The MediStori.
A personal health record and standardised self-management toolkit.

Incorporated Review, Report and Evaluation
2012 - 2015

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Comprising Report: MediStori Pilot Study in Two National
Acute Hospitals & Multiple Community Settings 2015
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Keeping a personal health record has been demonstrated time and time again how it can improve service quality through the provision of accurate, timely information and user empowerment.

However, if there is a lack of a national mandated, coordinated approach and resource constraints then this impedes personal records from being implemented in our health system.

(Department of Health, HSE, 2010)
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Authors Note:

The purpose of sharing this publication is to give an overview of the benefits of having a standardised, universal personal health record system, as recommended at point of care by health care professionals and health care organisations to patients and carers.

This paper will aim to show the benefits of a system which focuses on the main needs of all patients, even prior to diagnosis, such as medications, appointments, communication and the impact of having conditions. It will show how integration of specific components regarding disease, age and socioeconomic backgrounds of an individual can, and should, be added as required throughout the life cycle of a person. It will also explain the difficulty and confusion for patients, carers and health care professionals by having too many different types of systems and/or care plans across a health service. This document showcases the MediStori project as an example of this type of system. It also discusses its promoter and the founding principles for which this work is done - from concept, to date.

Hopefully by sharing this research more people will start thinking of the “patient” more as a "person" – from birth to end of life, and not just as a person with a condition or ailment, or as a child or old person. Hopefully all will be able to see the benefits of working collaboratively together; and involving patients in their work. There is also the hope that patients will see how to better store, record and communicate accurate health information, and better self-manage their own or their loved ones medications and conditions.

For this reason, this document is written in a tone which aims to be easily understood by any person(s) - be they patients, carers, health care professionals or researchers – and even those not working or using the health care service. Health is everyone’s business.

#sharingislearning
It has been demonstrated through copious research studies that a well-informed, educated, compliant and reassured patient has a far better chance of better health outcomes, and a far less chance of having issues such as recurring visits to their GP, taking their medications incorrectly or being readmitted to hospitals unnecessarily. It has also been widely documented that health care professionals whom engage, communicate and share decisions effectively with their teams and patients will have better, and safer outcomes for their patients. Sometimes though, no matter how proactive the patient is, or how engaged the health care professional is, there can be a need for physical, technological and/or educational interventions, projects or initiatives to help address the problems in hand.

Technology and devices as enablers
Across the globe, an urgent need for integrated health services is becoming more and more evident, and this is when technology, medical devices and personal health records can be of help. Toolkits of these sort can better enable a patient or carer remember important information, such as whether they took their medications; when was their last antibiotic or even help them store information about their condition or services. They can enable more effective communication between a patient, their health care professionals, family and carers; and also connect the various health services and systems up to one another. Together they can help tackle the needs of a patient for all their life, at every stage.

Patients are people
The complexity though in finding a unified, standardised solution which can help with this process across a vast population of patients stems from a fact that no two patients are exactly alike. Even if patients have the same diagnosis; are the same age; live in the same area, and are of the same sex, each patient will have unique issues, needs and wants. This is because every patient is a person first, and every person has a different lifestyle, personality, belief system and culture – outside of just being “sick”. More and more evidence emerges which is suggestive that when a patient is treated as a person, holistically, a greater potential for positive outcomes arises. It is the recognition of this in more and more health services across the globe which is starting to show a trend of person-centred care models being embedded into everyday practices.

People have needs, not just diseases
These models may be particularly helpful at addressing early stage needs, especially during the conversion time from when a “person” suddenly becomes a “patient”. It can be easy to presume that the general population “just know” how to best self-manage a health condition, but quite often, this is not the case – many do not even know the dangers of what taking too much paracetamol can mean for them. When a healthy person has never been sick before they may have no knowledge or experience in how to manage their own or their loved ones health. It is also important to note that for many patients, getting diagnosed can be a long and arduous ordeal, yet they will still require the same health services, treatments and information to help them manage their symptoms. Person centred care models aim to address the needs (as opposed to just the disease) of the individual, taking into account their lifestyle, cultures, family and community. These models look at a person’s journey, from birth to end of life.
Do all patients have the same needs?

Speaking from the patients perspective, I can safely say that all patients, regardless of the first time they use a health service; the severity of the symptoms/condition or their age, sex or locality will have the same overarching baseline needs at different stages throughout their health care journey. These, almost certainly, are as follows:

1) Managing, understanding and adhering to their medication and/or therapy
2) Accessing, managing and attending relevant health services and appointments
3) Communicating, storing and managing personal health care information
4) Coping with the emotional, physical, social or financial impact of having symptoms/conditions.

Subsequently, specialised needs for specific conditions are usually identified within these fundamentals.

Proactive vs reactive approaches to needs

Many solutions are designed to fix problems after they have occurred, but a lot of the time this doesn’t actually address the reason why it happened in the first instance. One proactive approach to ensuring all patients can be “well informed, educated, reassured and compliant” would be (at the very earliest point of care stage when using a health service) for health care professionals to give patients the most up to date and evidence based education, information and toolkits on how to best manage their symptoms and/or health care condition. This approach however, is not as simple as it sounds. With hundreds and thousands of research papers, schemes and aides readily available on the health care market, it can be confusing and time consuming for health professionals to know what best to recommend. Moreover, across public, private and charity sectors, hundreds of new ideas, initiatives and projects are brought to fruition every day, but many health care teams are working in silos and not engaging with others in the same space to approach solutions collaboratively. These somewhat unhealthy competitive cultures are not in the best interest of patients, health services or taxpayers money. All too often there can be so many competing options available, it can be difficult for patients and carers to make informed decisions.

The need for a standardised solution

This paper sets out to show the benefits for patients, carers, professionals and 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 that has been created using both quality improvement, lean and co-design methodologies throughout – from design, development and delivery. A system which motivates social prescribing and can contain the most up to date evidence based information for patients about their symptoms and/or condition, as supplied by their health care teams, charities or organisations. A system which can inform patients about where to access primary care and community based services and resources. 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. A system which promotes better self-management of health conditions. A system which can save health services time, money, resources, and most importantly, lives.
Putting the person, not just the patient, at the centre – for life.

