

An Approach for Enhancing Adoption, Use and Utility of Shared Digital Health Records in Rural Australian Communities

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Abstract. Internationally, shared digital health records are considered an important addition to improving modern health care provision. Australia launched its version, My Health Record (MyHR), in 2012 but has experienced low adoption and challenges in practical implementation and evaluation. Individuals living with complex and chronic conditions in rural and remote communities often experience challenges in obtaining equitable access to health care provision. They are also supposed to face additional barriers to adopting and using eHealth services. This paper reports on research investigating adoption, use and utility of MyHR, in rural remote Australian community settings. Based on this research an approach for improving national roll out of MyHR is presented. The approach highlights a means to understand and engage communities with complex care needs, to support their adoption and use of digital tools. It also draws attention to holistic methods for evaluating and assessing impact at individual, community and health care provision levels.

Keywords. My Health Record, rural communities, digital complex care pathways.

1. Introduction

Internationally, shared digital health records are being acknowledged as fundamental in modern health care provision. Governments and policy makers are responding to the challenges; recognising adoption of individual shared digital health records will improve integration thereby delivering improved quality and efficiencies. The support required by individuals to access their health data electronically is an approach, which appears to be being underestimated [1-5]. The use of an individual shared digital health record can offer a continuum of equitable health care provision in disease prevention, management, treatment and reduction in disparities in care [3, 6].

Those individuals who could benefit most from shared digital health records are those who create the largest burden on health care delivery; people with complex chronic conditions, living in rural remote communities, disadvantaged because of their limited access to efficient, quality health care provision [1, 3].

Australia launched its shared digital health record, My Health Record (MyHR), in 2012; it remains without significant adoption or any evident holistic implementation

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and evaluation framework. This paper reports on research investigating the adoption, use and utility of MyHR, in rural remote Australian community settings. Based on this research, an approach for improving national roll out of MyHR is presented. This approach highlights a means to understand and engage individuals and communities with complex care needs, to support their adoption and use of digital tools and draws attention to holistic methods for evaluating and assessing effects at individual, community and health care provision levels. The contribution being to support future successful implementation and uptake of similar projects.

2. Method

Individuals involved in a rural remote lifestyle modification program expressed an interest in recording and reflecting their lifestyle goals and modification progress, initiated the eHealth research project. The tool for documenting the intervention was the Personal Health Notes, a designated section within MyHR.

Based on a participatory philosophy, a qualitative community based participatory eHealth research project was developed and conducted in southern Tasmanian rural remote community health care settings [7]. Once ethical approval was granted (HREC-H0013781), 21 research partners, 15 females and six males, 40-89 years, with two or more complex chronic conditions, were recruited from three rural remote settings.

Data were collected in three phases: pre-adoption, adoption and post-adoption of MyHR. Data collection tools were: groups convened in the three rural remote settings, held in each phase, the partners adopting and initiating use of MyHR during phase two, and partner semi-structured interviews held during phase one and three. All encounters were audio recorded and transcribed verbatim. Group memos, MyHR personal health notes, a reflective diary and project documentation provided additional evidence.

Data analysis was structured using a systematic, flexible thematic framework approach. This was achieved in three stages: data management, data description and data explanation [8]. Data transcription ran concurrently with data collection, which assisted confirmation of transcripts, by individual partners and the groups and ensured a comprehensive, consistent in-depth systematic data analysis.

3. Results

Three key findings emerged, which support a dynamic conceptualisation of MyHR.

3.1. *Individual, Community and Societal Understanding is Inherent*

For an individual with complex chronic conditions equitable, person-centred, integrated health care provision is fundamental and can be enabled by and embedded in MyHR, irrespective of physical or cognitive ability. The research partners agreed there is a need for a flexible individualised digital health care record. They want a role, ownership of and responsibility for their health and health information. Those who need MyHR most, need the most support; MyHR should not exclude anyone. There is an inherent desire to have MyHR where they can engage and play a meaningful role in

defining and communicating their: identity, complex chronic conditions, and main problem, as part of their digital complex care pathways.

two individuals may have the same diagnosis, but how it affects them and where they go from there can be totally different...what I try to get through to a lot of people ... is I know my body and how they affect me. If [MyHR] allows me to communicate that ... It doesn't need to be just doctors. It's our bodies and our lives that this is all about and the two should be working together... but that tends to get lost (CH23).

3.2. Individual, Community Skills are Recognised and Valued as Shared Experiences.

Using MyHR lead to increased knowledge, competence and confidence and a changed perception of computer use. As the research partners became experienced they evolved, finding new ways of using MyHR. When a diverse group of individuals was offered the opportunity to engage in a collaborative, coordinated, community project, they became familiar with the use of MyHR, issues of design and utility emerged. When rural communities are involved and supported through adoption and initial use of MyHR, they become engaged, innovative and knowledgeable providing an irreplaceable source of user information and experience.

this research is great, everybody likes to be involved and feel they have an opportunity to give ... We're starting learning together ... learning computer together you share so much instead of individuals wondering how do I get back to it...working with buddies... you always learn by how somebody uses something. That's been really good and the research has tapped into the local [groups] and all these initiatives around. Yes if you want to know how anything is going to work you give it to the users (CH13).

