Connecting the System to Enhance the Practitioner and Consumer Experience in Healthcare
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Recommendations for Enhancing the Implementation and Utility of Shared Digital Health Records in Rural Australian Communities

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Abstract. Internationally, shared digital health records are becoming an important addition to improving contemporary healthcare provision. In 2012, Australia launched its version of a shared digital health record, My Health Record, but enrolment is slow and there remain challenges in its practical implementation. Further, people living with complex and chronic conditions in rural and remote communities often experience challenges in obtaining equitable access to contemporary healthcare provision, including eHealth services. This paper reports on research that explored the experience of and engagement with My Health Record, in a rural Australian community setting. Based on the key research findings, recommendations are presented for improving national roll out of My Health Record. The findings highlight, to understand and engage vulnerable communities and support their adoption and use of shared digital health records, there is a need to move away from traditional models of healthcare delivery toward person-centred care delivered from a digital complex adaptive systems perspective.

Keywords. Shared digital health records, My Health Record, complex chronic conditions

Introduction

Internationally, shared digital health records (SDHRs) are becoming acknowledged as essential in the delivery of quality contemporary healthcare provision. However, the evidence also suggests many SDHRs have been designed and implemented relying too much on commercial companies, designers, or researchers. Those who identify a perceived user need, rather than involving the intended end user [1-3]. Further, the perceived user needs of SDHRs and their resulting design have focused on meeting the requirements of healthcare provider or healthcare system, while overlooking the needs of the healthcare user [4-7].

The use of a SDHR can offer a continuum of equitable healthcare provision in disease prevention, management, treatment and reduction in disparities in care [8]. Individuals who could benefit most from SDHRs are those who create the largest burden on healthcare delivery: people with complex chronic conditions (CCCs), living in rural

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remote communities, disadvantaged because of their limited access to efficient, quality healthcare provision [9]. Australia launched its SDHR, My Health Record (MyHR), in 2012; it remains without significant adoption or any evident holistic implementation and evaluation frameworks [10].

This paper reports on research, which aimed to emphasise practical outcomes identified by exploring the experience of people living with CCCs in a rural community during their engagement with MyHR. Based on the research findings, recommendations for improving national roll out of MyHR are presented. The approach highlights a means to understand and engage vulnerable communities, support their adoption and use of digital tools, and draws attention to person-centred care from a digital complex adaptive system perspective for evaluating and assessing effects at individual, community and healthcare provision levels; the contribution being to support future successful implementation and uptake of similar projects.

1. Method

Based on a qualitative participatory paradigm, a community based participatory research (CBPR) [11] approach was developed and conducted across a southern Tasmanian rural community (ethical approval H0013781). Through purposeful sampling 19 research partners, aged 40-89 years, with two or more CCCs, were recruited from three rural settings. The partners were involved in the research from inception to conclusion and with the researcher perceived as a research community.

Three phases of data collection were undertaken: pre-experience of MyHR, registration and early engagement with MyHR, and post-experience and engagement with MyHR. Data collection techniques included group meetings, individual semi-structured interviews and the researcher's reflective journal. The data collection tools included audio recordings, group and semi-structured interview guides, and live interaction with MyHR as a healthcare user. Data were collected over a 12-month period and incorporated concurrent data transcription and verification (member checking). Data analysis adopted a thematic 'Framework Approach' [12], which engaged the whole research community. The approach was structured in three phases: data description, data management and data interpretation. The phases were subdivided into five iterative stages: familiarisation, identifying a thematic framework, indexing, charting, mapping, and interpretation. By systematically linking the research objectives to 55 indexed labels, charted to 13 categories, mapped to three themes, which identified three key findings. The need for **tailored facilitation**, **resilience** and **reflection**. The approach to data analysis ensured the characteristics and experiences were thoroughly explored and consistently recorded.

2. Results

The three key findings highlight the necessity for SDHRs to be viewed as a digital health tool that supports person-centred care from a digital complex adaptive system perspective. The research identified, **tailored facilitation** recognises the diversity of the healthcare users' needs, and instils and supports competence and confidence required for acceptance of SDHRs.