This PHR system is called the MediStori and it focuses on the recording, storing and self-management of medications, appointments, symptoms and health information for use by people of all ages, genders, disease groups – and can be used from birth, right through to end of life. This innovative resource focuses on the individual needs of each patient and helps them record their own unique personal story, in line with that of their families. Family history, lifestyles and cultures, for instance, all impact on the possible medical tests a person may go through when being diagnosed or treated with a condition. Additionally, patients and carers often know more about themselves (or their loved ones) than anyone else and quite often are asked repeatedly to communicate up to date information about themselves to their health care teams – many clinicians trust the information they’re given and many often use it to help them make decisions regarding treatments, diagnostics and/or admissions. This is because it is recognised that the patient is the one living with the condition and they can be completely capable of reiterating medical data about themselves to their health care teams – especially information from how they managed in their home settings. The patient is the only link between all of their health care services and so when they have their most recent and accurate medical information to hand, at the point of care when they need it – this, by default, increases patient safety.

Delivery is just as important as design

Patient safety may also be improved if health care teams have better insights into patient’s situations. The conversation that can occur when a health care professional offers a solution to patients and carers to help manage medications, for example, can help to gently bring up the topics of nonadherence, or how they’re managing their condition and any other issues that are arising. By showing empathy, increasing education, engagement; communication and collaboration at this point can often be the key to changing behaviours. This, however, could potentially be disrupted if other health care settings are not involved in this process. For example, if a patient received a “cardiac diary” in a national hospital and brought it back to the local hospital, they may not want to engage with it. This is why if one standardised toolkit was recommended by all health care professionals, services and charities, together, there would be a much better chance of it being adopted and made habit forming. Furthermore, if a standardised system was in place of which everyone was aware of, it would then be easier to then integrate other more specific elements such as individual disease diaries - which could be useful for multiple conditions.

Validation is not just nice to have, it’s necessary

It is always important that all medical toolkits, aides and devices are proven to work, by all stakeholders they affect, and that they are demonstrated to not be a waste of money – especially in public health care services. It is also vital to learn about any areas which need improving. For these reasons, in 2015, an externally evaluated, randomised, comparative collaborative study was completed on the MediStori system. This project was led by patient, carer and expert by experience, Olive O’Connor, and was delivered through collaboration with a wide range of health care professionals, services and organisations, of which are mentioned later on in this paper. The study was funded by the Health Service Executive [HSE] to the value of €80,000 and was overseen by Lecturer of Psychology NUIG, Dr Pádraig MacNeela. It was championed and led through two national acute hospitals by two very different health professionals – one a Child Health Information Coordinator and the other a Chief Pharmacist.
Involving all stakeholders for implementation

Much of the time, however, toolkits may not be user friendly because they are not designed with those 1) who have the problems (i.e. patients) 2) those trying to help fix the problems (i.e. health care professionals) or 3) those delivering the solutions (i.e. health systems). The MediStori project involved every stakeholder at every stage of design, development and delivery, and so it covered the majority of issues, wants and needs. Feedback from all involved consistently showed that it would be the implementation model for which this toolkit was delivered which would be where the valuable culture differences would occur as regards to nonadherence, communication and patient safety.

Addressing two tier systems in health care

Likewise as part of this “culture change agenda” it was very clear that if MediStori were just another commercial retail product, it would again only be feeding into the two tier system that exists in healthcare – it would mean those who have money would have access and those who don’t wouldn’t. It was vital to be able to ensure that the toolkit needed to be available through all avenues – and especially for those from poorer socioeconomic backgrounds as more and more evidence showed that extra education, information and training should be provided, to truly impact on their health outcomes. So finding out the best way in which the project was to be implemented (especially if it were validated and national roll-out was on the horizon) was important; thus the toolkit was delivered in a number of ways to patients and carers. In one acute general hospital, namely Mayo University Hospital, it was given out to patients and carers by a trained patient educator, through all outpatient clinics. This was overseen by Chief Pharmacist, Ms. Blánaid O’Connell. In another acute specialised hospital, namely Temple Street Children’s University Hospital, it was given to patients and carers through specific outpatient clinics by clinical nurse specialists (CNS’s). This was overseen in this hospital by Child Health Information Co-Ordinator, Ms. Grainne Dowdall. Additionally, the toolkit was also given out to patients and carers online through the company’s website and as promoted through various national charities and organisations, including: Jack and Jill Children’s Foundation, Irish Children’s Arthritis Network [ICAN], Arthritis Ireland, Irish EDS and HMS, Irish Dysautonomia Awareness, Dyspraxia Ireland, EDS Awareness Ireland, and the Marfan Syndrome Support Group.

Needs assessment – before and after

It was important in this study to fulfil a baseline needs assessment of those involved in the study as this would help show insights into the patient’s perspective of how they saw health care services and how they were currently managing their medications, conditions and health information. A cohort of 251 participants were involved and they were asked questions upon receiving MediStori and then again six weeks later. The study showed that 95% of respondents were not giving or taking medication correctly – even though the WHO would show that approximately 50% of the population were not adhering properly to medications. It also showed that the majority of health care professionals [94%] were not recommending charities to patients and carers even though 86% of patients felt their charity was like an additional health service to them. It showed that 82% of participants were not given anything through an acute service to help them manage medications, meaning that many patients and carers were devising their own personal health record kits at home using diaries, notebooks and excel spreadsheets to help them manage their conditions and symptoms. These findings were important, not just for this project, but for health care services also, so they could know what needed changing, based on experiences.
Where best to deliver?
The results also showed that all participants wanted the MediStori delivered throughout all health care settings. Surprisingly, all involved in the study wanted MediStori rolled out nationally, and all would refer it to a friend or family member. 100% of participants said that MediStori was a good idea. These statistics were all verified by good quality detailed qualitative data – or in plainer terms, the patient’s voice. These same views were then reiterated by health care professionals when they too completed a survey asking them about their preconceptions of MediStori. The health care professionals also said that the MediStori would save health systems and health care professional’s time, money and resources, and all would recommend it to their patients and carers.

