
CONFERENCE ABSTRACT

The MediStori. A personal health record and standardised self-management toolkit which can improve integrated care systems.

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An introduction: (comprising context and problem statement) Integrated care is critical in today's health care settings. There are many causations for disintegrated services, but one critical component which may impact on the success of such projects in practice, could be said to be related to disconnected health information. This abstract sets out to show the benefits for all stakeholders in healthcare through delivering and implementing a standardised integrated personal health record (PHR) toolkit, which is continually updated and managed by a patient or carer, and promoted at the point of care by health professionals.

The founder of this project, a patient and carer to three children with differing conditions, ascertained through lived experiences, that most acute health care settings were fragmented – many focusing on one disease at a time, meaning most often, a holistic viewpoint was not considered, thus impacting on issues such as comorbidity, medication reconciliation and disconnected health information.

Initially for personal use, the founder created a toolkit, MediStori. The MediStori has a dual purpose – it is a paper-based PHR and it is a self-management toolkit. The major advantage of a PHR is that it collates all the relevant medical and related information concerning a patient in one place, in a manner that is helpful and usable (MacNeela, 2015) and could impact positively on integrated care in practice.

Furthering from its original developments, progression of the toolkit to make it available to others was initiated; using co-design and quality improvement methodologies throughout. MediStori aimed to keep all of family's information together, from birth to end-of-life; could help a patient or carer communicate relevant health information at the point of care in both primary and acute settings (a critical component for integrated care), and assist in the self-management of conditions in the home. As a patient is the only common denominator between all their health professionals, the principles upon which it was built were reliant on two theories 1) it should be promoted at the point of care and 2) integrated care should focus foremost on a person's needs, and thereafter, the disease, because, irrelevant of conditions, patients all had similar issues:

1) Managing, understanding and adhering to medications, treatments or therapies

- 2) Accessing, managing and attending health appointments
- 3) Communicating, storing and managing personal health information
- 4) Coping with emotional, physical, social or financial impacts
- 5) Understanding diagnostics, diseases, terminology or services

To investigate this theory, and progress the development of the toolkit, a national research project was funded by the Quality Improvement Division of the HSE. The research intervention included a national study on service users and health professionals to gain insights and feedback on the toolkit and their experiences of integrated health services. The study represented unique team collaboration between: Expert Patients; HSE Leads; Chief Pharmacists; Child Healthcare Coordinators; Clinical Nurse Specialists; General and Specialised Hospitals; National Charities; and an Academic Researcher, who oversaw and evaluated the outcomes of same. As integrated care is related to all disciplines, multiple surveys were used to elicit stakeholder input: one was community-based, through charity organisations and the second was of outpatients in acute hospital settings. Quantitative evaluations were triangulated between the settings using and the survey elicited considerable optional, qualitative feedback from participants. The collaborative approach to assess the cause and extent of the problem taken ensured that citizen perspectives, healthcare policy makers, organisations, NGOs, innovation developers and evaluation researchers could cooperate to achieve various goals: to assess the need for support around medication compliance, healthcare utilisation, information management – all needs associated with integrated care.

Short description of practice change implemented: Clinical Nurse Specialists & Self-Management Coordinators were trained to deliver the study and toolkit to service users and it was in this instance where implementation of integrated care services was delivered. The pilot study at the two acute hospital sites were designed to take advantage of the patient wait of between 45 minutes to 90 minutes before being seen by a doctor at outpatient clinics. This was an opportunity to engage with patients to educate them on the benefits of self-management, self-care and engagement through adoption of a personal health record system. Training on medication management, symptom monitoring, and keeping important information together were given during this time. Patients were recommended to utilise the toolkit and bring it to the various health professionals whom they engaged with. They were also advised to bring it back to return OPD clinic appointments. The information they input to the toolkit was then readily available for any health professional at the point of care, thus resolving the fragmentation of health information that had previously been occurring.

Aim and theory of change: A complex healthcare organisation includes many stakeholders, but the patient's knowledge and experience is often overlooked. A patient, irrelevant of disease, is the only common denominator which links together all of the system stakeholders. This abstract argues that, very often, patients are not consulted effectively in the process of communication of holistic health information. Many PHR's are related to age, gender, status or disease but this is not effective for person centred models of care, nor does it aid with integrated care processes. Furthermore, many toolkits do not include self-management aides,

nor do they allow for the integration of disease specific care plans. The aim for this research project was to gain valuable insights and domain knowledge on how best the toolkit, MediStori, could be utilised to improve integrated care processes and person centred models of care.

Targeted population and stakeholders: The inclusion criteria were for participants to possess literacy and fluency in the English language

as these were important characteristics for use. The study was for any patient, carer or parent - irrelevant of disease group, locality or gender and all participants had to be over the age of 16.

There were no restrictions for service users involved as the toolkit was designed using a need based approach, not specific to any one disease, age, culture or gender. Co-designed national multiple surveys were used to elicit stakeholder evaluations of the toolkit prototype. One was community-based, through charity partner organisations and the second was a survey of outpatients in acute hospital settings. Online and paper-based surveys were designed comprising core and specific sections. The survey elicited considerable optional, qualitative feedback from participants who used the toolkit on a trial basis. The collaborative approach to assess the cause and extent of the problem taken ensured that citizen perspectives, healthcare policy makers, organisations, NGOs, innovation developers and evaluation researchers could cooperate to achieve a key goal: to assess the need for support around medication compliance, healthcare utilisation, information management, and to appraise the toolkit to meet those needs. Health professionals were trained on how best to deliver the study to service users. Key champions within these settings were identified at early stages. All staff involved were given the opportunity to provide feedback.

