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A Participatory Information Management Framework for Patient Centred Care of Autism Spectrum Disorder

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A Participatory Information Management Framework for Patient Centred Care of Autism Spectrum Disorder

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Abstract

Patient-centred care (PCC) is grounded on the relationships formed between healthcare professionals, patients and patients' family members. This network of stakeholders is frequently found to be disconnected due to the absence of an enabling framework. Active online participation and continuous engagement improves patients' healthcare experience and healthcare professionals' understanding of the medical condition. The community setting of PCC further generates crowd intelligence which in turn complements the knowledge of clinical experts. This body of evolving knowledge is a valuable resource with long term impact for both current and new patients as well as healthcare professionals. It is highly relevant for spectrum disorders that usually span across the lifetime of a patient, such as Autism Spectrum Disorder (ASD). A framework provides structure to such a body of knowledge and defines functionality that delivers and sustains its use. This paper presents a participatory information management (PIM) framework for the delivery of PCC for ASD in a health, education and community service setting. The framework is founded on the updated IS participation theory. Driven by patient participation, it expands thereon to intersect community and clinician participation. As discussed in the paper, the potential outcomes are broad, ranging from improved healthcare quality to enabling translational research. An ongoing pilot project applying the framework to ASD is also reported in the paper.

Keywords

User participation, Patient centred care, Participatory medicine, Chronic illness, Autism spectrum disorder, Information management, Smart health information portal, Translational research

INTRODUCTION

The conventional approach to healthcare is being revolutionised globally with the introduction of patient-centred models for healthcare delivery. Popularised as Medicine 2.0, this includes the use of recent mobile technologies and the prevalence of the Internet to personalize healthcare, collaborate, and promote health education. Patient-centred models transcend traditional boundaries that separate patients and their families from clinical contexts. Patient-centred care was first featured in healthcare as one of the six aims for high-quality healthcare in a report 'Crossing the Quality Chasm' published by the Institute of Medicine (2001a). This report defines PCC as care that is "respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions". Epstein et al (2010) justify the need for PCC on both moral and ethical grounds. These include improved care, improved well-being, disparity resolution, value for money as well as personal autonomy and absence of abandonment.

Autism Spectrum Disorder (ASD) is defined as a group of developmental disabilities that cause significant social, communication, and behavioural challenges throughout the lifetime of a patient (Rutter 1978). A review commissioned by the Autism Early Intervention Outcomes Unit (AEIOU) estimated the annual economic cost, including the burden of disease, of Autism Spectrum Disorder (ASD) in Australia between $8.1 (low prevalence) and $11.2 billion (high prevalence). Despite this spending, the health and wellbeing outcomes experienced by affected individuals and their families are minimal. The lack of specificity within the context of health, education and community service settings is the primary reason for the absence of qualitative outcomes.

It is in this context that active participation and continuous engagement can eventuate better health outcomes for individuals and communities affected by ASD. Therein lies motivation for the proposed framework. The research proposition is to extend the participatory framework founded on the updated IS participation theory (Markus and Mao 2004) to suit the needs of the ASD community. The framework engages a network of stakeholders involved in the management of a chronic condition providing a common platform for improved healthcare outcomes. Although this paper focuses on ASD, the framework is relevant and applicable to other chronic medical conditions that require ongoing medical attention and healthcare for a considerable period of the patient's life.

The paper is organised as follows. Section two presents the updated IS participation theory, its disposition and features. Section three sets the context; a background study on patient centred models of healthcare and its prevalence in ASD. Section four applies the updated IS participation theory to PCC and highlights the elements relevant to the proposed framework. Section five presents the framework; defines actors, outlines activities, relationships and outcomes. Future directions of this study are discussed in section six and section seven concludes the paper.

IS PARTICIPATION THEORY

Traditional IS participation theory reports an empirically supported link between participation and system success (Swanson, 1974; Urquhart, 2001). Markus and Mao (2004) critically analyse traditional IS participation theory and propose the key elements of a new theoretical framework (Figure 1) that supersedes the previous. In this theory, the updated theory of IS participation, they redefine system success, differentiate among actors and refine the concept of participation.