All health care issues have one common denominator – the patient
As you will also see from just some of the research papers that are cited throughout this paper, there are many different theories regarding PHR’s and there are also many problems facing health systems. These all show evidence for different issues - why people end up being re-admitted; why there are such high incidents of medication non adherence and the prevalence of chronic illnesses. Few documents look at all of these issues together and even fewer solutions are mentioned to tackle these problems collaboratively. There should be no need for such disconnection in research or change reform - because the patient is the common denominator in every single issue of health care. There should be no debates about what a PHR is either – there are many different definitions out there and most think that a PHR has to be electronic – which isn’t so because paper based PHR’s existed long before electronic versions ever did (example NHS Personal Child Health Record15). The only way health systems will be reformed is by focusing on and asking the most important people in our health system, what are the problems, and how do they think they could be fixed – these are patients, carers and frontline health care professionals – along with everyone else who is part of this complex ecosystem. The way forward to finding solutions is having all stakeholders on board from the very beginning – and each being as valued as another.

This paper in its entirety shows the complete journey of one innovative idea that does just this. It demonstrates the importance of having a universal standardised self-management and PHR system in one, and how it could potentially save all stakeholders in healthcare time, money, resources.

And most importantly, lives.

It shows how everybody needs to work together, for the same solution – because in healthcare we are all here to either get better, or to help get someone better.

Ms Olive O’Connor
Patient, Carer and Mum
Promoter of Proactive Health and Founder of MediStori
Abstract

Introduction
This document describes the development and piloting of the MediStori, a paper-based personal health record that can be used by both individuals and families. The MediStori was evaluated in a variety of settings during 2015. It displayed a high level of user acceptability and end users have made recommendations to further enhance its utility for managing health records, medication plans, appointments, and other elements of the personal health record.

Within a health service provision model that still relies extensively on paper-based communication with end users, the MediStori is positioned as a user friendly means of enabling patients and families to monitor, record and store vital health care information, until such a time that standardised electronic patient held records are made available nationally. The MediStori was designed from a patient perspective arising from the personal experience of the developer and her family. A process of continuous improvement and amendment has been followed to bring the initial prototype forward.

Dual Purpose - Personal Health Record and Self-Management Support
The MediStori has a dual purpose – it is a paper-based PHR and it is a self-management toolkit. Self-management is supported through (a) techniques and tools to help patients choose healthy behaviours and (b) by supporting the transformation of the patient-caregiver relationship into a collaborative partnership (de Silva 2011) (The Kings Fund, 2012). A Personal Health Record (PHR) allows end-users to manage their health records, often arising from the context of chronic illness or being a carer. The major advantage of a PHR is that it collates all of the relevant medical and related information concerning a patient in one place, in a manner that is helpful and usable (MacNeela, 2015).

External Evaluation
The first usage of the pilot version of the MediStori took place through the involvement of voluntary sector organisations across Ireland, which made the MediStori available to the health service users and families that they serve. The second strand of piloting and evaluation took place by involving specific hospital services that provide paediatric care. Thirdly, a secondary survey was asked of health care professionals from various backgrounds to assess their preconceptions of the toolkit. This study explored acceptability and ease of use of the MediStori through feedback and further suggestions from patients and carers on how well suited it is to their specific needs.

The primary objectives of these investigations were to a) obtain user feedback to refine the MediStori b) to analyse pilot study responses from the MediStori users with respect to patient satisfaction, motivations for use, and usability c) to identify how the MediStori can be best integrated with the systems and processes of health care and d) to establish whether patients and carers evaluated the MediStori as a useful tool to manage their child’s health and treatment needs, including medication compliance (MacNeela, 2015).
**Recommendations**

Over 250 patients and carers across ten health care sites concluded that they would like to see the MediStori rolled out nationally after using it for a six-week period. In addition, all would refer it to a family or friend. There was also consensus that it was a good idea to promote the toolkit in the hospital setting, and 98% of the participants who received the MediStori through a charity expressed the opinion that it was a good idea to have the MediStori promoted through charities, underscored by the view of 86% of participants who felt that their charity was like an additional health service to them. The MediStori was perceived initially very positively by all of those who took part in the study.

Nearly all of the participants initially rated the MediStori positively on these dimensions: 97% liked the size of the MediStori; 96% liked the colour of the MediStori; 96% thought that the MediStori was a good idea; 96% liked the way the MediStori was demonstrated to them; 96% thought it might help them with their specific needs; 100% thought it was a good idea to have it promoted in the hospital setting; 78% said they would like to see an electronic version also. All of the participants who were recruited online said they thought MediStori was a good idea and a vast majority of these respondents (92%) reported that the MediStori had met their specific needs, with a similar proportion rating the MediStori positively on the dimensions of size, colour and effectiveness of its initial demonstration.

**Medication Management & Specific Needs**

In this study, 95% of respondents who were taking/giving medications recorded one or more difficulties with the management of medications. Yet 82% said they did not receive a medical device in a hospital setting to help them manage medications. This helps to explain why 93% of respondents from the acute setting who were administering or taking medications reported using the Medicine Memo, a feature of the MediStori that enables users to write down their medication and the times the medications were given.

<table>
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<tr>
<th>Participants were asked had they ever...</th>
<th>Charities</th>
<th>Hospitals</th>
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<tr>
<td>Found it difficult to remember what time they took/gave medications at</td>
<td>75%</td>
<td>57%</td>
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<tr>
<td>Forgot to take/give medication on time</td>
<td>75%</td>
<td>59%</td>
</tr>
<tr>
<td>Found it difficult to remember if they took/gave medications or not</td>
<td>72%</td>
<td>52%</td>
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<tr>
<td>Thought that other people may not give the medication correctly</td>
<td>59%</td>
<td>58%</td>
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<tr>
<td>Forgot to take/give medication altogether</td>
<td>54%</td>
<td>24%</td>
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<tr>
<td>Thought that they may not have taken/given enough medication</td>
<td>51%</td>
<td>14%</td>
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<tr>
<td>Got confused about how to give/take medication</td>
<td>27%</td>
<td>9%</td>
</tr>
<tr>
<td>Thought that they may have given themselves/someone too much medication</td>
<td>25%</td>
<td>12%</td>
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<tr>
<td>Got confused as to why they were taking/giving medication</td>
<td>21%</td>
<td>5%</td>
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<tr>
<td>Gave the wrong dose of medication to themselves or someone else</td>
<td>19%</td>
<td>8%</td>
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<tr>
<td>Mixed up medications with one another</td>
<td>9%</td>
<td>0%</td>
</tr>
<tr>
<td>Gave the wrong medication to themselves or someone else</td>
<td>8%</td>
<td>2%</td>
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Related Findings in Regard to Medication Non-Adherence

- Prior to using the MediStori, 75% said they found it difficult to remember what time they took/gave medications. After using it, only 17% reported having this difficulty.
- 72% said they had found it difficult to remember if they took/gave medications, compared with only 10% after using the MediStori.
- 75% reported that they had forgotten to give/take medication on time, with 40% reporting this after using the MediStori.
- Prior to using the MediStori, 54% had forgotten to give/take medication altogether, compared with only 13% reporting this problem after using it.
- 19% had said they had given/taken the wrong dose of medication whereas no participants reported this after using the MediStori.

