Participatory Health Information Systems: Theory and Applications - Special Section

Guest Editors:

Daswin de Silva
La Trobe University
Australia.
d.desilva@latrobe.edu.au

Frada Burstein
Monash University
Australia.
frada.burstein@monash.edu

Doug Vogel
Harbin Institute of Technology
China.
isdoug@hit.edu.cn

Editorial

The graduation of healthcare delivery from its foundational mainstay into patient-centred care has widespread implications for health and wellbeing. Information systems and technology are front-runners in necessitating this transition. In its ideal form, patient-centred care is respectful of and responsive to individual patient preferences, needs, values and ensures that patient values guide all clinical decisions (Epstein et al. 2010). In both its ideal and actual forms, preferences, needs and values connote the significance of information in enabling patient-centred care.

Participatory health information systems (PHIS) are emerging platforms to capture, manage and understand this body of information. They aim to empower a network of support, consisting of healthcare institutes, practitioners, caregivers, family members and patients, to communicate, collaborate and contribute towards health and wellbeing objectives. Besides healthy outcomes and resource usage optimisation, PHIS facilitate the accumulation of multi-dimensional information on a broad spectrum of healthcare topics ranging from disease variations to patient lifestyle choices and behaviours. This information provides an entire body of knowledge that has an immediate impact on the advancement of medical and clinical research. Hence, it is in the strategic interest of policymakers, healthcare industry, as well as patients to endorse research, development and evaluation of participatory health information systems that enable patient-centred care.

To better understand the ground roots underpinning PHIS, it is pertinent to present a brief account of participation theory as reported in information systems (IS) literature. Traditional IS participation theory (Figure 1) is founded on the causal structure of contingency theory. It is assumed a causal association between participation and IS success exists and it is controlled by contingencies such as task uncertainty or system novelty.
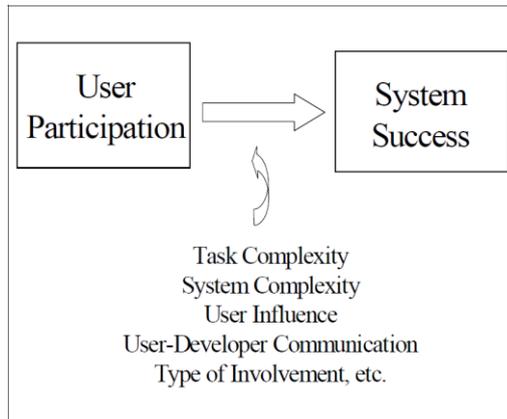
Figure 1: Traditional IS Participation Model (McKeen et al. 1994)

Markus and Mao (2004) presented the Updated IS Participation theory which overcomes the likelihood of a single causal process relating participation to outcomes. They redefine system success as two interdependent elements, system development success and system implementation success. They declare participation activities have varied effects on these two major outcomes and determine three further theories linking participation to system success (buy-in, system quality and emergent interactions). Gaps identified among these links led to the updated theory. Foundations of the updated theory lie in: 1) the distinction of system success into two concepts: system development success and system implementation success, with emergent reciprocal relations between them; 2) the description of groups of actors including stakeholders where participants are a subgroup, and change agents where IS specialists are a subgroup; 3) a reformulated behavioural concept of participation activities, characterized in terms of type and richness, methods and conditions; and 4) the hypothesis of emergent causal processes (Markus and Mao 2004). Updated IS Participation theory is illustrated in Figure 2.
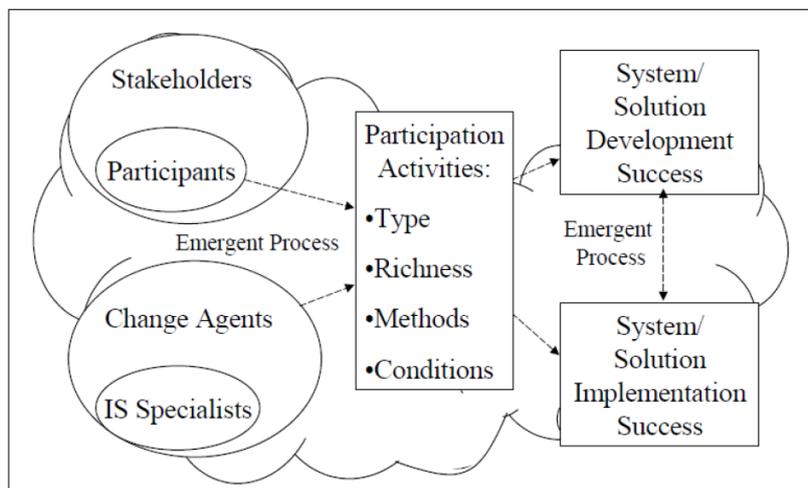

Figure 2: Updated IS Participation Theory (Markus and Mao 2004)

Taking into account that participatory information systems contribute towards increased stakeholder activity, increased systems adoption and enhanced health and wellbeing outcomes, this special section aims to advance research, development and evaluation of such systems by providing insights into emerging areas of research. The guest editors are pleased to announce a total of seven research articles focusing on a broad range of topics that reflect the diversity of participatory health information systems. Markus and Mao (2004) Updated IS Participation theory is featured prominently across these research articles. The separation of system success into development and implementation success, expansion of participants into

stakeholders and change agents with stakeholders assuming a variety of roles in system success, are some of the notable endorsements of the updated theory. Each article included in this special section focuses on a different stakeholder within the participatory healthcare delivery setting. A brief account of the seven articles follows.

