Avoiding Failure for Australia's Digital Health Record: The Findings from a Rural E-Health Participatory Research Project

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Abstract. Low adoption and use of Australia's digital health record has driven the Australian Government to trial 'opt-out' registration from mid-June 2016. The assumption that automatic registration will increase use and thereby deliver benefit requires further investigation especially amongst those sections of the population in rural, regional, remote Australia living with complex chronic conditions. This paper reports on findings from a community based participatory e-health research project based on an initiative where people with complex chronic conditions and their carers attended a rural health promotion and lifestyle modification program. Through co-operative enquiry, health promotion officers and their clients were actively supported to adopt and use Australia's digital health record as an intervention. Simultaneously they were encouraged to reflect on its design and their perceptions of its overall impact on their individual ability to self-manage complex chronic conditions. The findings, ultimately contributing to a conceptual implementation and evaluation framework for Australia's digital health record that could directly avoid failure of the new 'opt-out' approach being adopted.

Keywords. My Health Record, Participatory Research, Complex Chronic Diseases, Health Promotion and Lifestyle Modification

Introduction

Australia continues to struggle with adoption and utilisation of the digital health record, with only 11% of Australian individuals registered for My Health Record (MyHR) [1]. Part of the problem is a lack of transparency and inadequate community facilitation, compounded by a poorly articulated implementation and evaluation frameworks [2]. There is a concern that widening disparities in the quality and value of services, evident amongst communities serving vulnerable populations, including those people with complex chronic conditions (CCCs), may become embedded by an e-health divide [3].

Low adoption and use of MyHR has compelled the Australian Government to trial 'opt-out' registration. From mid-June 2016 most individuals in Northern Queensland and the Nepean Blue Mountains will have an automatically generated (be 'opted-in' to) MyHR [4], presuming if registration is generated on their behalf, use will automatically follow. However the literature shows meaningful adoption and use of any digital health record should be based on representation and consideration of all stakeholders

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requirements and ensure the digital healthcare record produced is usable, safe and useful for an optimal number of users [5]. Disappointingly, few complete digital health record systems are currently in everyday use. This makes evaluation and assessment of their effectiveness, in real settings, challenging. The situation presents an opportunity to investigate and evaluate the current systems being used and provide insights that may support improved rollout towards general implementation [6].

Chronic diseases are the leading cause of disability and death globally [7]. Obesity is a clear risk factor for chronic disease and a major concern; in 2014-15, 63.4% of Australians over the age of 18 were overweight or obese [8]. Given the high costs associated with CCCs [9], efforts should target the behavioural, environmental and social risks of obesity to support communities, to remain as healthy as possible [10, 11]. Australian Governments already recognise and support programs focusing on CCCs, including in rural areas [12, 13]. One rural Tasmanian initiative involves health promotion officers assisting communities, through health promotion and lifestyle modification (HPaLM) programs, providing safe environments for socialisation, recreation, physical and cognitive stimulation [6].

For people with CCCs maintaining these functions assists them to remain active community members. Nonetheless, at a local level, there is consumer reluctance to contribute and an ineffectiveness of staff to consult with consumers in service design, implementation and evaluation. In rural communities, many with distinctive and unique histories and values, mainstream services may also be inappropriate for people living with CCCs. Rural HPaLM programs can provide care and stimulus for consumers but unless the programs are compatible with the desired needs of these people, services are under utilised [14].

The paper reports on a subset of a broader study that investigates the use and impact of MyHR for people with CCCs participating in a 12 month HPaLM program. This contributes to the development, implementation and evaluation of a conceptual multi-dimensional framework improving the adoption, use and utility of MyHR for people with CCCs. However, the aim of this paper is to report the findings from people with CCCs experiences of MyHR that may contribute to improving the adoption, use and utility of Australia's implementation and evaluation of MyHR.

1. Method

The e-health research project "piggy backed" onto a community service review of rural HPaLM programs, for people with CCCs, recruiting participants with CCCs and their carers who had an interest in recording and reflecting on their HPaLM progress. The tool for recording their details, the intervention, was the Personal Health Notes, a designated section within the newly launched MyHR.