Similarly, 27% had said they had gotten confused about HOW to give/take medication and none had issues after use either. Finally, there was only a 1% reduction in participants getting confused as to WHY they were giving/taking medication (from 21% to 20%). (Interestingly, not knowing why a medication is used occurs due to a lack of knowledge or education of the medication, which is unlikely to be addressed by a health information management system.)

Cross Divisional Solution
These findings are reflective of the evaluation data obtained through the different methods employed to assess the potential role of the MediStori as a PHR in Irish health care, for patients, carers, health systems and health care professionals. The MediStori offers the potential for enhanced integration that elevates the autonomy and empowerment of patients and carers. The MediStori has something to offer with respect to many of the key issues of debate in health care provision at the moment, including:

Patient and Person-Centred Care
Patient Engagement
Recognition of Carers
Self-Management
Organisational Culture
Marginalised Groups
Disease Grouping
Readmissions

Informed Decision Making
Integrated Care
Health System Objectives
Health Care Provision
Health Service Reform
Digital Divisions
Medication Non-Adherence
Communication in Health Care

Health Care Professionals Perceptions
Health care professionals were also asked about their perceptions of MediStori.

- One hundred per cent said that patient/carer access to the MediStori could potentially help health care professionals and services save time, resources or money.
- None of the professionals regarded any element or feature of the MediStori PHR toolkit as likely to have a negative impact.
- All of them expressed the view that it was important that MediStori was given to patients and carer would recommend the MediStori to their team, colleagues or peers.
- Similarly all agreed that it should be made available in hospitals and other health care settings for patients with both acute and chronic conditions.
Struggled with Medication Management: 95%

Not Given a Medical Device in Acute Hospital: 82%

Used the Medicine Diary To Help Manage Medications: 93%

Participants Thought MediStori Was a Good Idea: 100%

PreUse - Expected MediStori Could Help With Specific Needs: 98%

PostUse - Felt that MediStori Had Met Specific Needs (Post Use): 93%

Participants were Awaiting Another Diagnosis: 60%

Participants Felt Charity Additional Health Service: 86%

Health Care Professionals Recommending Charities: 7%

Felt MediStori Should Be Promoted Through Charities: 100%

Would Like to See Electronic Version: 80%

Liked the Way it Was Demonstrated to Them: 98%
Supported with qualitative data...

- **83%** Impact Managing Their Own or Others Condition
- **93%** Impacted on Keeping All Family’s Data Together
- **70%** Felt MediStori Helped Link Between Health Services
- **100%** Felt it was a good idea for MediStori to be Promoted in a Hospital Setting
- **94%** Filled in Relevant Areas in the MediStori
- **50%** Filled in Emergency Information for Paramedics or Carers
- **89%** Didn’t Receive Any PHR from Health Services / Professional
- **93%** Felt it Important to Keep All Family Health Data Together
- **93%** Felt MediStori Should be Promoted via GP + Pharmacy
- **66%** Found it Difficult to Remember Appointments
- **80%** Felt MediStori Had Impacted on Managing Appointments
- **100%** Wanted MediStori Rolled Out Nationally

**100%** Said They Would Refer Friends or Family to Use the MediStori.
The MediStori toolkit was initially developed in 2012 by patient, carer and expert by experience, Olive O’Connor, when she first started looking after her father in her own home. After a nine-week stay in hospital, her father was diagnosed with multiple chronic conditions and was prescribed 22 medications.

Problems Arising
Upon speaking to her father’s medical team the day before his discharge from hospital, Olive started becoming concerned that she wouldn’t be able to administer all of the medications safely and so she asked the registrar if there was any device to help her with this. He told her that unfortunately hospitals didn’t provide such aids but he did recommend that she either go online to see if there was an “app” available or go to a pharmacy for help. Olive couldn’t access the Internet in the hospital that day, as there was no Wi-Fi available, so it was only when she got home did she go online. She quickly found thousands of apps available but found herself getting confused as to which one was the best to use. She wished that the doctor had recommended something specific for guidance. With her father coming back the next day, Olive knew she didn’t have time to spend researching technologies (or have time to learn how to use one). Her pharmacy offered her a blister pack to help with medication management. Olive thought this was a great solution but quickly realised that this would not accommodate her father’s medications, which came in the form of inhalers, patches, gels, oxygen, liquid, injections, etc.

Solution for Patients and Carers
At the time, Olive herself also suffered with multiple chronic conditions that required medications and treatments in the form of injections, pain relief patches and liquids. She also cared for her three young daughters - each of whom suffered with chronic conditions ranging from congenital heart defects, juvenile arthritis and sporadic blood pressure problems. Olive recognised that none of her children’s medications were pills either, and none of them could be blister packed. She had always kept her own hand made diary to log the children’s health history, appointments, medical tests and the times she gave them their medications. She knew the only way to keep track of everything for her father was to do the same. And so this is what she did.

