol.9, no.2, pp.73–89. doi:10.1080/15710882.2013.788193.

Bowen, Simon., Andy Dearden, and Matt Dexter (2014) "Wearing Two Hats : Reflecting Alongside Authentic Designing." In *Proceedings of DRS 2014*. Umea, Sweden: Design Research Society. http://www.webcitation.org/6XqbSfhyW.

Bowen, Simon., Andy Dearden, Dan Wolstenholme, and Mark Cobb (2011) "Different Views: Including Others in Participatory Health Service Innovation." In Buur, Jacob (ed) *PINC 2011: Participatory Innovation Conference* 2011, pp.230-236 Sonderborg: University of Southern Denmark. http://www.webcitation.org/6XqZmyhEg.

Bowen, Simon., Andy Dearden, Peter Wright, Daniel Wolstenholme, and Mark Cobb (2010) "Participatory Healthcare Service Design and Innovation." In *Proceedings of the 11th Biennial Participatory Design Conference*, pp.155–158. Sydney, Australia: ACM. doi:10.1145/1900441.1900464.

Bowen, Simon., Kerry McSeveny, Eleanor Lockley, Daniel Wolstenholme, Mark Cobb, and Andy Dearden (2013) "How Was It for You? Experiences of Participatory Design in the UK Health Service." *CoDesign* vol.9, no.4, pp.230–246. doi:10.1080/15710882.2013.846384

Carlile, Paul R. (2004) "Transferring , Translating , and Transforming : Framework for Managing Knowledge Across Boundaries." *Organization Science* vol.15, no.5, pp.555–568. doi:10.1287/orsc.

Dearden, Andy., Peter Wright, Simon Bowen, Fazilatur Rahman, Mark Cobb, and Daniel Wolstenholme (2010) "User-Centred Design and Pervasive Health: A Position Statement from the User-Centred Healthcare Design Project." *Proceedings of the 4th International ICST Conference on Pervasive Computing Technologies for Healthcare*: pp.8–11. 22-25 March, Munich, Germany: IEEE, doi:10.4108/ICST.PERVASIVEHEALTH2010.8837.

Earnshaw, Valerie A., and Diane M Quinn (2012) "The Impact of Stigma in Healthcare on People Living with Chronic Illnesses." *Journal of Health Psychology* vol.17, no.2, pp.157–68. doi:10.1177/1359105311414952.

Earnshaw, Valerie A., Diane M Quinn, and Crystal L Park (2012) "Anticipated Stigma and Quality of Life among People Living with Chronic Illnesses." *Chronic Illness* vol.8, no.2, pp.79–88. PMID: 22080524

Gonzales, Michael, and Laurel Riek (2013) "Co-Designing Patient-Centered Health Communication Tools for Cancer Care." In *Proceedings of the 7th International Conference on Pervasive Computing Technologies for Healthcare and Workshops*, 208–215. Venice, Italy: EAI. doi:10.4108/pervasivehealth.2013.252109.

Greenhalgh, Trisha., Glenn Robert, Fraser Macfarlane, Paul Bate, and Olivia Kyriakidou (2004) "Diffusion of Innovations in Service Organizations: Systematic Review and Recommendations." *The Milbank Quarterly* vol.82, no.4, pp.581–629. doi:10.1111/j.0887-378X.2004.00325.x.

Grocott, Patricia., Rebecca Blackwell, Conchita Currie, Elizabeth Pillay, and Glenn Robert (2013) "Co-Producing Novel Wound Care Products for Epidermolysis Bullosa; an Empirical Case Study of the Use of Surrogates in the Design and Prototype Development Process." *International Wound Journal* vol.10, no.3, pp.265–73. doi:10.1111/j.1742-481X.2012.00972.x

Heart Foundation. "Cardiovascular Wellness for People Living with HIV." http://www.webcitation.org/6XqUbkVHa.

Jones, Peter H. (2013) *Design for Care: Innovating Healthcare Experience*. New York: Rosenfeld Media ISBN 9781933820231

Julier, Guy (2013) "Experience-Based Design, Innovation and the NHS." *Social Design Talks on WordPress.com*. http://www.webcitation.org/6XqZasSRX.

Kaplan, Bonnie., and Kimberly D Harris-Salamone (2009) "Health IT Success and Failure: Recommendations from Literature and an AMIA Workshop." *Journal of the American Medical Informatics Association* vol.16, no.3, pp.291–299. doi:10.1197/jamia.M2997

Koshy, Elizabeth., Valsa Koshy, and Heather Waterman (2011) *Action Research in Healthcare*. London, UK: Sage Publications Ltd. ISBN 978-1-84860-189-5

Lab4Living (2015) "Lab 4 Living | Cultural, Communication and Computing Research Institute | Sheffield Hallam University." Accessed January 11. http://www.webcitation.org/6XqaVQQ9v.

Lyng, K M and B S Pedersen (2011) "Participatory Design for Computerization of Clinical Practice Guidelines." *Journal of Biomedical Informatics* vol.44, no.5 pp.909–918. doi:10.1016/j.jbi.2011.05.005

Mahajan, Anish P., Jennifer N Sayles, Vishal A Patel, Robert H Remien, Sharif R Sawires, Daniel J Ortiz, Greg Szekeres, and Thomas J Coates (2008) "Stigma in the HIV/AIDS Epidemic: A Review of the

Literature and Recommendations for the Way Forward." *AIDS (London, England)* vol.22, Suppl 2 pp. 67–S79. doi:10.1097/01.aids.0000327438.13291.62.

McHattie, Lynn Sayers., Grant Cumming, and Tara French (2014) "Transforming Patient Experience: Health Web Science Meets Medicine 2.0." *Medicine 2.0 2014* vol.3, no.1, e2. doi:10.2196/med20.3128.

Mockford, Carole., Sophie Staniszewska, Frances Griffiths, and Sandra Herron-Marx (2012) "The Impact of Patient and Public Involvement on UK NHS Health Care: A Systematic Review." *International Journal for Quality in Health Care* vol.24, no.1, pp.28-38 doi:10.1093/intqhc/mzr066.

NHS (2014) "Experience Based Design for Clinical Commissioning Groups and the Engagement Cycle." *NHS Patient Experience Portal*. http://www.webcitation.org/6XqZVO0zX.

Pickles, John., Elaine Hide, and Lynne Maher (2008) "Experience Based Design: A Practical Method of Working with Patients to Redesign Services." *Clinical Governance: An International Journal* vol.13 no.1 pp.51–58. doi:10.1108/14777270810850634.

Pilemalm, Sofie., and Toomas Timpka (2008) "Third Generation Participatory Design in Health Informatics-Making User Participation Applicable to Large-Scale Information System Projects." *Journal of Biomedical Informatics* vol.41, no.2 pp.327–339. doi:10.1016/j.jbi.2007.09.004.

Qu, Yan, and Derek L Hansen (2008) "Building Shared Understanding in Collaborative Sensemaking." In *Proceedings of CHI 2008 Sensemaking Workshop.* ACM New York, NY, USA. http://www.webcitation.org/6XqfWOMcW.

Reidpath, D D., and K Y Chan (2005) "A Method for the Quantitative Analysis of the Layering of HIV-Related Stigma." *AIDS Care* vol.17 no.4 pp. 425–32. doi:10.1080/09540120412331319769.

Rogers, Yvonne (2004) "New Theoretical Approaches for HCI." *Annual Review of Information Science and Technology (ARIST)* vol.38. http://www.editlib.org/p/97535/.

Ross, Lorna (2014) *FjordKitchen Talks: Lorna Ross "Service Design in Health and Health Care."* Vimeo. [Video file] http://www.webcitation.org/6XqY2M7nl.