Based on the philosophy of co-operative inquiry, identifying with a subjective ontology and an extended epistemology, a qualitative community based participatory research (CBPR) project [15] was developed and conducted over a 12-month period in rural southern Tasmanian community healthcare settings. Once ethical approval (HREC-H0013781) was granted, three health promotion officers convened three groups in three rural locations. 19 participants, people with two or more CCCs, their carers and two health promotion officers, were recruited from the HPaLM program.

The CBPR implementation was developed and delivered in six iterative stages, providing flexibility to respond to emerging needs of participants and their community

relative to their CCCs and MyHR experiences. A validation checklist reaffirmed each stage [16]. Data collection tools were; three focus groups in each area and two semi - structured interviews per participant. All group and interview encounters were voice recorded and transcribed verbatim. Field notes obtained, during and immediately following encounters, from focus group and interview observation, MyHR personal health notes and project documents provided additional evidence.

Data analysis, a five stage thematic 'Framework Approach' [17], ran concurrently with ongoing data collection. Transcribed data from each focus group were analysed between meetings, influencing the clarification, requirements and refinements of questions in subsequent meetings. The researcher systematically handled data sets from the numerous sources of evidence, performed cross case and theme comparison and provided evidence for ensuring quality research. Adopting and applying 'Framework Approach' data analysis allowed for a complete review of the collected stories, as determined by the participants' original accounts and experiences, providing a comprehensive, consistent, in-depth systematic analysis.

2. Findings and Discussion

The findings in this paper only report those, which may assist Australia in avoiding further failure in the roll out of the digital health record.

The demographic data revealed greater than half the participant's self-reported in excess of four CCCs and more than four professional healthcare providers. This is worthy of note because the greater the number of CCCs; the greater the complexity, number of health professionals involved, medications prescribed and healthcare costs, leading to greater risks and greater need for precise and timely communication [9, 10].

Less than half the participants reported any form of regular carer support. However self-management of any CCC requires day-to-day understanding and collaboration especially as it progresses [11]. Irrespective of age participants (40-89yrs) reported a wide range of CCCs frustrating their ability and availability to access social, recreational, physical and cognitive stimulation.

"I try to participate as much as I can, for the company, … I don't want gossip, and so I pull back, I feel useless honestly, I stopped driving. I shall remain active with the [HPaLM] program. I think technology is marvellous it opens a whole new world. I go to the access centre if I need a computer. I may not be as fast. I don't see it. I gave it [computer] away. I need a decent screen and enlarged type face" (CH14).

All of the participants had or were using a computer, professionally or personally, the majority of participants firmly believe computer technology to be an invaluable source of information and a form of communication. This indicates ability or at the very least an awareness of the possibilities electronic communication offers.

"I use a computer every day. They changed my life and change society dramatically over the last 30 years…From data collection right through to communication" (CH11).

The central concept that emerged from this study was; there is a requirement of communities and individuals to be engaged and valued during their transition through their CCCs supplemented by MyHR, which has the capacity to provide a meaningful role during any healthcare transition. The three main themes underpinning the central concept (1) <u>self-identity</u> (2) <u>knowledge and </u>(3) <u>access</u> are summarised.

2.1. Self-identity

Described in context as, an internal, community and societal understanding of oneself.

" two people 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 including doctors is I know my body and how they affect me. If [MyHR] allows me to communicate that in some form. 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 that's been my concern for a while" (CH23).

For a person with CCCs person-centred proactive, collaborative healthcare is fundamental and can be facilitated by MyHR, irrespective of physical or cognitive ability. The participants agreed there is a need for a flexible personalised digital healthcare record. They want a role, ownership of and responsibility for their health and health information. Those who need MyHR most, need the most support. Participants' express logical desires to have a personal MyHR where they can engage and play a meaningful role in defining and communicating their identity, their CCCs and their main problem, during their health transition [11].