"[E]verybody likes to be involved and feel they have an opportunity to give ... We're starting and learning together the same as learning computer together you share so much instead of individuals wondering ... working with buddies ... you always learn by how somebody uses something. Yes if you want to know how anything is going to work you give it to the users" (CH13).

Tailored facilitation not only accommodates but also learns from the knowledge and expertise of vulnerable healthcare users, their ability to establish partnerships, and develop trusted learning environments that generate community knowledge. **Tailored facilitation** contributes to the way knowledge and understanding, of the lived experience of CCCs, information computing and technology skills, and the experience of and engagement with MyHR are communicated, for the end user and the researcher.

Resilience involves the ability to adapt to life events and approach sources of stress as positively as possible. The results indicate vulnerable healthcare users should be encouraged to demonstrate and build **resilience** to inform quality healthcare provision and the implementation of SDHRs. Shared information is a practical enabler of personal and community **resilience**. Healthcare provision and community members need to work interactively and transparently to ensure that the correct information is communicated in a timely and effective manner.

"I know my body and how they [CCCs] affect me. It may not be what's written in the books but I need to communicate that ... I think a lot of people are going to the Drs and following what they are saying without question. What happens if that doesn't work for me, or makes me bad? We need a two way street." (CH23).

Combining **resilience** demonstrated and built upon by vulnerable healthcare users with engagement with MyHR, as an enabler of person-centred care from a complex adaptive system perspective, can facilitate the emergence of **resilience** and health in individuals and communities through adaptability, self-organisation, and empowerment.

Reflection demonstrates the benefits and challenges of applying a CBPR approach and principles to digital health research [11]. Benefits would not have emerged through a researcher-focused paradigm. The challenges required strong researcher–community partnerships developed through time, trust and flexibility. **Reflection** also identified challenges associated with the CBPR principles and provided insight into how to address them. Notably researchers should consider extending the principles of CBPR to accommodate digital healthcare and vulnerable communities. **Reflection** considers that building technical and digital healthcare capacity affects the way vulnerable healthcare users engage with their healthcare provision. Therefore, it is worth resourcing CBPR so that it can evolve to incorporate the principles of technology and digital healthcare capacity-building. On **reflection,** these extended CBPR principles will provide opportunity to establish partnerships, with all end users, with a focus on digital healthcare. These partnerships, if appropriately resourced, can assist with identification and dissemination of CBPR best practices within digital healthcare and promote the use of consistent, validated measures for the engagement with and effectiveness of SDHRs.

3. Discussion

In Australia, there is a relatively small body of work that specifically relates to the vulnerable healthcare user's experience of and engagement with MyHR. The findings of this research recommends attention and value should be placed on organisational and policy, community and personal, and research areas.

There must be a diffusion of rights and responsibilities between healthcare users, health professionals and policy-makers, to place more trust in decisions made by healthcare users and communities. Health professionals and policy-makers need to support healthcare users in co-constructing their own identity rather than accepting one constructed by 'experts'. The practical feasibility of greater co-production cannot be measured from a small research study. Further research will identify the practical scope for co-production in other contexts. Even when vulnerable people are informed, empowered, and physically and cognitively able (and especially when they are not), they rarely experience the world of research [13]. They live in the context of a transitional world of a particular person in a particular family or community. **Tailored facilitation** offered real-world opportunity to gain experience of and engagement with MyHR and provides a valuable source of 'here-and-now' healthcare user experience.

Contemporary evidence-based healthcare emphasises the importance of listening to and acting upon the experiences of all stakeholders to help shape future strategies. These must include and be responsive to the diversity of personal capabilities and experiences [14]. Valuing **resilience** and expertise of vulnerable healthcare users empowers them to consider interactive, cooperative relationships with healthcare providers. At policy levels, there needs to be understanding and recognition of personal and community experiences and perspectives, key in the delivery of digital quality healthcare provision [7, 14]. The outcomes of this research indicate that people living with CCCs in a rural community have the capacity to determine, engage, collaborate, and communicate their healthcare needs. In doing so derive opportunity for equity, empowerment, and satisfaction. Using a participatory person-centred approach engages directly with traditionally invisible or hard-to-involve, but directly affected, people and communities. The approach captured knowledge, ability, and opinions, while facilitating a process of understanding and empowerment that has been largely marginalised in digital health research, to the detriment of results and solutions [15].