Sanders, Elizabeth (2002) "From User-Centered to Participatory Design Approaches." In *Design and the Social Sciences*, edited by J.Frascara. London, UK: Taylor & Francis Books; ISBN: 0-415-27376-5

Sanders, Elizabeth, and Pieter Jan Stappers (2008) "Co-Creation and the New Landscapes of Design." *CoDesign* vol.4, no.1, pp. 5–18. doi:10.1080/15710880701875068.

Schon, Donald A. 1992. "Designing as Reflective Conversation with the Materials of a Design Situation." *Research in Engineering Design* 3 (3) (September 1): 131–147. doi:10.1007/BF01580516.

Segalowitz, Miri., and Margot Brereton (2009) "An Examination of the Knowledge Barriers in Participatory Design and the Prospects for Embedded Research." In *Proceedings of the 21st Annual Conference of the Australian Computer-Human Interaction Special Interest Group* pp. 337–340. ACM New York, NY, USA. doi:10.1145/1738826.1738890.

Simonsen, Jesper, and Toni Robertson., ed (2012) *Routledge Handbook of Participatory Design..* Taylor & Francis. London, UK; Taylor & Francis ISBN: 978-0-203-10854-3

Slater, Larry Z, Linda Moneyham, David E Vance, James L Raper, Michael J Mugavero, and Gwendolyn Childs. 2012. "Support, Stigma, Health, Coping, and Quality of Life in Older Gay Men With HIV." *The Journal of the Association of Nurses in AIDS Care : JANAC* vol.24, no.1, pp. 1–12. doi:10.1016/j.jana.2012.02.006.

Spool, Jared M (2012) "From Critique, A Language Emerges." *User Interface Engineering: Brain Sparks*. [web log post] http://www.webcitation.org/6XqgzLGZL.

Stolterman, Erik (2008) "The Nature of Design Practice and Implications for Interaction Design Research." *International Journal of Design* vol.2, no.1, pp.55–66. http://www.webcitation.org/6XqbNc2NZ.

Tsianakas, Vicki., Glenn Robert, Jill Maben, Alison Richardson, Catherine Dale, and Theresa Wiseman (2012) “Implementing Patient-Centred Cancer Care: Using Experience-Based Co-Design to Improve Patient Experience in Breast and Lung Cancer Services.” *Supportive Care in Cancer* vol.20, no.11, pp. 2639–2647. doi:10.1007/s00520-012-1470-3.

Wenger, Etienne (1998) *Communities of Practice: Learning, Meaning and Identity*. Cambridge: Cambridge University Press. Cambridge: 318pp. ISBN: 978-0-521-66363-2

Wright, Peter., and John McCarthy (2010) *Experience-Centered Design: Designers, Users, and Communities in Dialogue*. *Synthesis Lectures on Human-Centered Informatics*. Vol. 3. doi:10.2200/S00229ED1V01Y201003HCI009

Wright P., Jayne Wallace, John McCarthy (2008) Aesthetics and experience-centered design. *ACM Trans Comput Interact.* Vol.15, no.4, p.1–21. doi:10.1145/1460355.1460360.

Appendix D

2015 revised draft of Paper 3.

‘Dipping a toe in the water’: addressing the effects of stigma and non-use when designing social media features for people with HIV.

APPENDIX D ‘Dipping a toe in the water: addressing the effects of stigma and non-use when designing social media features for people with HIV

'Dipping a toe in the water': addressing the effects of stigma and non-use when designing social media features for people with HIV

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Abstract

Stigma contributes to social isolation for many people living and ageing with HIV. When designing the HealthMap Study chronic disease self-management technology for People With HIV (PWHIV), social isolation was recognized as an important factor influencing self-efficacy in managing risk factors.

We explored the role of stigma, the potential for social media technology to support PWHIV and the evolution of empathic design understanding around experiences of stigma.

We present two frameworks: i) 'Designing in the face of stigma: a design tension framework' and ii) 'Finding meaningful support in the face of stigma: a design tension framework'. These frameworks illustrate the significance of technology 'non-use' in coping with stigma. We developed the 'Finding meaningful support' framework to include sensitivity to 'non-use' coupled with 'meaningful activity' as a means to encourage technology-based social experiences for PWHIV.

Keywords

1. Background

People with HIV and on combination antiretroviral treatment are facing a future unprecedented in human history. While the medical establishment and healthcare system adapt from managing HIV in an acute care model to a chronic disease care model, the experiences that PWHIV face are largely uncharted territory. There are no precedents for ageing on HIV treatment and care pathways for people to follow are unclear.

1.1. The HealthMap Study

The HealthMap Study is an Australian National Health and Medical Research Council funded randomised control trial to investigate how to support PWHIV in self-management of coronary heart disease (CHD) and the chronic diseases of ageing. The HealthMap intervention is aimed at those most at risk of CHD, namely smokers over the age of fifty. In Australia, 80% of PWHIV are men who have sex with men.

HealthMap offers social support for health through web-based health coaching modules and moderated online live-chat programs. It does not include social media features.

1.2. Stigma

The stigma associated with HIV/AIDS has been present since the earliest days of the epidemic in the 1980s. Although the discrimination faced by many PWHIV in the 80s has diminished, HIV stigma persists as a multilayered psychosocial experience (Herek, 1999; McDonald, Elliott and Saugeres, 2013; Mahajan, et al., 2008; McDonald, K., et al. (under review) Chronic Disease Self-Management by PWHIV; Slavin, 2012). In developed countries HIV stigma can include sexual orientation, sexual behaviour, drug use, ageing, medical co-morbidities, treatment side-effects, financial hardship and loss of social status (Mahajan, et al., 2008; Slavin, 2012; Vance, et al., 2008).

Stigma is a complex socio-cognitive and socio-cultural phenomenon that has been observed and discussed from a number of viewpoints since Goffman's seminal work in the 1960s. This work defined stigma as a socially discrediting attribution of 'deviance' that compelled the stigmatized individual to view themselves, and others to view them, as discredited (Goffman, 1990). The concepts of external stigma and internal stigma, experienced stigma and anticipated stigma, enacted stigma and felt stigma, structural stigma/structural violence and sexual stigma have all been applied to HIV/AIDS stigma (Earnshaw and Quinn, 2012; Quinn and Chaudoir, 2009; Slavin, 2012). The complexity and variability of HIV stigma has long proved a challenge to designing effective HIV prevention and treatment programs (Mahajan, et al., 2008).

The presence of stigma can have a detrimental effect on health outcomes for PWHIV, in particular through diminished access to healthcare and social support (Earnshaw and Quinn, 2012). Stigma also negatively affects mental health and wellbeing directly as a stressor and by eroding resilience and the capabilities to maintain mental health (Slavin, 2012).

1.3. Stress coping

When analysing the impact of stigma on PWHIV it can be useful to understand stigma as a stressor in the lives of PWHIV (Slater, et al., 2012). A number of HIV stigma studies have used stress as a defining characteristic of stigma (Chenard, 2007; Earnshaw and Quinn, 2012; Quinn and Chaudoir, 2009; Slater et al., 2012; Slavin, 2012). The stress coping strategies described in the Lazarus and Folkman's Stress Coping Theory have been reported from the experiences of PWHIV, with 'avoidant behaviour' a common way to manage anticipated stigma (Lazarus and Folkman, 1984; Quinn and Chaudoir, 2009).