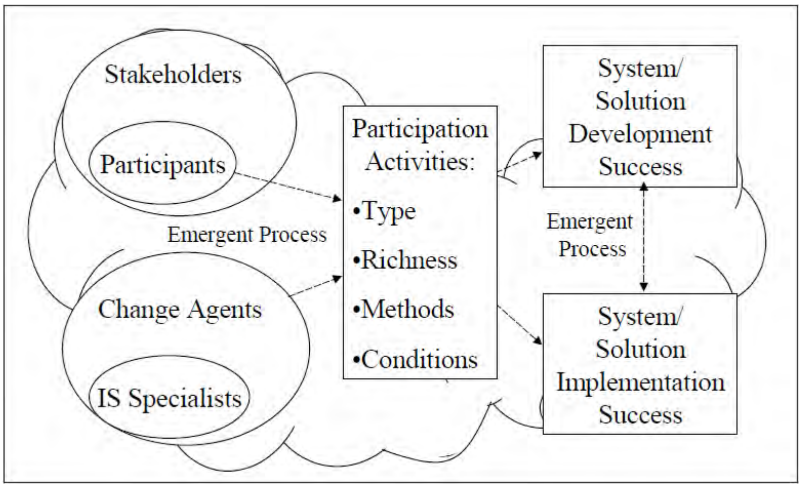

Figure 1: Updated Participation Theory (Markus and Mao, 2004)

The motivation of their work was to segregate participation's effects on various types of outcomes that are clustered together as system success. They identify three theories linking participation to system success (buy-in, system quality and emergent interactions) and determine conceptual gaps in these links that lead 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).

Following on from these foundations, we draw on other dimensions of participatory design processes as suggested by Bergvall-Kaareborn, et al (2010), e.g. "Designing for users" and "Designing with users". Comparing these two processes, the authors rightly emphasise and empirically demonstrate the advantages of the latter in creating an opportunity for closer engagement between the IS developers and users. Such participatory design process results in the "voice" of the users to be fully appreciated and better understood, together with the new opportunities that flow from discovering their needs in an act of active engagement from the planning phase to implementation and commercialisation of the final product. In this sense new tools and techniques can be employed for "tracing user needs" by continuously monitoring their behaviour both implicitly and through shared data management, as well as by making users express their "voices" in online diaries and other social media engagements.

A review of 82 empirical studies of user participation in IS development performed by He and King (2008) demonstrate that user participation is not a uni-dimensional success factor. It should be treated within the context and expectations of overall benefits from the system. Applying it in healthcare area, the role of user participation was further explored at more granular levels to include a variety of roles and cultural context (Maail, 2011; Litwin, 2010). These studies confirm that on one hand user participation relevant to the modern systems development requires a clearly stated purpose and a sense of shared benefits articulated to the users and on the other, they should be approached in a democratic way where the boundaries of participation can be negotiated. Integration of the updated IS participation theory and its extensions are revisited in section four where it is applied to the PCC context.

THE CONTEXT

This section reviews the context of the proposed framework, patient centred care and ASD. Descriptive definitions of PCC reported by Robinson et al (2008) are combined with observations by Gruman et al (2010) to connote the research background. The ensuing subsection reviews PCC efforts in ASD.

Patient Centred Care

The main difference between PCC and the traditional illness centred approach is the healthcare professionals' focus on the patient rather than the illness. In the traditional approach, the clinician addresses the medical condition and thereby cures/improves health of the patient whereas with PCC this becomes a shared responsibility between the healthcare professionals, the patient and family members. Robinson et al (2008) report definitions of PCC from four perspectives - public policy, economic, clinical, and patient.

The public policy definition lays foundation for other definitions and also shapes the vision of healthcare (Robinson et al 2008). It is adopted from the IOM definition which is, "a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patient's wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care" (IOM 2001b). Furthermore, Robinson et al (2008) tabulate a useful comparison of the four perspectives based on the two indicators of patient involvement and individualised care (Table 1).

