

Data Timelines as Paths of Expression for Organizational Reflection in Healthcare Participatory Design*

Clare Villalba

Queensland University of Technology
Brisbane, Australia

clare.villalba@hdr.qut.edu.au

Jared Donovan

Queensland University of Technology
Brisbane, Australia

j.donovan@qut.edu.au

Anjali Jaiprakash

Queensland University of Technology
Brisbane, Australia

anjali.jaiprakash@qut.edu.au

Deborah Askew

University of Queensland
Brisbane, Australia

d.askew@uq.edu.au

Jonathan Roberts

Queensland University of Technology
Brisbane, Australia

jonathan.roberts@qut.edu.au

Anthony Russell

University of Queensland
Brisbane, Australia

a.russell@uq.edu.au

Ross Crawford

Queensland University of Technology
Brisbane, Australia

r.crawford@qut.edu.au

Noel Hayman

Southern Queensland Centre of Excellence in Aboriginal
and Torres Strait Islander Primary Health Care
Brisbane, Australia

Noel.Hayman@health.qld.gov.au

ABSTRACT

This paper discusses the early stages of a healthcare participatory design project, where historically recorded ‘hard’ data was used to engage participants in organizational reflection about related (but unrecorded) ‘soft’ data. This uncovered the interconnected history of the organization and allowed participants to collaboratively identify and prioritize design opportunities that could be taken up in subsequent phases of the healthcare design. We share our method for presenting the available recorded data in the form of ‘data timelines’ to start and structure collaborative reflection. We then present the outcomes of our use of this method in the context of the wider healthcare service design project and reflect on the qualities and practicalities of the approach within participatory design.¹

CCS CONCEPTS

• • Human-centered computing~Participatory design

KEYWORDS

Organizational reflection, participatory design, healthcare, diabetes, stakeholders

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1 INTRODUCTION

Participatory organizational reflection on the past can enable learning, better decision making and improvements. Development in organizational learning has identified ‘hard’ factors, such as technical objectives or quantified data often are interconnected with accompanying ‘soft’ factors [1], such as culture and trust. Likewise, soft factors are also shaped by hard factors, which influence how people make sense of them.

In health research, studies on soft data or combining hard and soft data are becoming more common, but are still a minority [2, 3]. In practice, even if individuals recognize the importance of soft factors within their work, more organizational focus in this field tends to be given to hard factors [2–5], for example in reporting, quality improvement and funding. Organizations may overlook that which they cannot count, especially if it is intangible [6]. Due to this ongoing attention, hard data is valued by health organizations and dominates their historical records. This presents a challenge for design researchers examining the historical context of health organizations, in that only part of the historical story is available. Yet this also gives rise to an opportunity to use the hard data as a ‘path of expression’ [7] for sharing of past experiences and collection of undocumented, historical ‘soft’ data.

In the context of a healthcare participatory design project, we used historical hard data to engage participants in discussion and reflection around soft components in order to understand the organizational history and identify potentials for future action.

1.1 Participatory Organizational reflection

Participatory design practitioners view design as a social process, valuing the involvement of stakeholders and emphasizing the designing this involvement [8–11]. In critical design, materials are used to provoke conversation such as

ethnographic data [12] or prototypes [13]. Designers use these methods in participatory design and to “inquire about why things are the way they are and envision how things might be different” [14]. Generative techniques encourage people to tell a story using creative artefacts [15]. Based on psychological theories of memory and creativity [16], generative techniques aim to enable a ‘path of expression’ [17] of meaning, which can be hidden beneath the surface [18].

The use of participatory design methods in health often focus on changes to products or services. Less consideration has been given to the organizations who must implement and maintain these changes [14, 19]. Learning Histories are a method for organizational reflection that use interviewing and feedback to enable change, through semi-public documents [20]. The documents use events of the past to engage people at all levels of the organization in action towards ideals for the future [21]. Visual History mapping methods have also been used as a hands-on approach to assist organizations in reflecting, [22, 23] and learning about their past.

Building on the foundation laid by learning histories and inspired by the use of provocations and generative techniques in participatory design, this research explores a visual technique of using ‘data timelines’ as a path of expression of organizational histories. The method was applied in a health setting, using ‘hard’ clinical and historical data as a provocation in participatory design. This visual method of organizational reflection aims to enable staff to reflect on their organization's history and prepare for joint action.