Anticipated stigma is the extent to which people expect to experience prejudice and discrimination directed at them in the future (Earnshaw and Quinn, 2012; Earnshaw, Quinn and Park, 2012; Farnham and Churchill, 2011; Quinn and Chaudoir, 2009). Anticipated stigma plays a key role in the stigma management coping behaviours of PWHIV because HIV is often a concealable stigmatised identity (Earnshaw and Quinn, 2012; Earnshaw, et al., 2012; Quinn and Chaudoir, 2009). For concealable stigmas, the avoidance of disclosure can be significant, with the appearance of normalcy a guiding motivation (Earnshaw and Quinn, 2012; Chenard, 2007). To avoid anticipated disclosure many avoidant behaviours can be employed, including limiting social interactions (Goffman, 1990; Quinn and Chaudoir, 2009; Vance, et al., 2008). Avoidant behaviour is also a common coping strategy for men generally and makes men more likely to avoid accessing professional help or seeking social support (Cohen et al., 1986). Stress coping strategies, can be triggered by events or anticipated scenarios not directly related to a source of stress. Psychologists describe this response as ‘over-generalization’ (Cohen et al., 1986). ‘ Over-generalization’ is defined as a stress coping response applied to situations that are not stressors. Over-generalization often has the effect of diminishing an individual’s quality of life. Cohen et al describe over-generalization as one of the ‘costs of coping’, the other costs being cumulative fatigue effects and coping side effects (Cohen et al., 1986:8). Importantly, these coping costs can arise as secondary effects of successful coping, where an individual apparently adjusts well to the effects of stress (Cohen et al., 1986). We understand that due to the effects of stigma and the possible effects of ‘over-generalization’ there can be a relationship between avoidant stress-coping and anticipated disclosure.

1.4. Social isolation

Social isolation for PWHIV can arise from multiple factors. The relocation, bereavement, reduced financial means and illness that can accompany ageing are often linked to increased social isolation (McDonald, et al., 2013; Slater et al., 2012; Vance et al. 2008). Social isolation is also a typical outcome from avoidant stress-coping strategies (Quinn and Chaudoir, 2009; Vance et al. 2008). The experiences of discrimination mixed with an avoidant response to the stress of stigma can make social isolation a common experience for many PWHIV. Earnshaw and colleagues observe that

> *People living with concealable stigmatized identities who experience stigma are more likely to socially isolate themselves, and this social isolation is associated with decreased social support.* (Earnshaw, Quinn and Park, 2012:80)

Social support is an important tool to reduce the impact of stigma. Insufficient social support can exacerbate the effects of stigma, provoking further avoidant behaviours (Quinn and Chaudoir, 2009). In this way, social isolation, stigma and avoidance can overlap and interact in a vicious cycle of decreasing self-confidence, decreasing social connections, and decreasing access to social support. Many PWHIV are at risk of depression and impaired mental health from the effects of stigma and ageing (Earnshaw and Quinn, 2012; Earnshaw, et al., 2012; Quinn and Chaudoir, 2009; Slater et al., 2012; Vance et al., 2008). Figure 1 below illustrates this cumulative effect.

[*Figure 1 The effects of stigma on social support*]

1.5. Implications for chronic disease self-management

Strategies for reducing the impact of stigma, and for adopting healthy stress management, overlap in many areas with the successful self-management of chronic disease. Resilience, self-efficacy and good access to healthcare are all essential components to combating stigma, managing stress and managing chronic disease (Earnshaw and Quinn, 2012; Quinn and Chaudoir, 2009; Shively, et al., 2002; Slater et al., 2012; Slavin, 2012; Vance,et al., 2008). The characteristics of resilience and self-efficacy can be captured in the psychological term ‘adaptive help seeking’. Adaptive help seeking has been identified as beneficial to men and a key component of accessing professional help (Cohen et al., 1986). Resilience is a psychological process that describes a person’s ability to adapt to adversity in an adaptive way. When coping with stress an individual’s cognitive appraisal and their perception influences the strategy adopted. Resilience is a perception that enables a person to predict that they will be able to resist or recover from a stressful situation (Slavin, 2012; Li and Yang, 2009). Perception is not fixed, it can be influenced by external factors and internal reactions (Li and Yang, 2009). In social cognitive theory, self-efficacy is a person’s belief in their ability to achieve a desired outcome and have some effect on their environment

(Bandura, 1986). Resilience, self-efficacy and social connection often overlap and are recognized as facilitators of good wellbeing and self-management behaviours (Li and Yang, 2009; Quinn and Chaudoir, 2009; Slavin, 2012). Resilience and self-efficacy can resist avoidance or reduce the costs of avoidant behaviour, while social support is a domain of both resilience and self-efficacy (Addis and Mahalik, 2003).

Access to healthcare is essential for chronic disease self-management and is negatively impacted by stigma (Quinn and Chaudoir, 2009; Shively et al., 2002; Slavin, 2012). Discriminatory experiences when accessing healthcare, can lead to avoidance of the healthcare system and healthcare providers (Quinn and Chaudoir, 2009; Slavin, 2012). Figure 2 below shows the potential impact of stigma on chronic disease self-management.

[*Figure 2 Impact of stigma on chronic disease self-management*]

2. Objective

From this context of stigma, stress-coping, social isolation and chronic disease self-management it is clear that avoidant stress-coping plays a strategic role in the impact of stigma on social isolation and chronic disease self-management. Thus, stigma and avoidant stress-coping helped to frame the design for constraints of HealthMap social media features.

Although some 'off the shelf' social media features are good tools for supporting people experiencing social isolation, our expectation was that for highly stigmatised user groups, careful consideration was needed to inform the design.

This prompts the questions: i) What are the implications from stigma and avoidant stress-coping on designing social media features? and ii) What does the HealthMap research data tell us about opportunities for social media design?

2.1. Stigma and social media

It is evident that online sociability depends on the context and community of users as well as how the social experience is designed (Sieckenius de Souza and Preece, 2004). Sieckenius de Souza and Preece encouraged designers to focus on the social needs of users by addressing sociability first before deciding on the software design. They defined sociability as the perceived attributes of: Topicality, Reciprocity, Empathy, Trust, Identifiability, Common Ground, Politeness and Privacy (Sieckenius de Souza and Preece, 2004).

These sociability factors depend on contextual sensitivity and the particularities of user behaviour. For PWHIV, stigma is a pervasive contextual feature and avoidant stress coping can be a particularity of user behaviour. How to design sociability amongst anti-social stressors was the design challenge. The risks of discrimination and stigmatising experiences are not minimised when transferred to online contexts. In fact, online social interactions *often reproduce forms of social stigma encountered in everyday real life, as well as introducing new forms of stigma* (Harrell, 2009:49).

2.2. The role of 'non-use' in technology

Recent studies in Human-Computer Interaction have observed the phenomenon of 'non-use' in people's attitudes and behavior towards technologies. Satchell and Dourish (2009) describe six forms of 'non-use': lagging adoption, active resistance, disenchantment, disenfranchisement, displacement and disinterest. Baumer et al. (2015) advocate for the importance of considering use and 'non-use' not as a dichotomy, but as a "continually negotiated practice" between an individual and the technologies they encounter (Baumer et al., 2015:54). The concept of a ‘choreography’ between use and non-use is helpful to our discussion and we employ this framework in the following sections.

We can see non-use of social media in a number of attitudes, such as a desire for anonymity and privacy. These can be desirable for a number of reasons unconnected to stigma, yet they remain closely associated with avoidance of disclosure (Fogel and Nehmad, 2009). The urge to avoid disclosing identifying information is common for stigmatised groups in daily life and this urge can be heightened online as the risks of uncontrolled disclosure are greater (Fogel and Nehmad, 2009; Harrell, 2009). Conversely, an online context can allow people to feel more confident and less inhibited as anonymity and accessibility enable participants to share in a lower risk environment than face-to-face. The rise of online health fora and other forms of online social support provide myriad examples of this confidence (Chuang and Yang, 2010; Lamberg, 2003; Maitland and Chalmers, 2011; Oh and Lee, 2012, Oostveen, 2011, Sutcliffe, Gonzalez, Binder and Nevarez, 2011; Wang and Fesenmaier, 2003; Woelfer and Hendry, 2012).