Solution for Health Care Professionals
Olive adapted her father’s personal appointments diary to accommodate medical appointments, symptoms, correspondence, prescriptions and his full health history. The potential for the innovative notebook approach came to the fore several few months later when her father was taken ill and brought to hospital by ambulance. The emergency response team at the Emergency Department informed her that the notebook had been a great help in organising her father’s care. They were able to know exactly the last time he had taken his medications and what they could safely administer to him for treatment. They also had his chart number to hand so the hospital A&E teams were ready for her father when he arrived. His most recent prescription was stuck to the inside cover which meant medications could be written up for him straight away and so there was no need to ring the pharmacy. Olive began to wonder if her toolkit could help other patients, carers and health care professionals. She wondered too, if it could actually save health services resources, time and money?
The Patient becomes The Promoter

Expert by Experience
Olive’s experience in the health care field comes from personal circumstances - she herself suffers from psoriatic arthritis, asthma and cardiac arrhythmias. She is a mum to three daughters, each of whom chronic conditions have, including congenital heart defects, juvenile arthritis, sporadic blood pressures, GI problems, psoriasis, asthma and hypermobility. Olive’s husband [42] suffered a stroke [TIA] in 2013 and she also cared for her father. Olive (with her family) have used over twelve different health specialities; have attended nearly forty hospital appointments annually and managed complex medications, medication regimes and medical treatments including: administering methotrexate injections; tube feeding; handling regimes of morphine patches, endocrine gels and oxygen along with multiple cardiac, gastrointestinal and lung medications together; controlling asthma with steroids, inhalers and antihistamines; monitoring blood pressures; catchment of urine catecholamine’s – plus so much more.

The Expert “Patient”
Today, three years since developing the first version of the MediStori toolkit, Olive is referred to as an “expert patient” or “patient advocate” by those working in the health profession. She is most interested in her expertise in self-management and her “experiences” because –

- It is difficult to define an “expert patient” because, firstly a patient is defined as someone who uses health services. Additionally, whether you use a service once, or twenty times, does the amount of times determine if you are a patient expert? Or what about, a patient who may only take one medication, and another may take ten, but that one medication could be so aggressive [e.g. Methotrexate] it would be deemed as complex, and would require a level of expertise in administering it and knowing what to do if things go wrong. The same applies if a patient has four chronic conditions, and another could have just one, but again that one chronic condition [e.g. Cystic Fibrosis] could be so complex, its patient groups may too would be deemed as experts. So who could define which patient is the “expert”? Defining an expert patient is a difficult task - it could be much easier to refine this if a person has knowledge, experiences, and is experienced, in managing a health condition.

- The term “carer” is very often left out in health care policy even though the carer can often be more knowledgeable than the patient (e.g. the parent of an unwell child would know a lot more than the patient would). Using the term “expert patient” could mean that carers may not be resourced as experts to help inform health care policy or other areas in the health care arena.

- It is important that “patients” see themselves not as victims but as partners in their health care. Partnership has a number of meanings – including engagement and open communication; better management of one’s health conditions, medications, treatments and lifestyle; overcoming difficult emotions and action planning. Self-management courses intend to switch the thinking of “I can’t because I have a disease/or I am a patient” to “I can but I may have to do it differently because of my circumstances”. Removing the label at higher levels can help with this proactive approach.
Current Status of Promoter

Having first-hand experience in the issues that can arise from manoeuvring within the health system from being both a patient and carer, Olive has a passion to drive, promote and educate all stakeholders on the importance of engagement, partnership, self-management and self-care. For the last thirteen years Olive had worked in various voluntary, community and entrepreneurial settings while she also attended to the medical needs of her family. Olive trained in youth work, society and intercultural studies and chaired a 30+ committee to which raised €100,000 in funds for her local youth centre. She went on to qualify in business and legal studies and after graduating in 2012, Olive joined GMIT’s Innovation Hubs as she set out on a mission to see if the MediStori could be a feasible solution to help other people. She attended training in Lean Methodologies and felt she needed to further her education, so in 2015 she decided to undertake a fellowship with ISQua12 and started training in health literacy with NALA13. Olive has combined her love of community and healthcare, and facilitates the self-care to wellness programme, for people with chronic conditions through Mayo University Hospital and CIL - she is qualified as a Self-Management Facilitator of Chronic Disease through the HSE and Stanford University. Olive also currently supports and works collaboratively with many charities, with a particular interest in young person’s organisations and mental health. In her spare time, she runs a suicide awareness charity Easy Speak (10,000+ members) which allow people to get advice from with their own central support service. This charity does not raise funds as it is completely peer led. Olive has always been committed to local community and was an active scout leader and secretary to the local primary school for many years. Working now as a fulltime social entrepreneur, Olive has worked with an all-encompassing team to undertake extensive research with patients, carers and health professionals regarding the development of MediStori and many other projects which have impacted on policy and practice in healthcare. She has been co-author of various abstracts/posters: “Patient and Public Involvement in National Clinical Effectiveness Processes: A Systematic Review” plus numerous others of her own work as shown at both National Patient Safety Conferences in 2015 and 2016.

National and International Recognition

Support for Olive’s work and the MediStori has been granted by the HSE, the Carers Association, the Irish Patients Association, the Irish Pharmacy Union and many others. Olive’s work has also being recognised across the world by global health leaders - the Clinton Global Initiative showcased MediStori at their International Forum 2014 in New York through Aroyga – she was handpicked with just nine others out of 10,000 women to represent Ireland14, An Taoiseach, Enda Kenny endorsed the MediStori on international television, saying it “could save health services millions”15. Olive has also been recognised by Dr. Maureen Bisognano, Chairperson of IHI16; who showcased MediStori in Qatar at the International Quality Improvement Forum, describing how the power balance to the patient was changing within public health services. Olive was also invited to join the World Health Innovation Summit team as their International Patient Champion.

President and CEO of IHI, Maureen Bisognano showcases the MediStori in Qatar demonstrating the shift of “power to the patient” in the Irish health system.