Table 1. Comparison of the four perspectives on the definition of PCC (Robinson et al 2008)

Indicator	Public policy	Economic	Clinical practice	Patient
Patient involvement	Partnership, Education, Participation in care, Participate in decisions	Shared decision making, Empowerment	Self-care, Patient goals, Family Involvement	Involvement in treatment, Information provision, Partnership
Individualised care	Respect for patient wants needs, and preferences	Patient "demand" for cost, quality, convenience, and other concerns	Psychosocial experience, Knowing patient, Tailoring treatment, Humane care, Communication	Respectful treatment, Time for care, Communication, Patient as priority, Accessible care

The patient perspective is more relevant than the rest; therefore the authors propose the measurement of PCC to be based on patient perception. It is also clear from the above comparison that all perspectives emphasize active participation.

Separately, Gruman et al (2010) review patient education as a means of enabling patient engagement. It is presented as a means of addressing the lag between healthcare expectations and people's actual performance of behaviours. They define patient engagement as ''actions individuals must take to obtain the greatest benefit from the healthcare services available to them'' (Gruman et al 2010). The authors propose an engagement behaviour framework containing qualitative descriptions of the behaviours individuals should perform to optimally benefit from healthcare. Behaviours in this framework were methodically sourced from reviews of advocacy literature, research topics in published literature and systematic reviews. These were used to generate a list of patient behaviours and were evaluated using key informant interviews. The final phase was content analysis of scientific sessions at conferences relating to patient education to estimate the prevalence of behaviour. This mapping of behaviours to patient education showed that current research and practice in patient education is limited to certain behaviours (Gruman et al 2010). The study concludes highlighting the need for improved patient education to enable effective engagement in healthcare.

Patient Centred Care in ASD

Informed by the current trend towards active participation and patient education enabled engagement, it is pertinent to review research and practice that advance these concepts within the ASD space. A technical report published by the American Academy of Pediatrics (2003) encourages paediatricians to provide family-centred care. Despite this, the number of efforts in ASD towards inclusive care is limited. A ‘medical home’ is the earliest reference to a patient-centred approach to healthcare and was originally used to describe a single source of all medical information about a patient. The term now refers to any partnership approach with families to provide primary healthcare that is accessible, family-centred, coordinated, comprehensive, continuous, compassionate, and culturally effective (Sia et al 2004). Medical homes are based on partnerships between families and physicians that are characterized by mutual trust, respect, and shared decision making (Denboba et al. 2006).

A qualitative study was conducted by Carbone et al (2010) to examine the perceptions of parents and paediatricians on the needs of children with ASD within a medical home. Perceptions shared by both parties were dissatisfactory. Physicians do not fulfil parents’ expectations of early investigations, completeness of care and the level of family focus. Time constraints, lack of training and resources are the primary concerns for paediatricians. Another study cites parents identifying child-related agencies, healthcare facilities, and educational settings as an unsupportive system that contributes to a feeling of isolation for families (Woodgate et al. 2008). Carbone et al (2010) conclude their study emphasizing the need for “system level changes that produce sustainable progress towards effective community systems of services for ASD”.

A recent study by Jensen and Spannagel (2011) review the needs, services, and challenges in ASD. They highlight the importance of “continued education and ongoing advocacy to effectively and cost-effectively maximize overall function and quality of life for individuals with ASDs and their families”. They further propose policy-making to focus towards building collaborations among systems/stakeholders (i.e., consumers, families, professionals, the educational system, the medical community, public and community agencies, insurance companies).

The inadequacies of a medical home for ASD patients/families coupled with the propositions to address challenges in ASD leads to the need for active participation of patients, healthcare professionals and the continuous engagement of community. It is this void of a healthcare, education and community service setting that motivates the proposed framework. The following section applies the updated IS participation theory into PCC before bringing together the proposed framework.

PARTICIPATION THEORY IN PCC

It is pertinent to apply the updated theory in the context of its three core elements; redefinition of system success, differentiation among actors and refinement of the concept of participation (Markus and Mao 2004). The redefinition of system success segregates it into development and implementation success. They define system development success as a “high quality process of system development (methodologies used, interactions and conflicts, progress against schedules and budgets) and/or a high quality outcome of system development, namely a project, a system, or an IT artefact”. System implementation is defined as “high quality process of preparing the target user community for use of the system and/or a high quality change outcome, namely that the intended users adopt the system, use it as expected, and/or use it with the desired effects”.