2.2.1. Faceted identity

Anonymity is one way of managing ‘faceted identities’ commonly adopted on social media. Faceted identity stems from the observation that people have many identities in their self-concepts. These self-concepts are built on the number of roles people assume: such as social roles, familial roles and occupational roles (Farnham and Churchill, 2011; Woelfer and Hendry, 2012). People often aim to maintain separation between these roles and take steps to manage the disclosure or blurring of boundaries between roles. Social media that assumes a singularity of identity is inadequate “as people create connections to others from multiple areas of their lives” (Farnham and Churchill, 2011:359). The inadequacy of one type of ‘use’ is a design challenge. Projects such as The Advanced Identity Representation (AIR) project specifically seeks to empower users against the effects of stigma via identity management capability (Harrell, 2009). Woelfer and Hendry employ identity management to balance fostering pro-social ties and maintaining boundaries between communication spheres (Woelfer and Hendry, 2012). For a technology to support identity management, different modes of use and non-use need to be available.

2.2.2. Stigma, non-use and online health communities

We looked at a number of examples of online health communities (OHCs) to understand what may benefit HealthMap users. In making this comparison, it was important to consider that a primary design target user for HealthMap is men who have sex with men, over the age of 40. The similarities and differences between user groups had a significant bearing on how much we inferred for HealthMap. Research indicates that single working men are the most cautious about managing faceted identity and the least comfortable sharing on social networks (Farnham and Churchill, 2011). Older men are known to be at risk of declining social networks (Alaoui, Lewkowicz and Seffah, 2012; Sankar and Nevedal, 2011; Vance et al., 2008). Women are often more disposed to adopting social stress-coping strategies and they are generally the majority participants in health online communities. (Mo, Malik and Coulson, 2009). Predicting propensity to use social media is hampered by a lack of research into social media non-participation, but a generalisation can be made that people’s social media use mirrors their offline social behaviour (Hargittai, 2008).

Some studies have reported that people with higher risk-taking attitudes are more likely to create social media profiles and that similar social technology experiences can be empowering for non-stigmatized users while disempowering for stigmatized users (Fogel and Nehmad, 2009; Oostveen, 2011). This generalization is also borne out by an HIV-specific online support study that found frequent users were more likely to be young females (Mo et al., 2009). Sutcliffe et al observe *...that social affordances may have* *an indirect relationship with users' aims, motivations, and behavior...' indicating '...subtle relationships between theory, design, and use of SMTs...* [Social Media Technologies] (Sutcliffe, et al., 2011:1062).

While online support groups can clearly appeal to stigmatized groups who avoid face-to-face interactions, (Cooper, 2001), OHCs have not penetrated widely into the lives of people living with chronic disease or HIV. A 2010 survey of people living with chronic disease in California reported a 1.8% use of online support groups (Owen et al., 2010:442). Assuming that avoidant stress-coping is a constant, finding a successful approach to designing online social support for PWHIV poses a significant challenge.

Recent work in the design of 'object-centred' social networks suggests a possible approach. Ploderer, et al. described using digital content, 'objects' as stimuli to support varying degrees of indirect and direct online social interaction. They described their design as aimed at 'ambivalent socialisers', that is, people experiencing stigma in regards to behaviour change (Ploderer, et al., 2015).

2.3. Health information seeking

The picture painted from studies of health information seeking is more optimistic. In a 2013 Australian survey, 50.7% of PWHIV nominated the Internet as providing important sources of information about HIV treatment and about living with HIV (Grierson, Pitts and Koelmeyer, 2013). Since the earliest days of the AIDS epidemic, many HIV positive people have taken an active role in health advocacy and medical research. Many long-diagnosed PWHIV have experienced HIV activism, HIV peer support and HIV community organisations have had long associations with HIV researchers. In the past this led many people to actively seek diverse information on the clinical and social aspects of HIV (Grierson et al., 2013). For HIV self-management, many PWHIV are highly literate health consumers. However, while literacy around HIV treatment may be high, the future of ageing as an HIV positive person on combination antiretroviral treatment (cART) remains largely uncharted territory. There is a growing need for information to inform management of co-morbidities, 'premature' ageing, and access to care support services. The HIV Futures 7 Report reveals almost a third of PWHIV perceive that a lack of information makes some decision making difficult (Grierson et al., 2013).

The significance of information seeking in the lives of PWHIV presents information demand as a design opportunity. The role of non-use in information seeking and the socially affective elements of information behaviour will be discussed further.

3. Research Method

As action researchers, we reflected on the data from our immersion as HealthMap designers. For this paper, our guiding reflective question was: What does the data say with regards to the suitability of social media applications for HealthMap users? Our enquiry employed three strategies: i) we reflected on the design insights and working assumptions developed during the HealthMap design immersion with regards to social media; ii) we consulted literature across stigma, HIV stigma, stress coping strategies, ageing with HIV chronic disease self-management and non-use of technology; iii) the analysis of the HealthMap qualitative research data revealed the impact of stigma on social connections, health support and social media technology.

The results from the data were compared with findings from the relevant literature to develop further insights and to suggest implications for design. In this section we explain the HealthMap design phases (see Figure 3) and then describe our methods for reflective analysis of the design immersion and of the data.

[*Figure 3 The HealthMap design phases*]

3.1. HealthMap design data

HealthMap data generated during the design phases are described below.

3.1.1. Phase 1

In Phase 1, the design team comprised: an HIV social researcher, a hospital-based HIV treatment provider / clinical researcher, and an occupational therapy PhD candidate with special interest in HIV and chronic disease self-management. This domain expertise represents over 40 years of research and work with PWHIV.

During Phase 1, the team conducted a number of activities to inform design. These included: Concept Mapping workshops conducted with PWHIV and Key Informants (KI, e.g. peer support workers, practice nurses), semi-structured interviews with 33 PWHIV and 14 KIs, and a systematic review of technology-based interventions supporting chronic disease self-management. The PWHIV interview data addressed questions such as: the impact of HIV, interactions with healthcare providers, use of technology, approaches to self- management of health and wellbeing and psychosocial factors (Dodson, S., Batterham, R., McDonald, K., Elliott J. H. & Osborne, R., for the HealthMap Project Team (Under review). A systematic analysis of needs of people living with HIV in Australia: stakeholders views of the key elements for a healthy life).

3.1.2. Phase 2

During Phase 2, the data generated in Phase 1 was analysed and new data generated to identify potential design touch points. Project documents such as the original National Health and Medical Research Council grant application were also made available to designers. Design scoping was achieved through collaborative design workshops to create experience maps, empathy maps, and PWHIV personas and from a technology-use survey of PWHIV distributed through HIV treatment clinics (Williams et al, 2014). Designers also conducted their own analysis through affinity mapping and journey mapping.

3.1.3. Phase 3

Phase 3 was a Design Intensive to develop the HealthMap design principles and initial project concepts. The Cluster Randomised Control Trial primary and secondary outcomes were used as aims in shaping the design and gave direction when exploring data. Team sketching workshops were conducted for idea generation and concept critique and refinement.

Direct participation from PWHIV early in the Design Intensive was problematic because of time constraints and ethics approval constraints. However, in the later stages, user interviews were conducted with PWHIV and HIV treatment providers for data gathering and wireframe concept critiquing. The HealthMap intervention will be evaluated in a two-year cluster-randomised control trial that commenced 2015.

3.2. Reflexive analysis

For this paper, two main sources of data were explored: (i) the working assumptions that developed during the design phases, and (ii) the Phase 1 PWHIV interview data. Figure 4 below shows this process.