For an efficient, equitable model of engagement, involvement, and integration to work, there needs to be better understanding of regional and local infrastructure, and systems and training required to engage all stakeholders in the utility of MyHR. A tailored approach is required to redefine existing healthcare models. The specific findings of this research indicate there are several projects that can be undertaken to enhance the uptake and sustainability of MyHR and better understand its limitations.

The essential function of any SDHR is to deliver improvements in healthcare provision experience and ultimately outcomes. Any digital health application needs continuous evaluation to ensure accountability and ongoing improvement. This research has evaluated the experience of and engagement with MyHR. It recommends that the community not only look at how MyHR can help, but reviews the practicalities of the implementation process to achieve the goal of quality healthcare provision. When implementing the relatively new shared digital health solution, MyHR, it is important to separate healthcare provision, which needs to be maintained and enhanced, from processes that need to be changed and improved. Healthcare user and provider communication needs to look beyond the 'what we do', to include questions and explanations as to 'why do we do the things we do?' and 'how could we do things better?' Future research into SDHRs should consider how they translate those beliefs into actions, to extend and complement the current focus on shared decision-making.

A coordinated community participatory approach is required to redefine and contemporise existing healthcare provision models. Replicating this research in other communities: indigenous populations, professional groups in rural communities, a younger cohort, those with severe mental health disease or severe disability, is required to understand the benefits and challenges of MyHR [7, 14].

Follow up research to re-evaluate the personal and community engagement with MyHR after **tailored facilitation** has been removed will allow for assessment of whether MyHR continues to be used for personal healthcare notes and summaries, and level of healthcare professional engagement. This would provide further data on the personal advantages of MyHR and capacity-building in the form of, the community online centres provision of technology resources and volunteer support. It would also evaluate the opportunity for further roll out of the experience and engagement with digital health information and MyHR. As Julian Tudor Hart has long advocated [16] an approach such as **tailored facilitation,** should be considered as a community model for the successful implementation of contemporary healthcare provision. Future research needs to accurately reflect and acknowledge communities can identify research problems, be involved in research design, choice of outcome measures, and interpretation and dissemination of findings.

On **reflection,** researchers should become comfortable with: the use of participatory paradigms and extending the principles of CBPR for exploring vulnerable healthcare users in their real-world context, the dynamics of SDHRs as person-centred care from a digital complex adaptive system perspective, the use of extended CBPR principles to engage a multiplicity of communities, helping recruit more diverse and representative samples to digital health research, personally and contextually relevant evidence collected systematically 'here-and-now', evaluated for rigour, and valued as complementary to statistically significant evidence will encourage diverse approaches to digital health research and provide complementary insights.

4. Conclusion

This paper has reported on research, which aimed to emphasise practical outcomes identified by exploring the experience of people living with CCCs in a rural community during their engagement with MyHR. Data analysis revealed linkages between personal and contextual requirements, abilities to demonstrate and build understanding, capability, and access to digital healthcare provision. These have been discussed as **tailored facilitation**, **resilience**, and **reflection**, factors essential to consider when reviewing the experience of and engagement with MyHR.

Digital health knowledge is contributed to, at a substantive level, by gathering real-world evidence of the requirements of a vulnerable community experience of and engagement with their SDHR. The results demonstrate the successful delivery of participatory digital health research in a rural community, the value given by the research community to the use of and requirements for MyHR, and an improved understanding of the requirements for a person living with CCCs to experience and engage with MyHR.

At a methodological level, the participatory paradigm actively challenged, engaged and empowered vulnerable healthcare users (traditionally difficult to engage) community commitment and involvement in the process of identifying the value of digital healthcare provision. However, the methodological principles of CBPR need to evolve, to incorporate technology and digital health capacity-building and address the concerns of contemporary healthcare provision.

At a theoretical level, there is a need for research and healthcare provision to value healthcare users' capacity to demonstrate and obtain benefit from digital health tools.

SDHRs can be viewed as a shared digital health system operating within a broader context of preventative and continuing healthcare provision. This research commends that the person, community, healthcare provider, and educational institution view MyHR as an adjunct to quality healthcare provision, person-centred care from a digital complex adaptive system perspective.

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