Olive meets An Taoiseach, Mr Enda Kenny, and he endorses MediStori saying it can “save health services millions.”
Participant of Working Groups in Health Services

Olive took part in a number of working groups relevant to her work in healthcare:

- Paediatric Early Warning Score System (PEWS\textsuperscript{17}) Working Group (RCPI, NCEC Dr John Fitzsimons)
- National Maternity Strategy Focus Group (National Women’s Council, DoH\textsuperscript{18})
- National Clinical Programme Paediatrics & Neonatology (NCEC, Dr Alf Nicholson)
- Irish College General Practitioners (ICGP Public Representative Group, Dr. Margaret O’Riordan)
- Zero Harm Medication Initiative Launch (Tallaght Hospital, Mr Tim Delaney)
- PPI Literature Review for NCEC (Dr. Veronica Lambert, DCU\textsuperscript{19} and DoH)
- National Sexual Health Strategy 2016 Working Group (HSE & DoH)
- National Patient Forum, 2015 (HSE Quality Improvement Division)
- National Medical Card Form Review Panel, 2016 (HSE)

National Conferences and Events

Olive is a keynote speaker and has presented her work and ideas at a range of conferences and events:

- World Health Innovation Summit 2015, International Patient Champion [Cumbria UK]
- eHealth Ecosystem Keynote Speaker 2016 [Mr Richard Corbridge, CUI HSE], Ballsbridge
- National Medicines Forum 2015 [HSE, Dr Helen Flint] RCPI, Kildare Street
- National Patients Forum 2015 [HSE Quality Improvement Directorate], Aisling hotel
- St. Luke’s Symposium 2015 RCPI – Innovation in Healthcare from Patients Perspective
- Vasco de Gama (VdGM) WHO conference for Young GPs 2015, Chartered Accountants House
- ICGP Summer School 2015, Mount Wolseley, Tullow, Carlow.
- UCD, Forensic Medicine [Guest Lecturer Grade 8 Health Professionals], 2014 UCD

National Awards

Olive has won many national awards in the last three years including:

- 2015 Junior Chamber International (JCI) Outstanding Young Person in Medical Innovation
- 2015 Social Entrepreneurs Ireland Impact Awards Finalist
- 2015 Mumtrepreneur of the Year (Mums And Tots and Tesco)
- 2014 Judges Scul Choice Special Merit Enterprise Award
- 2013 Enterprise Ireland, New Frontiers Awards

Public Relations

Olive has extensive media experience discussing change in the health arena. To date Olive has been invited on to RTÉ news, Primetime, UTV news and Today FM. She has had articles published in numerous newspapers, magazines- and even has an interview published in a book written by Dragon Den’s pitch coach, Catherine Moonan\textsuperscript{20}. Olive aims to help others learn how to communicate more efficiently and so does not refer to herself as an advocate – but more an educator. Everything Olive writes comes from the patient’s perspective and is written in a manner in which she intends for anyone, from any background, to understand and learn from.

Dr. Pádraig MacNeela is a lecturer at the school of psychology, NUI Galway. He is co-leader of the community-engaged research in action research cluster at the institute for life course and society. He co-directs the PhD in child and youth research and is director of PhD studies at the school of psychology. Dr MacNeela has worked with community and voluntary sector groups on participatory research studies since 1999 and has a long standing track record in nursing and medical decision-making research. He has expertise in survey design and qualitative research methods with patients and practitioners.

Peer Reviewed Journals by Dr Pádraig MacNeela:

- **2005**
  - "From structures to attitudes: A process model of empowerment, job satisfaction and affective commitment"

- **2005**
  - "Managing and being managed: The experience of paid staff and volunteers in health and social care voluntary groups"

- **2005**
  - "Talking psychologically: Mental health nurses use of psychology in describing problems, interventions and outcomes"

- **2005**
  - "Modes of rationality in nursing documentation: Biology, biography and marginal 'voice of nursing'"

- **2006**
  - "Nursing Minimum Data Sets: A conceptual analysis and review"

- **2006**
  - "Developing a data dictionary for the Irish Nursing Minimum Data Set"

- **2007**
  - "Lost in translation or the true text: Mental health representations of psychology"

- **2007**
  - "Reconsidering the conceptualization of nursing workload: literature review"

- **2008**
  - "The give and take of volunteering: Motives, benefits and personal connections among Irish volunteers"

- **2008**
  - "Ambiguities and conflicting results: The limitations of the kappa statistic in establishing the interrater reliability of the Irish Nursing Minimum Data Set for mental health: A discussion paper"

- **2009**
  - "Judgement and decision-making"

- **2010**
  - "Psychosocial care in mental health nursing: a think aloud study"

- **2010**
  - "In the know: cognitive and social factors in mental health nursing assessment"
Research Themes

For the first 18 months of the MediStori project, as funded by Enterprise Ireland, Olive conducted primary and secondary research to inform the project. One common thread running through this research was that, while communication and education (or lack thereof) seemed to be a key cause of failures in healthcare settings, the realities of self-managing one’s health conditions seemed to be overlooked. Not much thought had been given to devising practical toolkits or resources to help patients achieve this goal, although a lot was given to just having information to hand. A number of themes arose in the literature reviewed on doctor-patient collaboration, implementation of PHRs and changing the culture of health care. These included:

Carers are Resources
“Increasingly, it is recognised that helping carers is one of the most effective ways of helping those in receipt of care. It is also acknowledged that the transition to life after caring, once the need for care has ended, can be difficult for some carers…caring can affect all aspects of a carer’s life”. (Department of Health, Ireland, 2012)

Medication Non Adherence
“Among patients with chronic illnesses, approximately 50% do not take medications as prescribed...today’s ever more complicated medical regimens make it even less likely that physicians will be able to compel compliance...” (Marie T. Brown et al, 2011)
“More recently [it was] estimated that $290 billion in avoidable medical spending across all chronic diseases could be attributed to drug-related problems, of which non-adherence to medications was a subset”. (Iuga & McGuire, 2014)

Prevalence of [Multiple] Chronic Conditions
“Comorbidity is associated with worse health outcomes, more complex clinical management, and increased health care costs.” (Jose M. Valderas et al, 2009) “The speed at which obesity, diabetes and vascular disease have become common causes of death in societies which, only a generation ago, were struggling with significant levels of under-nutrition, illustrates the speed at which social and cultural change has impacted health. ... All countries will need to manage this very substantial healthcare burden better as the potential impact of these diseases on economic growth in these countries is very significant. (Nolte et al, 2008) “This new study extends that systematic approach to hypertension, coronary heart disease (angina and heart attack) and stroke as well as updating earlier diabetes figures. It documents the chronic disease epidemic we are facing over the next 15 years and the challenges posed to our population, our health and social care systems, and our economies. It describes the unequal way in which the burden of chronic disease is distributed in Northern Ireland and the Republic of Ireland and highlights the pressing need for a greater emphasis on prevention, tackling health inequalities and addressing the social determinants of health. This requires action across government and by many sectors. Considerably greater benefits can be achieved by influencing policies of the non-health sector than by health policies alone.” (Balanda, 2010)
Unnecessary Readmissions
"Men are more likely than women to be readmitted to the hospital within a month after being discharged...at an estimated yearly cost of $17.4 billion... One approach included providing clear instructions to patients about what they need to do once they leave the hospital and following up with patients after discharge." (Shaula Woz et al, 2012)