[*Figure 4 Research process*]

3.2.1. Qualitative data

Excerpts from eighteen PWHIV interviews were analysed to identify observations, needs and ‘pain points’ for stigma, social connections, health support and social media technology. Using a rapid, lean design methodology, notes were made on colour-coded sticky notes and affinity maps were made to search for patterns and themes. These results were used to prompt direction for the literature search and to form the research objectives.

3.2.2. Working assumptions during design immersion

HealthMap designers developed a shared knowledge with the HIV domain experts and gained insight into the barriers against social media engagement for PWHIV.

Many early design suggestions for potential engagement with existing social media applications were rejected by the HIV researchers as not suitable. Exposure to the qualitative data allowed designers to empathize with the difficulties for many PWHIV, including discriminatory experiences, concern over data privacy and perceptions that social media sites were not benevolent environments. Careful consideration was needed for the design in relation to non-use of social media technology.

The Phase 2 and 3 collaborative workshops allowed the designers and HIV researchers to explore, test and agree on a variety of assumptions regarding patients’ lived experiences. These included social isolation and adoption or rejection of social media. This process of assumptions agreement was through collaboratively building patient personas (Williams et al. 2014). Two working assumptions for the HealthMap design were: (i) that both physical and psychosocial barriers to exercise, healthy eating and smoking cessation would need to be addressed, and (ii) that there was no scope to design social media features initially but pervasive social media might provide some opportunity in the future.

4. RESULTS

4.1. Working assumptions analysis

Social isolation is a common experience for PWHIV and impacts on wellbeing and self-efficacy, however it was not clear what the appropriate application of social features might be within HealthMap. During Phase 1 it became clear that many PWHIV experience varying degrees of social isolation and loss of social connections through causes such as ill health, bereavement, relocation, relationship breakdowns and lack of connection with HIV support organizations. The links between this loss of social connection and complex stigmas was clear from our data during the collection and analysis of Phase 1 data.

During Phase 2 design work we had developed a working assumption that stigma and other complexities made ‘off the shelf’ social media platforms, such as Facebook, unsuitable for the HealthMap intervention. This was supported by our Phases 2 and 3 ‘Technology Use Survey’ (See Table 1) that showed that although the majority of respondents had smartphones and computer access to the internet they were not frequent users of social media. These working assumptions were compiled through the team’s collaborative exploration of insights, from the qualitative data and the survey results.

Table 1 – HealthMap survey of PWHIV technology use

The HealthMap design priorities evolved to broaden PWHIVs existing interactions with healthcare providers, which were largely trusted and longstanding relationships. These were likely to offer fewer barriers to engagement than simply trying to stimulate new social behaviours. Additional social support is offered in HealthMap through health coaches and moderated online peer chat sessions.

4.2. Data analysis – Stigma

The HealthMap data showed strong evidence that stigma plays a significant role in the lives of people living with HIV. Stigma is more accurately described as ‘stigmas’ because there are multiple sources of stigma and attitudes to disclosure that cannot be attributed to just one source. The excerpts below give some examples of the types of stigmas experienced:

Excerpt 1 – Types of stigma

(a) So have you been seeing the same dentist?

> *I have but ... I’ve got to tell him that I am HIV positive, whereas he should be using total universal care and treating every single patient he has as HIV positive and it’s not fair, and I feel like it’s like coming out every single time*
>
> So you have to disclose every time you go?
>
> *Yes ... every six months I dread going to the dentist, so I actually put off the dentist – it’s actually* [the most] *infrequent health profession I see, and it’s because of that experience…*

(b) *But I also find sometimes I do need support, but my family, ... I can’t remember when I’ve heard the word AIDS or HIV come out of their mouths, it’s sort of, it’s there, but it’s not discussed, and they don’t even really ask, they never ask how I’m going or how are the numbers or, they just assume, I don’t know why, like if you had cancer surely people would be asking all the time, but HIV seems to still be a topic which people are very wary of getting into.*

4.3. Data analysis – lack of connection to HIV support organizations

A common theme in our data was a lack of connection to organizations supporting PWHIV. Some PWHIV had never accessed them, some had around the time of initial diagnosis but not continued, some had been closely involved with support organizations in the 80s and 90s but did not maintain the connection and others had low level or sporadic connections. Those most likely to be connected were facing challenges functioning in daily life and in need of quite high levels of support. This fitted with a perception by many PWHIV that HIV support organizations were for people not managing daily life or as a last resort if one faced practical difficulties. Not wishing to identify with people ‘not coping’ was one factor in the feeling that HIV support organizations were not for them. There was also a perception that HIV support organizations had become more impersonal since the time when they had been volunteer-led.

Excerpt 2 Lack of connection to organizations supporting PWHIV

(c) Have you accessed the services of PLC [Positive Living Cenre] or VAC [Victorian AIDS Council]?

> *I have gone to PLC and I have used the...kitchen and the whole bit. But if you are someone who, ... if you are someone who is earning decent money in whatever profession you are and happens to be positive, if you go to the PLC ... you don’t necessarily get a feeling that it’s the right place for you to be.... I have sent a couple of people there and I have gotten comments back, ‘ I found it really off putting’. ... it’s just not a place where professionals will go in and feel comfortable and want to hang out and stuff because it’s a little bit of a hangout for people who are not working.*
>
> What about VAC, did you try any of their services?

(d) *Yeah I went to VAC ... and saw a counsellor initially and that was fantastic. But I found VAC a bit clinical…then ACON took it over. And the minute that happened it slowly got eroded, you know they closed down, they moved it, they said the building wasn’t safe so they moved into the ACON building.*

> *People don't like going there because of what they do or don't do in there and they closed down the larder. It really does disenfranchise people, yeah they just, and they just don't seem to care, yeah.*

4.4. Data analysis – Support seeking / non-use

Most PWHIV interviewed had very limited sources of support for their health, often only including their HIV treatment provider. Reasons for not seeking support were varied and often had an explicit or implicit connection to stigma. Support seeking was often viewed as a disclosure of something undesirable (for example inability to function, HIV status, financial need) and therefore avoided.

Excerpt 3 Feelings of disclosure around support seeking

(e) *My main problem or concern right now is that my family are all in a regional town, ... I rarely see them. I am living on my own. And as I grow older I have nobody at home and if something goes wrong – God knows what's going to happen...I don't know frankly what's going to happen to me when I get to a stage where I can't look after myself.*

Is that something that you have discussed with your family ever?

No... they have their own problems to deal with. They don't want their ageing dad on their back as well.

And what about your friendship network? Do you have a lot of friends?

Not a great deal.

(f) *Well look everyone, everyone I know knows about it but when it comes to support the only person I really talk to about it is my doctor. Because the other people I know, I have, yesterday I went out with a friend of mine who is HIV positive and we just grumbled about the same thing, you know, he has the same problems too, you know...And yeah, yeah. I have friends who are heterosexual and not positive and I don't talk to them about it because they wouldn't understand...*

4.5. Support Seeking – accessing information

A number of interviewees expressed a desire for access to broad HIV information relevant to their health, wellbeing and to planning for the future.

Excerpt 4 Need to access information

(g) We have talked about technology. Can you think about any particular benefits of that, of technology especially?

Being able to ... look for information on a faceless value means that you don't have to tell people you know, what you have got…So this anonymity that comes with it, you know. And that's so beneficial, like it's paramount.

Can you think of any drawbacks?

No. No like I suppose it's less personal to certain extents, but that's not what I am looking for…The more ... the easier the access is to information the better it is for everybody.