2.2. Knowledge

Described in context as, an individual or community skill to engage, recognise and value individual and shared experiences.

"I think this research is great, everybody 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 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 council (HPaLM) and all these initiatives around. Yes if you want to know how anything is going to work you give it to the users" (CH13).

Using MyHR lead to an increased knowledge, competence and confidence and changed the perception of computer use. The project allowed participants to learn and become involved at their own pace. As they became more experienced participants evolved, finding new ways of using MyHR. As they gained familiarity and competencies with MyHR, a range of MyHR design issues emerged, which may fit more closely with aspects of their health and individual needs.

A diverse group of people who, when offered the opportunity to engage in a comprehensive, collaborative, coordinated, community project, within a short time became confident and competent in the use of MyHR. Issues of utility and design inevitably emerged. This indicates when rural communities are involved and supported through registration and early use of MyHR, they become engaged and knowledgeable providing an irreplaceable source of user information and experience [3].

2.3. Access

Described in context as engagement, a connection, allowing a flow of information between themselves, family, community, health professionals and health services.

" it must help in the long run, things are getting done, people are finding out about more of their diseases and things like that, 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).

Participants viewed MyHR, as a healthcare tool, which can provide multiple opportunities for the delivery of healthcare. During the project the participants learnt they were not alone, they had CCC and MyHR experiences acknowledged and confirmed by others.

" as the group were talking there was a familiarity and empathy between them as if they understood each other" (HPO3).

Once the participants were empowered to explore MyHR they learnt and shared not only the value of it as a healthcare tool but also the potential for personal engagement and an access point to wider health provision [6].

Prior to the project participants, all with CCCs were equipped with the fundamentals of 'self-identity' and some 'knowledge'. What they were not equipped with was fundamental 'access' to their MyHR. In 2012 MyHR espoused an opportunity, for those who wished, to 'opt-in', the ability to add and receive agreed health information. However, before the introduction to the research project, those participants who had heard of MyHR were unsure of its purpose; none had registered. When the researched community was offered the opportunity to learn, register and be supported through their early use of MyHR, every participant engaged, immediately increasing their knowledge and opportunity to communicate and access their health information. Once the opportunity to engage and use their MyHR, had been provided, without reservation, all participants, irrespective of their ability, could see the advantages and impact a single digital health record would have on future involvement in their management of their CCCs. Whilst some participants found having access to MyHR personally useful, fulfilling and necessary, regardless of the level of healthcare professional involvement, others communicated disillusion because of the lack of commitment by their healthcare professionals.

The CBPR project provided an opportunity for a community to engage and communicate their identity, become knowledgeable about their healthcare and access their personal healthcare information via MyHR. Although access to health provision and healthcare professional may have improved, through the community sharing of experiences and the provision of a community HPaLM program. Shared access to information prepared by healthcare professionals via MyHR was not possible. Contrary to the literature the project did not find disinterested or disengaged consumers, rather it was their healthcare professional who presented in such away [3].

"I tried to get my Drs involved, I tried to get my specialist ... I gave them access when I went down for my appointment and I talked to her about it. She was saying she 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 her. I know it's my record but that was her and it was her point of view and her choice"(O3).

3. Conclusion

During the 12-month CBPR project, participants, as a community, learnt to overcome issues of technophobia and identified a need for infrastructure, which supports the adoption and use of MyHR and highlights the necessity to educate healthcare professions regarding their ongoing resistance to the professional use of information

and computing technologies. The findings provide valuable information, for all stakeholders, toward the development of a multidimensional complex adaptive implementation and evaluation framework built around the concept; there is a requirement of communities and individuals to be engaged and valued during their transition through their CCCs, supplemented by MyHR. The authors believe switching from 'opt-in' to 'opt-out' alone will not engage individuals in meaningful use of their digital health record. Without a planned, designated support and stakeholder engagement an 'opt-out trial' will prove fruitless. In summary this transferable project provided the impetus for a community, not without it's challenges, to commit and engage in MyHR. It can provide valuable insights if Australia is to avoid future failure in the roll out of MyHR.

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