1.2 Context

With the rise of diabetes comes an upsurge in related complications, the most common being the eye-disease, diabetic retinopathy (DR). Almost all vision-loss due to DR is preventable, yet it still has the potential to be the leading cause of blindness worldwide [24]. Aboriginal and Torres Strait Islander Australians are more than three times as likely than non-Indigenous Australians to have diabetes [25] and retinal screening rates of are just over half (53%), even in major cities.

We present the initial organizational reflection stage from the ‘Working Together’ project, an ongoing participatory service design project with The Southern Queensland Centre of Excellence in Aboriginal and Torres Strait Islander Primary Health Care (CoE). The CoE is a government-funded primary healthcare facility located in Brisbane, Australia. The CoE provides high-quality, culturally appropriate care and has improved urban access to healthcare for Aboriginal and Torres Strait Islander people from the surrounding area [27]. The Australian Diabetes Society’s guidelines for the management of DR, recommend annual screening for Aboriginal and Torres Strait Islander people with diabetes [28]. As part of providing quality diabetes care, ensuring completion of the Annual Diabetes Check (ADC) [29] and with the aim of increasing access, the CoE introduced a DR screening program in 2007.

In 2016, The Australian Government granted \$4.8 Million (AUD) of funding for equipment and training to set up DR screening in more primary healthcare services [30]. Australia’s healthcare system introduced publicly funded coverage for the cost of DR screening in primary healthcare [31].

The ‘Working Together’ project combines participatory design and action research approaches, to enable critical reflection on the history and future of this service [32]. Participatory methods are fitting within this study as they enable community engagement and meaningful collaboration, in alignment with the guidelines for research with Aboriginal and Torres Strait Islander people [33].

2 Methods

This study focuses on a history mapping technique using ‘data timelines’. It was applied in the initial stages of the Working Together project, aiming to enable collective reflection and identification of opportunities.

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Initially, the designers looked to the health service records to understand the history of care, but these focused heavily on

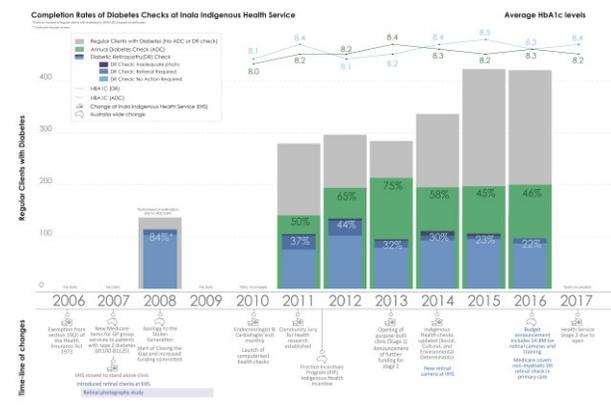


Figure 1: Data timeline visualization version 1
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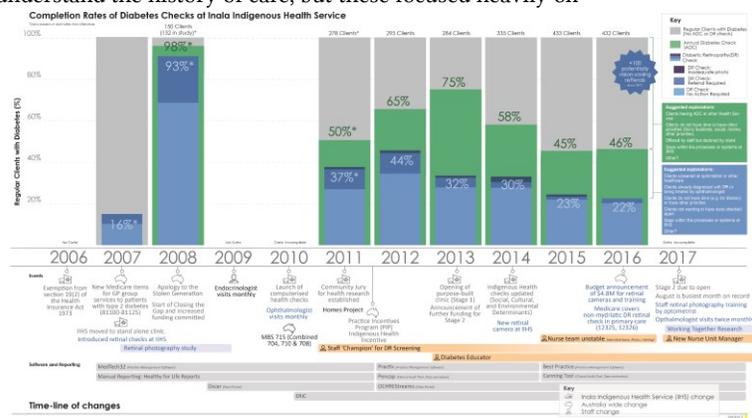


Figure 2: Revised data timeline visualization.
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hard data, leaving gaps in the story. Recorded data included information such as yearly screening rates, yet omitted information such as the staff turnover and the underlying reasons for fluctuating screening rates. A ‘data timeline’ visualization of the organizational history was developed (Figure 1) using available data sourced from the CoE clinical databases, research publications [27, 34–38], government publications [30, 31, 39, 40] and peak-body reports [41, 42]. There was a large amount of clinical and events data available. This was narrowed based on the scope of the research: investigating DR screening as part of the ADC in the years following its introduction at the CoE.