(h) What kinds of things would help you? What kind of apps or… internet based kind of services would…

You know, what are your basic services? Where are key places in that state to go for support, for mental health support period, just say mental health support? You know, ... These are the places to go

> *where you know you can actually go to a place where someone is non judgmental of the situation you are in but is there to help you for whatever reason… These are places, you know, etc., that are not necessarily ... a haven but they are not going to judge you.*

4.6. Social media

Attitudes to social media were diverse, and seemed to reflect demographic patterns, such as age. Some interviewees had no interest in online social media. Many had very compartmentalized approaches to social media, accessing Facebook, email and online fora for very specific purposes, often not HIV-related. Many reported negative experiences when participating in online social applications, Facebook and online sex/dating/chat sites were given as examples of discrimination and rejection on disclosure of their HIV status. Others reported witnessing discriminatory attitudes while 'browsing' which did not encourage them to participate.

Excerpt 5 Stigma and social media

(i) Do you do any dating or cruising picking up on[line]?

> *Look the sites are there and I have tried. But everyone is so ... there is this thing you know like what do you look like? .... I've got a Facebook stalker..* They went to a lot of trouble to set up a false profile with a picture…And *I thought who is this?... I thought oh they must have went to school with me. And then it slowly started. And then '*[Name] *the Homo', we don't want your sort at the thing school reunion… I went and saw the Federal Police about it…*

(j) You don't use any of the social networking?

> *I have done, but no, no, nothing but bloody trouble. I don't do Facebook, I refuse. You know, after my experiences on Gaydar or whatever these things are, not where I want to go, you know, I was naïve enough to say well who knows who you're going to meet, but I wasn't looking for what they were looking for you know. It was hideous. No.*
>
> So you don't do any of that?
>
> *No…I have done, I have tried it, you know, had a look and no, it's not for me.*
>
> OK
>
> *You find out the hard way.*

4.7. Literature analysis

In consulting the literature addressing stigma, support seeking and stress coping, we note that HIV stigma is pervasive, multilayered and leads to social isolation. We also note the stress coping strategy of avoidance as a pervasive behaviour through the effects of over-generalisation; though this is subject to a number of influences at any given point and is not static. We recognize the key role that resilience and self-efficacy play in combating the effects of stigma and the role that social support can play in building resilience and self-efficacy. At this point in time social media and online health communities are not widely utilized sources of social support for health by PWHIV, especially by those who are longer-term diagnosed (Kalichman, et al., 2006; Mo, et al. 2009).

In addition to social support, access to relevant health information is valued by PWHIV and is also an important tool for building self-efficacy (Earnshaw and Quinn, 2012; Pope, Eaton and Kalichman, 2005). Like online social contexts, online information behaviour, (beyond just information seeking) has been shown to mirror peoples’ existing behaviours, (Godbold, 2006). These findings present designers with an awareness of design constraints and with a range of design opportunities. Constraints appear in the continued presence of non-use. When seeking information online people can avoid what they perceive to be dissonant with what they wish to find, they can avoid information from sources they perceive as unreliable and they can actively destroy information (Case, et al., 2005; Godbold, 2006; Wilson, 1999). For PWHIV the internet can present an overwhelming volume of information from varying sources. Some HIV information can be medically unreliable and not evidence-based. Ascertaining quality of information can be a persistent challenge and barrier to accessing support.

Opportunities are presented through the information seekers’ intrinsic motivation to ‘bridge a gap’ in personal knowledge, through the inherently social exchange of information sharing and information endorsement, and through potential semantic features that support the perception of empathy and social support (Bojārs, et al., 2008; Clemens and Cushing, 2010; Godbold, 2006; Wilson, 1999). Engeström observes how successful social media are typically built around ‘objects’ or activities that mediate social interaction between strangers (Engeström, 2005; Ploderer et al., 2015). In this way, information seeking may act as a meaningful activity that counterbalances types of non-use. Informational support has been credited with greater impact on perceived empathy than social support (Nambisan, 2011). From the domain of HIV research, informational support has been equated with emotional support and described as having a positive impact on quality of life (Quinn and Chaudoir, 2009; Slater et al., 2012; Veinot, 2009). The question of how trust is built in OHCs reinforces the potential for information seeking as a socially affective experience. Also allowing people time to adjust their involvement is essential to building trust (Veinot, 2009). Fan demonstrates how OHC characteristics, such as perceived similarity and informational quality, can foster a perception of benevolence and empathy even in the absence of direct communication between users (Fan, et al., 2010).

These insights contribute to a richer understanding of technology ‘use’ and ‘non-use’ and the fluctuations between these two modes in the way people approach technology (Satchell and Dourish, 2009; Baumer et al., 2015).

5. Discussion

The HealthMap data concur with the findings from the literature reviewed. They clearly show a prevalence of non-use among PWHIV and reveal a range of stigma arising from: HIV, sexuality, ageing, drug use, loss of fitness, loss of function, body dysmorphia, cognitive impairment, sexuality, ethnicity, mental health, unemployment, financial need and loss of social status. In our data there was a perceived lack of social support, which existed for both the socially isolated and the socially connected. There was also a perceived lack of accurate and relevant information to support planning, decision-making and access to care with a concurrent desire to access relevant information.

5.1. Design Tensions

From our data and from our review of related literature on stigma and stress-coping strategies we have developed an understanding of the tension that stigma inherently brings when designing for social support. This is presented as Designing in the face of stigma: a design tension framework’, (Figure 5).

[*Figure 5 Designing in the face of stigma: a design tension framework*]

This framework illustrates the barriers to accessing potential support due to the effects of stigma. Stigma and non-use remain as constants, with the effect that any anticipated access to support is, at the same time, an anticipated act of disclosure, possibly triggering an avoidant stress-coping response. We suggest that attempting to design to ameliorate the direct effects of stigma is not likely to succeed, due to the complexity and multi-faceted nature of HIV stigma. Instead we propose designing to accommodate non-use, in a sense supporting non-use, but adding the motivating factor of a meaningful activity to potentially override an initial avoidant response. The possible impact of a meaningful activity is shown in the 'Finding meaningful support in the face of stigma: a design tension framework'(Figure 6).

[*Figure 6 Finding meaningful support in the face of stigma: a design tension framework*]

5.1.1. Accommodating non-use

How to accommodate non-use is a design challenge for further research. We suggest designs that enable the user to moderate their levels of engagement and exposure within a platform could support fluctuations in willingness to interact. A design that allows users to 'dip their toe in and out of the water', to disengage and re-engage over time will possibly support users when they feel avoidant and when they feel motivated to enter the platform. Being able to 'dip in and out' could also support trust-building over time.

From the relevant literature and the HealthMap data we know that sensitive identity management, and allowing users to control levels of anonymity and disclosure, will play a key role in maintaining an individual's confidence in a platform. We equate 'dipping a toe in and out' of HealthMap with the "continually negotiated practice" advocated by Baumer et al., (2015:54).

5.1.2. Meaningful activity

In order for an activity to be meaningful to the user it must be derived from the user's own priorities, needs and desires. This predicates the need for any design to take a user-centred, empirical approach. Many design methods exist for eliciting and identifying end-user goals: the fields of User-Centred Design, Participatory Design, Service Design and Community-Based Design research are all methodologies that offer best practices for co-design with highly sensitive user groups (Clements-Nolle and Bachrach, 2010).