In the context of PCC, both elements are present. Participation is required from patients, families and healthcare professionals during the development phase to determine exact requirements and expectations. The positive outcomes derived from PCC are inherently dependent on participation. An information management solution comprising a community and expert driven body of knowledge can only be sustained by ongoing usage. Thereby, participation is crucial for implementation success.

Actors are split into three groups; stakeholders, participants and change agents. Table 2 defines these groups and determine their roles in the domain of PCC. The refinement of participation is particularly relevant to the proposed PIM framework. It endeavours to capture both the behavioural experiences of participants and the considerations of change agents during creation of participation opportunities for stakeholders.

Table 2. Actors, definitions and their roles in PCC

Actor	**Definition**	**Role in PCC**
Stakeholder	The actors affected by a solution. Actively involved in acceptance and use of the solution. Logical candidates for participating in solution development or implementation	Patients Carers Patients' family and friends Healthcare professionals Hospitals Advocacy groups Researchers
Participant	A subset of stakeholders that actually participate in solution development or implementation	Patients, healthcare professionals, and advocacy groups involved in pilot phases
Change agent	Individuals responsible for designing and executing participation opportunities for stakeholders. Decides who participates, how and what participation techniques are used.	Domain experts, Project owners/managers

The authors also differentiate between types and richness of participation from the participant's perspective and from the change agent's perspective, methods and conditions of participation. This too is relevant to PCC as ongoing participation by both parties (patients and healthcare professionals) and the conditions through which they participate greatly contribute towards levels of richness of knowledge. A prime example here is the cohesion of crowd intelligence from the patient's end and expert intelligence from the clinician sphere along with its synergetic outcomes on PCC.

THE PIM FRAMEWORK

Motivation for the PIM framework lies in the eventuation of better health outcomes for individuals and communities affected by chronic conditions and illnesses through active participation and continuous engagement. The framework is positioned at the intersection of the patient sphere, healthcare professionals (clinician) sphere and importantly the research sphere. Figure 2 illustrates the proposed PIM framework. It maintains the same elements as the updated participation theory and these are explicated below.