Self-Management for All
"Research has also demonstrated that self-management of chronic conditions can improve clinical health outcomes as well as reduce unnecessary health service use. The benefits of self-management and examples of each benefit are summarised as: 1) Client benefits: quality of life, ability to attend school/go to work, and self-confidence 3) Health benefits: related to depression, blood pressure, haemoglobin levels, pain, and use of medication 2) Health service benefits: planned and emergency visits to emergency departments or general practitioners, and cost of health care. (Dept of Health Western Australia, 2007)

Specific Disease Focus and Individualised Care
"The goals of chronic care are not to cure but to enhance functional status, minimize distressing symptoms, prolong life through secondary prevention and enhance quality of life... it is clear that these goals are unlikely to be accomplished by means of the traditional approach that focuses on individual diseases...the ability of patients to develop individualized treatment plans is, therefore, of critical importance for effective care. (Nolte et al, 2008)

Patient Engagement
"A patient's greater engagement in healthcare contributes to improved health outcomes, and information technologies can support engagement. Patients want to be engaged in their healthcare decision-making process, and those who are engaged as decision-makers in their care tend to be healthier and have better outcomes." (HIMMS, 2007)

Cultures of Blame, Not Learning
"The patients blame doctors and nurses. Doctors and nurses blame patients. And everybody blames the hospitals. The problem, everyone seems to agree, is that hospital discharges are a mess." (Gleckman, 2013)

Communication Breakdown
"57% of GPs had seen patient safety put at risk because of poor quality discharge information and 7 out of 10 doctors reported that clinical care had been compromised because discharge information was late, incomplete or both...the most common risk to safety was incomplete or inaccurate information about medicines patients had been prescribed." (Nuance, 2013)
"Patients don’t understand what they need to do after they go home: They don’t see their GP, they don’t take their medications properly, and they land back in the hospital. That revolving door jeopardizes their health and costs billions...It is more important than ever that doctors and nurses learn to talk to patients and that hospitals vastly improve discharge programs that, too often, are the broken link in the health care chain." (Gleckman, 2013)
Unhealthy Competitive Cultures
“Leaders must understand when and how to morph from competitors to collaborators. Bringing to market better, faster, thinner, greener products involves competition. But the second we begin competing with team members and business partners, we lose value.” (Rosan, 2009)

Poverty and Health Status
“The link between poverty and ill health has been well established by international and national research such as that outlined above. The poor get sick more often and die younger than those in the higher socio-economic groups. Poverty directly affects the incidence of ill health; it limits access to affordable healthcare and reduces the opportunity for those living in poverty to adopt healthy lifestyles. Healthcare exclusion is a major dimension of poverty and social exclusion.” (Cori, 2008)

Innovation, Collaboration and Values
“We need a public service that does ‘better for less’, providing real value for money for the Irish taxpayer by maximising efficiency and eliminating waste, and that is innovative in its approach to providing services...putting in place the building placing customer service at the core of everything we do; maximising new and innovative service-delivery channels; radically reducing our costs to drive better value for money; leading, organising and working in new ways; and a strong focus on implementation and delivery. (Howlin, 2012)

Integrated Care Approaches
“Social inclusion plays a key role in supporting equity of access to services and provides targeted interventions to improve the health outcomes of minority groups...Members of these groups characteristically present with a complex range of health and support needs which require multi-agency and multi-faceted interventions. The Health Service promotes and leads on integrated approaches on different levels across statutory and voluntary sectors. A critical success factor is the continued development of integrated care planning and case management approaches between all relevant agencies and service providers.” (Hennessy, John (HSE), n.d.)

Shared Decision Making
“Angela Coulter and Alf Collins in their recent Kings Fund report, ‘Making Shared-Decision Making a Reality’ define shared decision making as; ‘a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient’s informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and a system for recording and implementing patients’ informed preferences.” (PiF, 2012)

Patient Centred Philosophy
“Hospitals that provide patient-centred care reap a number of financial benefits, including: Reduced length of stay, lower cost per case, decreased adverse events, higher employee retention rates, reduced operating costs, decreased malpractice claims, increased market share.” (Charmel PA1., 2008)
Research about PHRs and EHRs

As the research continued it was becoming increasingly important that the MediStori was being developed in line with current and future trends of the sharing of health information.

HIMSS Definition

Health records maintained by and accessible to individual consumers are referred to as personal health records (PHRs). The Healthcare Information Management and Systems Society (HIMSS., 2007) defined a PHR (or ePHR) as follows:

“A universally accessible, layperson comprehensible, lifelong tool for managing relevant health information, promoting health maintenance and assisting with chronic disease management via an interactive, common data set of electronic health information and e-health tools. The ePHR is owned, managed, and shared by the individual or his or her legal proxy(s) and must be secure to protect the privacy and confidentiality of the health information it contains.”

Main Elements of PHRs

The main elements comprising a PHR are reflected in the MediStori. Archer et al. (2011) lists the main elements of a PHR as including:

- Personal information; family history; social history, lifestyle
- Problem lists; major illnesses; examinations, diagnoses
- Procedures, hospitalisations
- Medications; lab tests, appointments
- Provider list
- Home monitor data
- Preventative health recommendations
- Immunisations; allergies; notes

Archer et al. (2011) carried out a systematic review of 92 PHR studies, focusing on design, functionality, implementation, applications, outcome, and perceived benefits. These focal areas are instructive in considering how the MediStori can be evaluated. Much of the literature is framed in terms of ePHRs, which are described as having the potential to make health information more accessible to patients and to function as a decision support system for patients who have to manage chronic conditions (Price et al., 2013). Similarly, these are key aims for the MediStori. It was important that digitalisation did not impact negatively on patient safety for those in need.