The HealthMap research suggested that the most commonly identified meaningful activity was access to relevant information regarding ageing on HIV treatment. Several interview participants expressed the desire for a 'one-stop-shop' where broad information could be accessed to offer support when experiencing difficulties and to enable forward planning. There are a number of areas HealthMap can explore to design a socially affective experience when providing information. Rather than direct social features, such as discussion groups and allowing comments, more indirect features can allow a perception of shared experience, benevolence and empathy. 'Object-centred sociality' deliberately includes 'like' buttons, 'favourite' stars, number of views counters and comments fields to provide 'social traces'. These suggest a shared space with people having similar experiences (Ploderer et al., 2015). There is also the opportunity for sociability through allowing users to suggest or contribute information. Reliability, accuracy and relevant of information would all require a content strategy that includes careful curation and moderation of any user contributions. Existing digital information collaborative features such as social bookmarking and user-defined category tags (folksonomies) provide interesting opportunities for socially affective information seeking and sharing (Bojārs et al., 2008; Golovchinsky, Qvarfordt, and Pickens, 2009),

6. Conclusions

Through reflecting on the three areas of: (i) HealthMap design assumptions, (ii) HealthMap qualitative data and (iii) the literature on HIV stigma, stress coping, social support, chronic disease self-management, online health communities and technology 'non-use' we conclude that 'off the shelf' social media features are not suitable for PWHIV experiencing social isolation. The basis for our conclusion is captured in the ’Designing in the face of stigma’ design tension framework which displays the pervasive impact of complex HIV stigmas in the lives of PWHIV, their role in preventing PWHIV from accessing support and the role of technology non-use a stress coping strategy.

Another contribution of this paper is to articulate the persistent presence of stigma in the lives of PWHIV that requires design solutions accommodating non-use while at the same time supporting attempts to access support. In this way, designs need to allow for fluctuating attitudes towards participation within an individual user, allowing the user to ‘dip their toe in and out of the water’ of an online social platform. We identify sensitive management of faceted identity as a key component to maintaining user engagement across fluctuating attitudes and an area that requires further research.

We further contribute a design strategy employing a user-defined ‘meaningful activity’. This allows a design approach that can deliver socially affective user experience, even for those commonly ‘non-users’ of social media. This proposed design strategy is demonstrated in the ‘Finding meaningful support in the face of stigma’: design tension framework. This framework, adds meaningful activity to the ‘Designing in the face of stigma’ framework. The aim of the framework is to disrupt the support seeking/non-use pattern and invite the user to take a different approach.

For HealthMap, the meaningful activity identified through research was information seeking. Therefore we recommend testing design for collaborative information features to enable access to support and potentially alleviate the effects of social isolation for PWHIV. We also recommend testing design for social ‘trace sensing’ features for existing HealthMap content.

Limitations

As this is a reflexive paper, the frameworks and strategies proposed are untested. We recommend further design work and research to evaluate how the design frameworks can support health technology design strategy.

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References

Addis, M. E., & Mahalik, J. R. (2003) Men, Masculinity, and the Contexts of Help Seeking. American Psychologist, 58(1), 5–14. doi:10.1037/0003-066X.58.1.5

Alaoui, M., Lewkowicz, M., & Seffah, A. (2012) Increasing Elderly Social Relationships Through TV Based Services. In Proceedings of the 2nd ACM SIGHIT International Health Informatics Symposium (pp. 13–20) Miami, Florida, USA: ACM. doi:10.1145/2110363.2110369

Bandura, A. (1986) The Explanatory and Predictive Scope of Self-Efficacy Theory. Journal of Social and Clinical Psychology. New York, NY, USA: Guildford Publications Inc. doi:10.1521/jscp.1986.4.3.359

Baumer, E. P. S., Burrell, J., Ames, M. G., Brubaker, J. R., & Dourish, P. (2015) On the importance and implications of studying technology non-use. *Interactions*, *22*(2), 52–56. doi:10.1145/2723667

Bojārs, U., Breslin, J. G., Peristeras, V., & Tummarello, G. (2008) Interlinking the so- cial web with semantics. IEEE Intelligent Systems, 23(June), 29–40. doi:10.1109/ MIS.2008.50

Case, D. O., Andrews, J. E., Johnson, D. J., & Allard, S. L. (2005) Avoiding versus seeking : the relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts. Journal of the Medical Library Association : JMLA 93(3) Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1175801/

Chenard, C. (2007) The impact of stigma on the self-care behaviors of HIV-positive gay men striving for normalcy. The Journal of the Association of Nurses in AIDS Care : JANAC, 18(3), 23–32. doi:10.1016/j.jana.2007.03.005

Chuang, K. Y., & Yang, C. C. (2010) Helping you to help me: Exploring supportive interac- tion in online health community. Proceedings of the American Society for Information Science and Technology, 47(1), 1–10. doi:10.1002/meet.14504701140

Clemens, R. G., & Cushing, A. L. (2010) Beyond everyday life: Information seeking behavior in deeply meaningful and profoundly personal contexts. Proceedings of the American Society for Information Science and Technology, 47(1), 1–10. doi:10.1002/ meet.14504701228

Clements-Nolle, K., & Bachrach, A. M. (2010) Community-Based Participatory Research for Health: From Process to Outcomes. In M. Minkler & M. Wallerstein (Eds.), Com- munity-Based Particpatory Research (2nd ed., pp. 175–186) John Wiley & Sons LTD. ISBN 978-04-709-3249-0

Cohen, S., Evans, G. W., Stolols, D., & Krantz, D. S. (1986) Behaviour, health and en- vironmental stress (pp. 1–23) Springer US. ebook ISBN 978-1-4757-9380-2 doi:10.1007/978-1-4757-9380-2_1

Cooper, G. A. (2001) Online Assistance For Problem Gamblers : An Examination Of Participant Characteristics (Doctoral dissertation) University of Toronto. Retrieved from http://www.cghub.org/Cooper_Dissertation_2001.pdf

Earnshaw, V. A, & Quinn, D. M. (2012) The impact of stigma in healthcare on people living with chronic illnesses. Journal of Health Psychology, 17(2), 157–68. doi:10.1177/1359105311414952

Earnshaw, V. A, Quinn, D. M., & Park, C. L. (2012) Anticipated stigma and quality of life among people living with chronic illnesses. Chronic Illness, 8(2), 79–88. doi:10.1177/1742395311429393

Fan, H., Smith, S. P., & Lederman, R. (2010) Why People Trust in Online Health Communities : An Integrated Approach. In 21st Australasian Conference on Information Systems. Brisbane. Retrieved from: http://ssrn.com/abstract=1775303

Farnham, S. D., & Churchill, E. F. (2011) Faceted Identity , Faceted Lives : Social and Technical Issues with Being Yourself Online. Information Systems Journal, 359–368. doi:10.1145/1958824.1958880

Fogel, J., & Nehmad, E. (2009) Internet social network communities: Risk taking, trust, and privacy concerns. Computers in Human Behavior, 25(1), 153–160. doi:10.1016/j. chb.2008.08.006

Godbold, N. (2006) Beyond information seeking: towards a general model of information behaviour. Information Research-an International Electronic Journal, 11(4) Retrieved from http://informationr.net/ir/11-4/paper269.html

Goffman, E. (1990) Stigma: notes on the management of spoiled identity (2nd ed.) London: Penguin. ISBN 978-0140124750

Golovchinsky, G., Qvarfordt, P., & Pickens, J. (2009) Collaborative information seeking Computer, 42(3), 47–51. doi:10.1109/MC.2009.73

Grierson, J., Pitts, M., & Koelmeyer, R. (2013) HIV Futures Seven: The Health and Well- being of HIV Positive People in Australia (Monograph) Melbourne: The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia. Retrieved from http://pozhet.org.au/wp-content/uploads/2013/11/HIV-Futures-Seven- Report.pdf

Hargittai, E. (2008) Whose Space ? Differences Among Users and Non-Users of Social Network Sites, Journal of Computer-Mediated Communication 13(1), 276–297. doi:10.1111/j.1083-6101.2007.00396.x

Harrell, D. F. (2009) Computational and Cognitive Infrastructures of Stigma : Empowering Identity in Social Computing and Gaming. In Proceedings of the seventh ACM conference on Creativity and Cognition (pp. 49–58) Berkeley, California, USA: ACM. doi:10.1145/1640233.1640244

Herek, GM. (1999) AIDS and stigma. *The American Behavioral Scientist, 42*(7), 1106-1116.