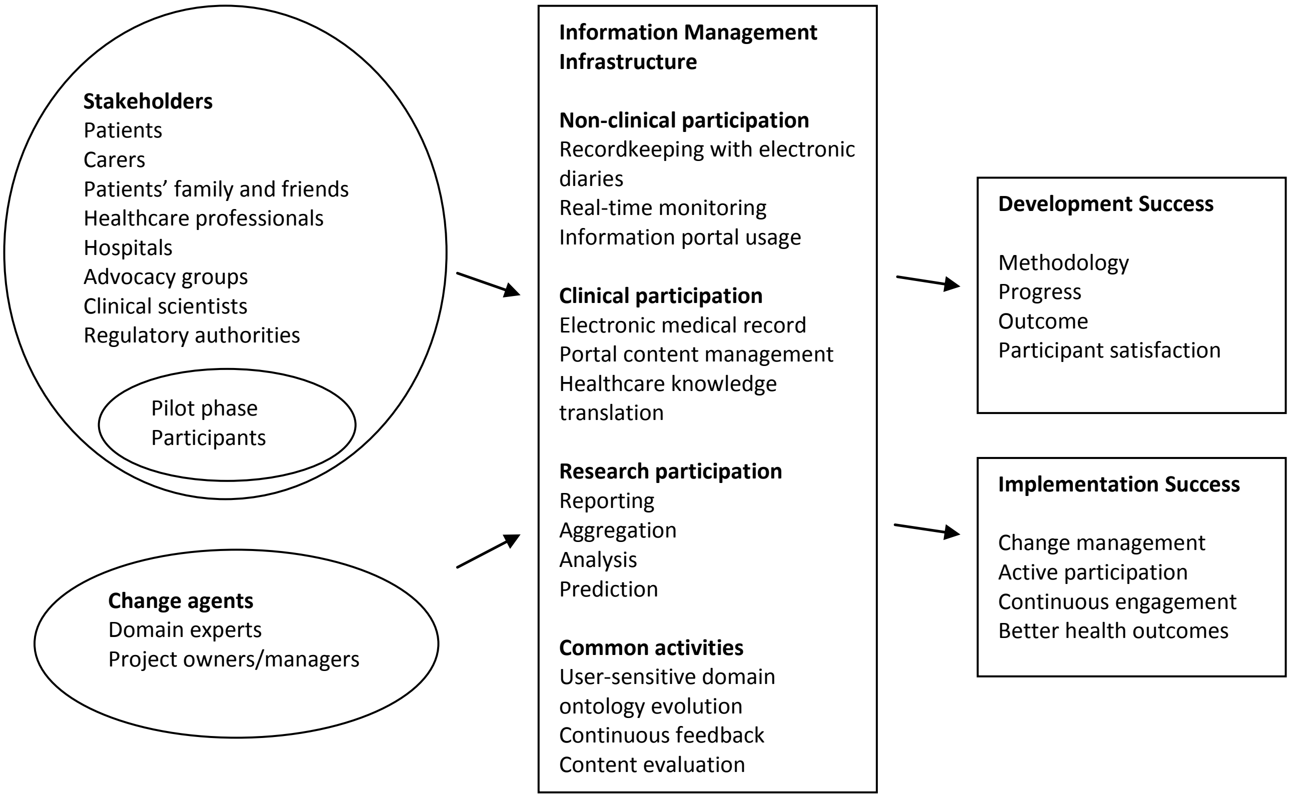

Figure 2: Proposed Participatory Information Management Framework

The actors are split into three groups, stakeholders, participants and change agents. Within stakeholders, patients, carers, family and friends represent the patient sphere while healthcare professionals, hospitals and advocacy groups form the clinical sphere. Clinical scientists and clinicians form another group focused on research. Funding bodies and regulatory authorities are particularly prevalent in the health sector are another type of stakeholder. Participants are simply a subset of these actors. Domain experts are cross-disciplinary involving both IS specialists and healthcare professionals. Along with project owners/managers they belong to the group of change agents. As noted in Figure 2, participation activities of the PIM framework constitute an information management infrastructure for supporting information exchange between stakeholders. These activities were derived from discussions based on a multidisciplinary literature review and consultations with healthcare professionals specialising in chronic disorders. The activities are categorised into four groups, non-clinical, clinical, research and common. They are discussed below.

Non-clinical participation

This is the main type of activities that contribute towards patient centeredness of the framework. These activities are performed by stakeholders in the patient sphere.

Recordkeeping with electronic diaries: Electronic diaries are user-friendly means of maintaining an accurate and up-to-date record of the patient's condition from the patient's perspective. Entries can be made by the carer, family members or friends of the patient. Diaries are useful for members of the patient sphere to review the disease state over time as well as for the clinician to monitor progress and improvements. E-diaries have been trialled in other chronic illnesses, as reported by Burton and Sharpe (2007), Benhamou (2011) and Stinson et al (2013). The prerequisite of training and the need for patient commitment have been noted as drawbacks to the use of diaries (Aarhus et al 2009). The accumulated information on a patient's perspective on different phases of an illness is a substantial resource for clinical research on the same.

Real-time monitoring: The use of modern mobile technology to capture and record incidents relating to the patient's condition through audio, visual or sensory devices. These are recorded in the electronic diary and can be used as clinical observations and as a de-identified educational tool. Further, raw data from real time monitoring can be processed by decision support technologies to suggest interventions or raise alarms.

Information portal usage: A health information portal is a gateway to a diverse collection of information on a specific domain of health. It attempts to aggregate information from multiple sources and present these in a useful form to targeted groups of users (Collins 2002). A portal will maintain information resources relevant to a wide audience affected by the condition, including clinicians and researchers. Each resource aims for relevance and attempts to strike a balance between quality and personalisation. Besides its primary purpose as an educational tool, it also serves to identify the information needs and information preferences of the target audience.