Timeline: Research ethics approval was obtained from both hospitals before commencement of the study, beginning in Jan 2015. Quantitative evaluations were then triangulated between the settings using Time 1 and Time 2 surveys between February and October 2015.

Highlights: (innovation, Impact and outcomes) All of the participants recruited through hospitals (100%) thought it was a good idea to have the MediStori promoted in the hospital setting, and 93% thought it should be promoted in GP surgeries and pharmacies as well. All of those recruited through charities felt similar - 100% thought it was a good idea to have the MediStori promoted in the hospital setting, and 100% thought it should be promoted in GP surgeries and pharmacies as well. 100% felt it was important to have it available through their charity. Some comments were made regarding where participants felt it should be promoted. To give an example of the needs identified in Time 1 surveys, patients were consistently finding it difficult to manage medications [>95%]; communicate effectively with healthcare professionals on health information [>89%]; recall vaccination administration [>45%]. In Time 2 results, all [100%] respondents evaluated the toolkit as making a positive contribution toward meeting their needs and capacity for accessing healthcare providers' support to do this, thus effectively impacting and alleviating much of their initial concerns.

The Time 2 responses were an endorsement of the potential for the MediStori to have a positive impact on patient outcomes. Three quarters (79%) of participants said that it had impacted on their management of medications; eighty per cent said it had impacted on how

they managed health care appointments; nearly 80% indicated it had an impact on how they communicated health care information to health care professionals. For over two thirds (77%), the MediStori had had an impact on how they felt in their ability to manage their own or their loved ones condition. In combination with positive perceptions of the MediStori's usability, the Pilot Study findings are indicative of a strong potential for making a contribution to health care practice (MacNeela, 2015) as ninety three percent of all participants had used the Medicine Memo to write down their child's medication and the times the medications were given. Similarly, 100% of those who responded indicated that it was a good idea to have the MediStori to manage their own or their loved ones medication.

A number of suggestions were made to refine the toolkit before redesign, thus saving time, money and resources, impacting on system cost savings. We recognised that patients can become sick at later stages and so all could not complete Time 2 surveys within the time frames, so in the future we would increase our limitations.

Comments on sustainability: All health care professionals engaged in the research relayed that promoting and engaging with this toolkit at the point of care did not impact negatively on their work processes; and often found that by patients having it, improved communication and diagnostic processes. However, sustainability of this project was restricted due to lack of financial resources for the toolkit.

Comments on transferability: The ease of transferability of the toolkit was showcased in the process of where the toolkit was recommended: through two acute hospitals [one specialist, one general]; through eight national charities; and through online resources. All data within the toolkit could easily be translated to various languages, and as the toolkit was needs based, could be implemented globally.

Conclusions: (comprising key findings) This paper set out to show the benefits for patients, carers, professionals and integrated health systems by supporting an evidence based, standardised and collaboratively designed personal health record (PHR) and self-management system – as recommended to the patient or carer at the first point of care by health care professionals. A system which could contain the most up to date evidence based information for patients about their symptoms and/or condition, integrating their health care teams, in acute and primary settings. An interoperable system between patient and professional which helps join up a disjointed health system – in real time – with the patient leading the way. A system which tackles miscommunication, disengagement, medication non adherence, appointment mismanagement, readmissions, unnecessary diagnostics, uninformed decision making processes and disconnectedness of medical information – all issues related to integrated care. Based on the evidence from this research, this toolkit, and the person centred model of care, is an example of how integrated care in practice can be led by an expert patient in collaboration with an ecosystem of health professionals.

Discussions: Through doing this process, discussions arising the involvement of service users and health professionals together for proactive patient safety initiatives, could create mutually relevant and motivating goals – therefore impacting on integrated health services. Without perspectives of various stakeholders, initiatives often fail to be implemented – costing long term wastes on resources and finances in systems. Collectively using quality

improvement processes (such as PDSA cycles) and co-design methodologies allowed for a more practical approach to improving projects and services. It was also found that, very often, patients were not consulted effectively in the process of designing new organisational processes, meaning a genuine stakeholder approach is typically not implemented. We learnt that, as a result of under-involving patients in design; time, money and resources are not put to effective use within health services. Issues that could benefit from more extensive patient consultation include process re-design, staff re-deployment and infrastructural planning. There is a direct link to be made between this failure to include patient perspectives in patient safety outcomes. There is much to be said for continuing multiple stakeholder collaboration that has demonstrated its viability into a future phase of rollout and implementation, we would highly recommend putting into practice best QI and PPI processes.

Lessons learned: A direct learning from the study was the recognition that patients can become sick at later stages after initially joining the study, and so all could not complete Time 2 surveys within the time frames, so in the future we would increase our limitations. Additionally, limited resources can impact on sustainability of projects such as this, even when they are evidence based using best practice. All in all, it was learned that through building a practical platform for integrated care: delivering change that matters to people, can be achieved.

Keywords: health records; person centered care; quality improvement processes; integrated care; co-design