Herek GM. (2004) Beyond “Homophobia”: Thinking about sexual prejudice and stigma in the twenty-first century. Sex Res Soc Policy [Internet]. 2004 Apr;1(2):6–24. Available from: http://link.springer.com/10.1525/srsp.2004.1.2.6

Kalichman, S. C., Cain, D., Cherry, C., Pope, H., Eaton, L., & Kalichman, M. O. (2005) Internet use among people living with HIV/AIDS: coping and health-related correlates. AIDS Patient Care and STDs, 19(7), 439–448. doi:10.1089/apc.2005.19.439

Kalichman, S. C., Cherry, C., Cain, D., Weinhardt, L. S., Benotsch, E., Pope, H., & Kalichman, M. (2006) Health information on the Internet and people living with HIV/ AIDS: information evaluation and coping styles. Health Psychology: Official Journal of the Division of Health Psychology, American Psychological Association, 25(2), 205–10. doi:10.1037/0278-6133.25.2.205

Lamberg, L. (2003) Online empathy for mood disorders: patients turn to internet support groups. JAMA : The Journal of the American Medical Association. doi:10.1001/jama.289.23.3073

Lazarus, R., & Folkman, S. (1984) Stress, appraisal and coping (1st ed.) New York: Springer New York.

Li, M., & Yang, Y. (2009) Determinants of problem solving, social support seeking, and avoidance: A path analytic model. International Journal of Stress Management. doi:10.1037/a0016844

Mahajan, A. P., Sayles, J. N., Patel, V. A., Remien, R. H., Sawires, S. R., Ortiz, D. J., … Coates, T. J. (2008) Stigma in the HIV / AIDS epidemic : a review of the literature and recommendations for the way forward. AIDS, 22(2), 67–79.

Maitland, J., & Chalmers, M. (2011) Designing for peer involvement in weight manage- ment. Proceedings of the 2011 Annual Conference on Human Factors in Computing Systems - CHI ’11, 315. doi:10.1145/1978942.1978988

McDonald, K., Elliott, J., & Saugeres, L. (2013) Ageing with HIV in Victoria: Findings from a qualitative study, HIV Australia 11(2), 13. Retrieved from http://search.informit.com.au/documentSummary;dn=564861079707209;res=IELHEA

Mo, P. K. H., Malik, S. H., & Coulson, N. S. (2009) Gender differences in computer- mediated communication: a systematic literature review of online health-related support groups. Patient Education and Counseling, 75(1), 16–24. doi:10.1016/j. pec.2008.08.029

Nambisan, P. (2011) Information seeking and social support in online health communities: impact on patients’ perceived empathy. Journal of the American Medical Informatics Association : JAMIA, 18, 298–304. doi:10.1136/amiajnl-2010-000058

Oh, H. J., & Lee, B. (2012) The effect of computer-mediated social support in online com- munities on patient empowerment and doctor-patient communication. Health Commu- nication, 27(1), 30–41. doi:10.1080/10410236.2011.567449

Oostveen, A. (2011) The Internet as an Empowering Technology for Stigmatized Groups : a Case Study of Weight Loss Bloggers. In Proceedings of the 25th BCS Conference on Human-Computer Interaction (pp. 114–119) British Computer Society Swinton, UK. Retrieved from http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2003129

Owen, J. E., Boxley, L., Goldstein, M. S., Lee, J. H., Breen, N., & Rowland, J. H. (2010)Use of Health-Related Online Support Groups: Population Data from the California Health Interview Survey Complementary and Alternative Medicine Study. Jour- nal of Computer-Mediated Communication, 15(3), 427–446. doi:10.1111/j.1083-6101.2010.01501.x

Ploderer, B., Smith, W., Pearce, J. O. N., & Borland, R. O. N. (2014) An Object-Centred Approach to Encourage Online Participation in the Context of Behaviour Change. Computer Supported Cooperative Work, 1(26), 1–27. doi:10.1007/s10606-014-9212-3

Quinn, D. M., & Chaudoir, S. R. (2009) Living with a concealable stigmatized identity: the impact of anticipated stigma, centrality, salience, and cultural stigma on psychological distress and health. Journal of Personality and Social Psychology, 97(4), 634–51. doi:10.1037/a0015815

Sankar, A., Nevedal, A., Neufeld, S., Berry, R., & Luborsky, M. (2011) What do we know about older adults and HIV? A review of social and behavioral literature. AIDS Care, 23(10), 1187–207. doi:10.1080/09540121.2011.564115

Satchell, C., & Dourish, P. (2009) Beyond The User: Use And Non-Use in HCI. *Proceedings of the 21st Annual Conference of the Australian Computer-Human Interaction Special Interest Group: Design: Open 24/7*, 9 – 16. doi:10.1145/1738826.1738829

Shively, M., Smith, T. L., Bormann, J., & Gifford, A. L. (2002) Evaluating Self-Efficacy for HIV Disease Management Skills. AIDS and Behavior, 6(4), 371–379. doi:1090-7165/1200-0371/0

Sieckenius, C., Souza, D., & Preece, J. (2004) A framework for analyzing and understanding online communities. Interacting with Computers, 16, 579610.doi:10.1016/j. intcom.2003.12.006

Slater, L. Z., Moneyham, L., Vance, D. E., Raper, J. L., Mugavero, M. J., & Childs, G. (2012) Support, Stigma, Health, Coping, and Quality of Life in Older Gay Men With HIV. The Journal of the Association of Nurses in AIDS Care : JANAC, 1–12. doi:10.1016/j.jana.2012.02.006

Slavin, S. (2012) Results from the stigma audit: A survey on HIV stigma in Australia [on- line]. HIV Australia, 10(1), 27-28. ISSN: 1446-0319. Retrieved from http://search. informit.com.au/documentSummary;dn=642100431762582;res=IELHEA

Sutcliffe, A. G., Gonzalez, V., Binder, J., & Nevarez, G. (2011) Social Mediating Technologies: Social Affordances and Functionalities. International Journal of Human-Comput- er Interaction, 27(11), 1037–1065. doi:10.1080/10447318.2011.555318

Vance, D. E., Moneyham, L., Fordham, P., & Struzick, T. C. (2008) A model of suicidal ide- ation in adults aging with HIV. The Journal of the Association of Nurses in AIDS Care : JANAC, 19(5), 375–84. doi:10.1016/j.jana.2008.04.011

Veinot, T. C. (2009) Interactive Acquisition and Sharing : Understanding the Dynamics of HIV / AIDS Information Networks. Journal of the American Society for Information Science and Technology, 60(July), 2313–2332. doi:10.1002/asi.21151

Wang, Y., & Fesenmaier, D. R. (2003) Assessing Motivation of Contribution in Online Communities An Empirical Investigation of an Online Travel Community. Electronic Markets, 13, 33–45. doi:10.1080/1019678032000052934

Wilson, T. D. (1999) Models in Information Behaviour Research. The Journal of Documentation, 55(3), 249–270. Retrieved from http://ptarpp2.uitm.edu.my/silibus/model.pdf

Williams I., Brereton M., Donovan J., McDonald K., Millard T., Tam A., Elliott J.H., (2014) A Collaborative Rapid Persona-Building Workshop: International Journal of Sociotechnology and Knowledge Development. IGI Global; 2014 6(2):17–35 doi:10.4018/ijskd.2014040102

Woelfer, J., & Hendry, D. (2012) Homeless young people on social network sites. Proceedings of the 2012 ACM Annual Conference on Human Factors in Computing Systems - CHI ’12, 2825. doi:10.1145/2207676.2208686