Clinical participation

These activities performed by actors in the clinical sphere. The basic activities executed by clinicians in a disease centred approach are enhanced to address the needs of active participation and continuous engagement.

Electronic medical record: Medical observations ranging from symptoms, diagnosis to medical prescriptions are contained within a medical record maintained by the healthcare professionals. The framework proposes to maintain these in electronic format so that authorised/limited access can be granted to stakeholders in the patient sphere as well. Electronic availability also improves record management via mobile interfaces.

Portal content management: Boiko (2005) outlines content management to be composed of three phases, the first is creation or collection of content, the second phase is managing storage and retrieval, versioning over time and multiple languages etc. The third phase involves publication and delivery of the content. Clinicians and domain experts work together towards the management of information portal content. The key focus is to maintain high quality and personalised content that suits a broad spectrum of the target audience.

Healthcare knowledge translation (HKT): HKT incorporate methods for closing the knowledge-to-action gap from a clinical perspective. Quoting from the Canadian Institutes of Research (2013) which has also been adapted by the World Health Organisation (Straus et al 2009), HKT is defined as a dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to improve healthcare. HKT is differentiated from translational research where the latter is limited to research findings while the former incorporates all forms of knowing (Straus et al 2009).

Research participation

Research participation engages clinicians and clinical scientists in translational research; research that converts laboratory discoveries into clinical interventions (Butler 2008). Clinical scientists are responsible for elucidating factors associated with disease risk, identification and progression and providing a platform to medical professionals for the diagnosis and management of disease. Given the nature of chronic conditions, longitudinal research is a strong contributor towards better health outcomes. A mass of data generated by this framework through active participation and continuous engagement is a wealth of data for translational research.

Reporting: the variety of data accumulated by the framework makes it is possible for scientists to generate reports of varied granularity. These can range from weekly reports on individual behaviours to yearly reviews of patients exhibiting similar symptoms/behaviour.

Aggregation, Analysis and Prediction: Intelligent analytical techniques can be used on the accumulated data, from both the clinician and patient perspective, in search of valuable insights for the treatment of the chronic condition. The raw data can be aggregated using a data warehouse based on different dimensions of interest, basic dimensions such as age, gender, time period and also compound dimensions such as quality of life, treatment plan and combinations of symptoms. Aggregated information drives clinical decision making (Burstein et al 2013) and is also the source for further analysis and prediction. Analytical paradigms such as probabilistic and statistical models, symbolic learning, neural networks, evolution-based algorithms, and fuzzy logic can be utilised to discover temporal and spatial patterns in diagnosis, treatment and illness progression. Such findings become the basis of predictions and recommendations for new patients.

Common participation

Common activities are inclusive to the framework and imperative for the achievement of its main objectives. They are performed by stakeholders in both clinician and patient spheres.

User-sensitive domain ontology evolution: Domain ontology rigorously defines each concept and relationships among these as it attempts to draw up a comprehensive representation of knowledge of the domain (Staab and Studer 2009). While this is very well suited to uni-disciplinary scenarios, it is inadequate for interdisciplinary and multidisciplinary scenarios. The PIM framework is essentially multidisciplinary and multi-audience. Therefore it is necessary to maintain an ontology that is user-sensitive. Users include actors in both patient and clinician spheres. The domain ontology will be iteratively and incrementally evolved as it is being used by all stakeholders to access the body of knowledge within the framework.

Content evaluation: Periodic evaluation of portal content and interfaces to the information infrastructure should be conducted by both clinician and patient groups. This is to ensure that the mechanisms to access the framework are usable and the knowledge maintained within it is relevant and up-to-date.

Continuous feedback: Feedback is essential for the sustenance of any information system and more so for the PIM framework which is founded on participation. Feedback can be obtained via formal reports, access logs, questionnaires and exit surveys. Furthermore, quantitative and qualitative metrics should be used to measure the attainment of key objectives of active participation and continuous engagement.

Participation leads to system success and as outlined by Markus and Mao (2004), system success is split into implementation and development success. Development success is determined by quality of the development process. Implementation success is the more significant metric as it measures the benefits to the key stakeholders and the achievement of the core objectives of the framework.