Key CoE staff were invited to a kick-off workshop for the project and a number of follow up sessions were conducted, where the ‘data timeline’ was shared. Participants were invited to add events, share stories, provide interpretations and identify opportunities. This was done verbally or by posting sticky notes on the printed ‘data timeline’ (Figure 3).



Figure 3: Data timeline with participant contributions
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Audio recordings of the workshops were collected. Researcher reflexive notes were recorded and peer debriefing with the research team was used to reflect upon the process and findings as they were identified. The participant discussion, feedback and the reflexive notes were used to update the ‘data timeline’ between workshops.

3 RESULTS AND DISCUSSION

Eighteen CoE staff members took part in the history mapping over 6 workshops, with some staff attending more than one session. The final ‘data timeline’ is shown in Figure 2.

3.1 What did we learn about the health service?

The original ‘data timeline’ (Figure 1) displays ‘hard data’, including completion rates of annual checks, number of regular clients and notable events. The workshop outcomes (for example the staff sticky-note recordings in Figure 3) allowed for the identification of the reasons behind the rates of the DR screening that had led to this resulting ‘hard’ data. Key findings were included in the final ‘data timeline’ (Figure 2).

The process enabled the development of a more complete story of the CoE’s DR screening history, including both hard and soft components. It now tells a story of a health service that continues to expand and gain the trust of the Aboriginal and

Torres Strait Islander community. The CoE introduced DR screening in 2008, initially increasing screening rates to almost 95%. Yet as regular client numbers continue to rise, challenges of maintaining screening coverage have emerged. Staff were able to reflect on these various components (hard and soft as well as tangible and intangible) and identify the interconnections between them. This reflection invited participants to play an active role in critiquing their current service and imagining their future, in alignment with other future workshop methods, allowing them to contribute ‘their knowledge, thereby helping the “right” problems to be solved’ [43].

Staff developed a shared understanding of the history, strengths and opportunities. The findings highlight CoE DR screening was successful as it provides comprehensive eye healthcare from screening to treatment, all annual care is provided in one appointment, and they have a client-focused environment. To ensure future success, staff recognized need for ongoing maintenance and quality improvement focused on client experience; rigorous data; and the supported by engaged staff.

The process also highlighted differences in opinion. There were differing opinions and a lack of clarity regarding which clients should receive an eye check. This arose as patients diagnosed with early-stage DR can be monitored by their GP [28, 44, 45]. Yet new health policies only cover general practice screening for undiagnosed people [46].

Based on this reflective process staff instigated a number of actions: refresher training was organized; discussion commenced regarding redefining roles; staff investigated the feasibility of a diabetes client database; and forms were combined to reduce double-entry. Next steps and priorities for the project were also identified, including interviewing clients of the clinic to understand their experiences.

This organizational reflection spring-boarded the design process. Staff shared important aspects regarding their expectations of the outcomes of the project, including that it would be person-centered, result in outcomes that would have tangible impacts in the clinic and possibly be transferable to other health clinics. Making these requirements explicit enabled the researchers and participants to develop a shared understanding and increases the likelihood that the changes made will be successful [14].

3.2 What did we learn about the process?

Developing the initial ‘data timeline’ was not a straightforward process. The aim of the visualization was not to communicate one meaning or an individual story. It was to enable others to share their own stories and construct their own meaning. This approach contrasts the basic principles of data visualization, which aim to provide a clear story with facts and answers to questions [47, 48]. Segel and Heer have identified the need for balance between author-driven elements and reader-driven elements when developing narrative visualizations [49], yet this is a novel concept in the visualization of health data. Considering this redefined aim, the researchers had to follow slightly different data visualization principles. Two principles

were developed in the process; ‘enabling constructive conversation’ and ‘meeting participants’ expectations’. When considering whether data should be included or excluded, we had to weigh up if it would enable conversation and exploration of soft factors to move forward constructively.