3.3. Rural Communities Need to be Included in all Digital Health Care Interactions

The research partners viewed and valued MyHR, as a digital health care tool that can provide multiple opportunities for the delivery of their health care. The research partners learned they were not alone; they had MyHR and complex chronic condition experiences acknowledged and confirmed by others. Once the partners were empowered to explore MyHR they learned and shared the value of it as potential for engagement and an access point to wider health care provision.

things are getting done, people can find out about more of their diseases ... it's got to be an improvement to find out these things. It's an opportunity especially a rural community like this. It helps, it gets people together, they discuss things and it makes it a lot better (CH6).

In 2012 MyHR espoused an opportunity, for those who wished, to 'opt-in', the ability to add and receive agreed health information. However, pre-adoption of MyHR, those research partners who had heard of MyHR were unsure of its purpose and none had registered. When the community identified an opportunity to experience MyHR, every research partner engaged, immediately increasing their knowledge and opportunity to communicate and access their health information. Without reservation, all research partners, irrespective of their ability, described the benefits MyHR would have on their future engagement in their digital complex care pathways. Some partners found having access to MyHR useful and rewarding, regardless of the level of provider involvement. Others communicated frustration because of the lack of engagement by their health care providers [9].

Although access to health care provision may have improved, through the sharing of resource experiences and provision of a community lifestyle modification program, shared access to information prepared by health care providers, via MyHR, was not

possible. The research did not find the community, disinterested or disengaged because of limited access to efficient, quality health care provision. However, their health care providers were reported being dismissive.

I tried to get my Drs involved, ... my specialist ... I gave them access when I went for my appointment and I talked to [them] about it. [They were] saying [they] didn't like the fact that other doctors could see basically, or other people could see. If my other Dr had what was it, access to it then he could see my [disease] stuff and stuff like that. It wasn't a problem to me but it's a problem to [them] (O3).

4. Discussion

Everyday living and working with complex chronic conditions requires understanding and acknowledgment of their multifocal complex non-linear care requirements [10]. In context, these individuals and their carers, living in a rural community, a complex adaptive model of care can assist by conceptualising MyHR, as one component embedded within a digital complex care pathway, which equitably engages in an integrated, person-centred approach to health care provision [11]. Using the characteristics of complex adaptive system theory: *agents who learn*, individuals can and will learn and react to changes in information; *interconnection*, changes in patterns of interactions, among agents and introducing; *self-organisation*, order can be created without explicit hierarchical direction; and *coevolution*, the system and the environment influence each others development, to the research findings provides a conceptual framework, which can support the meaningful, adoption use and utility of MyHR within digital complex care environments [12].

Embedding MyHR within all digital complex care pathways may assist in; the adoption use and utility of MyHR, for individuals with complex chronic conditions, and all health care providers in their transition from linear, episodic, medico-centric models of health care provision, toward achieving equitable, person-centred, integrated health care provision.

The function of any digital health care system is to deliver improvements in health care provision and experience; new eHealth technology should be evaluated to ensure accountability and continued improvement [13]. This requires looking at how MyHR can help and spending time and effort to review process to achieve the ultimate goals: efficiency and quality. When implementing the relatively new digital health record solution, MyHR, it is important to separate health care provision, which needs to be maintained and enhanced, from process that needs to be revised to include questions and explanations as to why we do the things we do and how could we do things better? [1-4]. Including complex adaptive system theory, within an adoption, use and utility of MyHR framework, for all stakeholders involved in the delivery of digital complex care pathways could be instrumental in answering these questions.

5. Conclusion

The adoption of MyHR will take place nationally but for use and utility to be realised regionally and locally, communities require engagement, information and support, or critical mass will not be achieved [14, 15]. The research demonstrates the importance of listening to all stakeholder experiences to help shape future strategies, which are

responsive to the diversity of illness, individual and community experience. Valuing the expertise of people with complex chronic conditions empowers them to adopt interactive and cooperative relationships with their health care providers. Understanding the individual's experiences is key in the delivery of digital, equitable person-centred care, integrated care.

During the research, the community learned to overcome issues of technophobia and identified a need for infrastructure, which supports the adoption and use of MyHR, highlighting the necessity to identify and educate all health care providers regarding; their continued resistance to shared digital health information, and the professional use of information and computing technologies. There is a requirement of communities and individuals to be engaged and valued during their transition through their complex chronic conditions supplemented by MyHR.

This research provided the impetus for a community to commit to and engage with MyHR. In Australia and internationally a digital complex care framework should; engage individuals and communities with complex care needs, and be incorporated to provide a holistic approach toward future roll out, evaluation and assessment of impact at individual, community and health care provision levels.

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