PILOT PROJECT

A pilot project to establish empirical evidence supporting the purpose and outcomes of the proposed PIM framework has been initiated by the authors of this paper in collaboration with medical practitioners and engaging members of the ASD community. The project focuses on ASD and consists of several phases (Figure 3).

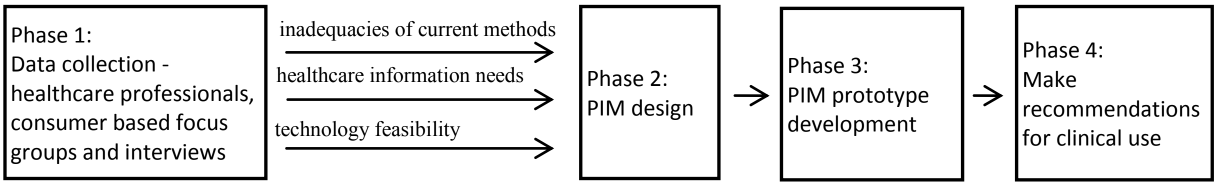

Figure 3: Phases of the Pilot Project

The first phase will collect data from healthcare professionals, consumer based focus groups and interviews to determine the inadequacies of current methods and expectations of healthcare information delivery for ASD. It will also determine to what extent the communication and data sharing between the healthcare professionals and patients can be trusted to involve technological solutions, and what technology are likely to be helpful and within the reach of the ASD community. These findings will be used as the basis for the PIM design of information infrastructure along the concepts and definitions elaborated in this paper. The information infrastructure will then be prototyped to address healthcare information needs of the ASD community. It will also support information flows between stakeholders involved, taking into account mobility and accessibility needs of ASD patients. Given the diversity of clinical care processes at different institutions, the PIM framework will be adapted to suit the requirements of such processes. When fully implemented, the infrastructure will facilitate patient-centred support for healthcare decision making that involves integration of medical data from multiple sources with patient specific data, including psycho-social factors, patient values and circumstances. The outcomes of this pilot project will also shed light on the implications of instantiating the updated IS participation theory in this context. We will also identify the specificities and constraints related to healthcare information systems implementation. Economic factors defining the success of this innovative solution would also be reflected upon. The project has been approved by the Human Ethics Committee and the interview process is under way.

CONCLUSION

Chronic disorders and illnesses require frequent medical attention and continuous healthcare. ASD is a condition that requires active participation of the patient, carers, patient's family and friends. Healthcare for chronic conditions is gradually shifting from disease focus to patient centeredness. ASD community is particularly ready to embrace the PCC, because the nature of this condition requires constant participation of multiple professionals and the information about the condition and services is constantly revised. The PCC approach aims to deliver individualised care through increased patient involvement. Recent literature further emphasizes the need for patient education to drive patient participation. The role of appropriate information systems in this context is hard to underestimate. However, such systems have to be developed and designed having specific needs of the stakeholders in mind. The updated IS participation theory provides a clear underlying principles for such systems design and implementation. It identifies the role of stakeholders and change agents in participation activities, granularity of participation itself and refines the concept of participation that leads to system success. This paper reviews the updated IS participation theory, applies it to healthcare context and advances a participatory information management (PIM) framework for healthcare of chronic illnesses based on its core elements. The framework integrates participants from three spheres, patient, healthcare professionals and researcher in a health, education and community service setting. Participation activities are grouped into clinical, non-clinical, research and common activities. The effectiveness of the framework can be measured by the system success reflected in the level of active participation and continuous engagement of all stakeholders. The framework is generic and applicable to any chronic illness. This paper focused on ASD as an example of a long-term condition of a complex nature, which engages a network of stakeholders often disconnected because of a lack of common information infrastructure. We acknowledge the lack of empirical studies to better understand the information needs of the community, their willingness to contribute personal information for better healthcare outcomes, and the level of technical preparedness to embrace a common platform for communication. The paper notes a pilot project on ASD to acquire such empirical evidence that confirms the underlying assumptions of the purpose and benefits of this framework.

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