Article 1: Exploring mHealth participation for emergency response communities (David Schwartz, Abdelouahab Bellou, Luis Garcia-Castrillo, Antonella Muraro and Nikolaos Papadopoulos)

This article explores a unique challenge in mHealth (mobile healthcare information systems); the active participation in emergency events by members of emergency response communities. As noted by authors, interventions in such environments are primarily short-term interactions which require clear and precise decision-making and constant tracking of potential participants in responding to an emergency medical event. The increasing prevalence of chronic conditions is a strong indication of the importance of creating emergency response communities with the support of mHealth applications to reshape society's response to individuals in medical distress, specifically when conventional emergency medical services are not available immediately.

Article 2: Can health 2.0 address critical healthcare challenges? Insights from the case of how online social networks can assist in combatting the obesity epidemic (Nilmini Wickramasinghe, Carolin Durst and Janine Viol)

A further exploration of the dynamics of mobile technology in healthcare, this article investigates the potential of online social networks and social media to address the obesity epidemic. Authors design, implement and test the Calorie Cruncher, a health 2.0 application, to explore the influence of online social networks on individual's health-related behaviour. The research unravels three forms of influence, an individual's norms and value system, social control and pressure of social connections as well as social relationships that provide emotional support. It further provides a platform to understand the effect of obesity propagation in online social networks, identify potential online intervention strategies to disseminate health-related information to the right group of people, offer services fostering positive health-related behaviours and promote behaviour change advice.

Article 3: How do the participatory design features of health hackathons contribute to participatory medicine? (Karen Day, Gayl Humphrey and Sophie Cockroft)

Hackathon is a relatively new and emerging concept for participatory development of technology solutions or prototypes. In this article, authors present a descriptive case study approach focusing on the role of hackathons in participatory medicine. Participation in design and development of a system/solution encompasses the strategic advantage of post-implementation participation. Following interviews, observations, twitter feeds and pre-surveys during weekend-long hackathons, authors identify a number of success factors, group size, maturity of the idea, level of involvement of a mentor and involvement of students. Furthermore, five skills of successful health hackathon participants have been recognised. They are knowledge, patient-focus, analytical skills, software design skills and professional perspective.

Article 4: A participatory model for multi-document health information summarisation (Dinithi Nallaperuma and Daswin de Silva)

Continuing on the importance of participation in design and development, this article presents a new model for multi-document health information summarisation that takes into account the role of end-user participation. Retrieval of relevant and reliable health information is becoming a formidable challenge with increasing volumes of resources available for perusal via the Internet. Although information retrieval needs of health information consumers have been appropriately addressed by a substantial body of research literature, authors highlight the need for a multi-document information summarisation approach to effectively peruse the increasing volume of online content. The proposed model integrates both extractive and abstractive summarisation processes with continuous participatory inputs to each phase. A

prototypical implementation of the model was evaluated by both domain experts and health information consumers, with results confirming the generation of relevant and accurate summaries for diverse audiences.

Article 5: An examination of the mediating role for a nursing information system (Lemai Nguyen and Nilmini Wickramasinghe)

Mediation is a vital element in participatory healthcare. It is important for all healthcare practitioners to mediate/intervene as and when appropriate. In this paper, authors report findings from an examination of a nursing information system using Activity theory. The nursing information system provides real-time nursing documentation in acute care hospital contexts. Its objective is to enable superior nursing care by providing nurses with the opportunity to document patient care data into a tablet computer located at the patient bedside. The system was evaluated in a not-for-profit acute care hospital ward during its implementation. Analysis of nurse interactions and perceptions showcase positive attitude towards the system and identified potential mediation capabilities and opportunities.

Article 6: The decision-making role of the patient in localised prostate cancer treatment (Luke L Wang and Weranja K.B. Ranasinghe)

Prostate cancer is one of the most common non-skin cancers affecting an increasing number of individuals worldwide. Treatment selection for prostate cancer is a complex process involving multiple factors. Authors conduct a systematic literature review of patient participation and decision-making in the treatment selection process for localised prostate cancer in order to evaluate capacity for improvement. A majority of patients prefer an active or collaborative role in decision-making, highlighting the importance of participation in the treatment selection process. Personal aspects of the process and its influence on the final decision remain inadequately explored. Authors recommend future research should be combined with ongoing study of multidisciplinary care and individualised risk based decision-making tools.

Article 7: The effectiveness of SMS reminders and the impact of patient characteristics on missed appointments in a public dental outpatient clinic (Emilia Bellucci, Lasitha Dharmasena, Lemai Nguyen, and Hanny Calache)

Focusing on operational aspects of participation, this article reports on the effectiveness of reminders delivered to a mobile phone as well as patient demographics on missed appointments in a public dental outpatient clinic. A rich dataset collected over a time period of 46 consecutive months from the public outpatient dental clinic is analysed using descriptive statistics and inferential statistics techniques to determine if patient characteristics predict non-attendance and to examine the associations between different variables. Pre-reminder and post-reminder attendance was found to be statistical significant. Demographic and appointment profile of patients less likely to attend are also reported. Authors recommend clinics focus on eliciting patient profiles to better understand non-attendance instead of adopting a generalised approach to encourage attendance.

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