For example, the inclusion of HbA1c data (a blood test used in monitoring diabetes management) in the ‘data timeline’ was considered at length in the iterative process. At the outset, the researchers were informed HbA1c is a valuable measure for patient outcomes, so yearly average HbA1c levels were included in the first ‘data timeline’ as a line graph (Figure 1). When the participants discussed this data in the visualization, it became clear the averages did not have enough detail to inform the story of the data. Based on this feedback the measure was then updated for the next iteration to a stacked bar graph showing more detail, but participants still were not able to use the data to inform the story. This presented a bind. The value placed on the data by some of the participants made us reluctant to remove them from the visualization. Yet participants were not able to link this hard data to the organizational history. This detail was removed in the final version (Figure 2). Still, it remains an open question for us whether there might have been an alternative way to present the HbA1c data to scaffold a constructive discussion.

Participatory design projects run in other health contexts found engagement can be limited if participation impacts clinical duties [50, 51] or cannot fit with the pressurized schedules of health staff [52]. Some of these issues could be overcome in this project due to the iterative technique. Staff were able to attend a workshop that suited them and would fit with their schedules, reducing disturbance to clinical time and enabling contributions from a range of key staff members.

Participatory improvement projects can discourage sharing if they fall into unproductive habits, such as ‘shooting the messenger’ [53] and need to find ways to deal with issues that arise without assigning blame [20]. The visual history mapping technique enabled critical reflection on the service without the designers or participants placing judgment on people involved. It provided a useful way of reframing negatives as an inevitable part of working in complex systems [53] and highlighted opportunities to continue to improve.

3.3 Using ‘hard’ data as a generative tool

Collective reflection on ‘soft’ factors was enabled through the ‘data timeline’. Staff discussed the meaning of the data, suggested reasons for gaps in completion rates, questioned and validated the data and shared stories from different perspectives. For example, staff reflected on when the retinal camera was introduced at the CoE:

“I remember these days and there was a lot of excitement ... And we were showing the photos, there was an engagement, not just, ...by doctors, the nurses and the patients, but there were people coming in going can I get my eyes checked” (Dr Clare Maher, MD)

Our earlier point that ‘hard’ factors can be interconnected with ‘soft’ factors, should not be taken to imply an either-or choice between focusing on ‘hard’ or ‘soft’ factors. Rather, we

see these different data as intimately entangled. By taking ‘hard’ historical data about screening rates, numbers of diagnoses, and historical events, we could open a space for discussion about ‘soft’ factors and how the two unfold simultaneously including what stories, questions and opportunities lay behind these numbers. Latour’s distinction between matters of fact and matters of concern is useful in this respect [54, 55]. The ‘hard’ data was able to express ‘matters of fact’, yet these could not be fully appreciated until they were presented to participants who could identify the interconnections and express their individual matters of concern. Concept formation as suggested by Vygotsky and expanded by Engeström [56] is also useful. Where scientific concepts and everyday concepts come together to progress knowledge sideways (rather than up or down). Staff from the CoE worked through an iterative process where intertwined hard and soft experiences were shared; as new knowledge was made available participants conceptualization of the health service would move sideways. Each providing a complementary, partial conceptualization of the history of the organization enabling us to piece together this history.

This study provides insight into the possibilities of the ‘data timeline’ technique. Yet the generalizability is restricted, as it was implemented in a single context of a health service focused on Aboriginal and Torres Strait Islander health and the organizational structure differs from other health services. Further research should be conducted investigating the use of the ‘data timelines’ in other health services and other ways available historical data, particularly ‘hard’ data, can be used in organizational reflection and participatory design.

4 CONCLUSIONS

This study explores a generative technique for engaging healthcare staff in participatory reflection through presenting available historical data as ‘data timelines’. This method exposed the intertwined ‘soft’ data that was not available in the recorded organizational history. We used this visual technique to map the history of a health service in a participatory design project to enable organizational reflection and identify improvement opportunities. Our reflections on the process and the outcomes provide an insight into the implementation and practicalities of this approach.

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