“The growth of the consumer society, coupled with explosion in information available on the Internet, is creating more empowered patients, a phenomenon acting to increase responsiveness with which health services are delivered. However, this may also compromise equitable access to care, as digital divides enable those who are most privileged to take greatest advantage, while those in most need are left behind.” (Nolte et al, 2008)
Electronic and Paper Based PHRs

“Personal health record (PHR) systems are more than just static repositories for patient data; they combine data, knowledge, and software tools, which help patients to become active participants in their own care. When PHRs are integrated with electronic health record (EHR) systems, they provide greater benefits than would stand-alone systems for consumers.” (Paul C. Tang et al., 2006)

Electronic and paper-based PHRs have been in use for a number of years in health systems internationally and tend to be appraised positively by patients. However, significant challenges arise in the implementation of PHRs, such as low acceptability of computer-based systems among health care users and lack of agreement at national level over the standard PHR format to use. Support and encouragement is required by health care providers to embed long-term patient adoption of the PHR. Despite the challenges associated with implementation, the PHR is highly attractive to many patient advocates, health care managers and practitioners. The goals with which it is aligned are powerful and important. It promotes the patient’s ability to retain critical information about their health care. This serves as a prompt to support medication and treatment adherence. Additionally, the PHR empowers the patient to communicate information about medication regime, treatment history, and needs, not alone to one provider but across the different health care settings encountered at acute, outpatient and primary care levels. PHRs have been shown to help increase engagement, decrease miscommunication, decrease late diagnosis or misdiagnosis, decrease readmissions and retesting, and help to address medication non-adherence. They have been shown to increase the quality of care and patient safety.

Research on the Effectiveness of PHRs Continues at a High Rate

A Personal Health Record (PHR) is a means to help end-users manage their health records, often in the context of having a chronic illness or being a carer. The major advantage of a PHR is that it collates all of the relevant medical and related information concerning a patient in one place. The MediStori is an example of a paper-based PHR. The electronic PHR (ePHR) has been subject of extensive research and standard-setting. While it is distinctive on the basis of its electronic format, there are a number of comparisons to be made with a paper-based PHR such as the MediStori.

Patients Perspective of PHRs

Nokes et al. (2013) makes the point that a personal health record (PHR) contains information that a client believes is important to his/her health status; it can be either paper or internet-based. A paper-based system has some advantages over an electronic record. For instance, Lafky & Horan found that people with disabilities identified support in an emergency as an important motivation for using a PHR (cited in Archer et al., 2011), a function that typically involves a paper record. A systematic review found that cancer patients welcomed paper PHRs (Gysels, Richardson & Higginson, 2006). Field studies report that the greatest interest in PHRs is manifested by chronically ill, frequent users of healthcare & by caregivers for elderly parents (Cocosila & Archer, 2014; Denton, 2001). Moreover, a traditional paper record may be more usable for some older health care users (Price et al., 2013), particularly given the costs of educational & technical support for users & providers in regard to access issues (Archer et al., 2011).
Paper based PHR in 2016

Self-efficacy in the use of paper-based PHRs can be higher than for computer-based PHRs, implying a higher degree of personal confidence in the ability to utilize a paper system (Nokes et al., 2013b). A further advantage of a paper-based PHR is the facility of integrating records of encounters with different healthcare providers (Tobacman, Kissinger, and Wells, 2004). Much of Irish healthcare organisation and communication with patients and providers is still predicated on paper-based systems (appointment cards, letters, notices, reminders, prescriptions, etc.).

PHR Conceptual Models

It was important in planning an evaluation study to situate the study within a conceptual model or framework. This study draws on some well-cited examples (MacNeela, 2015):

   - System Attributes: Capacity to record content using easy to understand language, inclusive of important attributes, understandable and credible architecture, privacy and security, perceived functionality (reflected in information collection, sharing and exchange, self-management, cost and financing).
   - Purpose: Patient-provider communication, prompt for education and lifestyle changes, utility in health self-management (e.g., medication adherence).
   - Adoption and Acceptance: Success in adoption and regular use, acceptance and satisfaction, usability.
   - Barriers to PHR Adoption and Use.
   - Clinical Outcomes and Process Changes.

   This is a model of information systems success, which incorporates inter-related measures of success, including system quality, use, user satisfaction, individual impacts, and organisational impacts.

3) (Cocosila, M., & Archer, N., 2014)
   This model prioritises perceived usefulness, which the authors describe as a widely known and strong extrinsic motivator of technology use (“the degree to which a person believes that using a particular system would enhance his or her job performance”, (Davis, 1989)

   This model is attractive in that it incorporates an ecological perspective. Alongside personal factors (such as attitudes, knowledge, etc.), environmental factors and technology factors are accounted for in gauging the impact of a PHR on self-management. The PHRAM contains five interacting factors: (1) personal factors, (2) environmental factors, (3) behaviour, (4) technology factors, and (5) chronic disease factors (each of which has sub-factors). Logue and Effken distinguish their perspective in stating that the success of access to integrated health records is based on integration with the patient’s existing health and social infrastructure. This model is particularly relevant when considering ecological and system-level barriers and facilitators.
These research and policy trends, combined with feedback from individual meetings and focus groups with stakeholders, highlighted the need for a universal, self-management health record toolkit that would address the baseline needs of all patients and carers. It should be able to be easily integrated into any other PHR, be it paper based or electronic (or vice versa). It should be available from birth to end of life, and be family centred if possible. It should not be disease, condition or symptom specific and should be able to store relevant health information; practically help users better self-manage medications, therapies or conditions; help increase communication, education and engagement; be available to all patients, irrelevant of their socioeconomic situation and should be promoted, when possible, to patients and carers at the first point of care.

The MediStori was developed to help address these, and many other needs. Feedback about the concept of the MediStori as a PHR in its own right was consistently positive.

Irish Patients Association: “CEO of the Irish Patients Association, Stephen McMahon highlights that the "MediStori is a “patient safety initiative...”

The Carers Association: “We feel that the MediStori is an invaluable tool to help carers keep their loved ones medical information together in one unit & to have their most accurate & up to date information, easily accessed at any one time, by any of the health care providers associated with that person. It offers carers a simple yet effective solution to help manage all aspects of one’s health, which in turn can increase patient safety & give the carer peace of mind.”

Irish Pharmacy Union: “Executive committee member Bernard Duggan, said, “Community Pharmacists support their patients on a daily basis in managing their complicated medication regimens. They ensure that they take their medications as prescribed & provide patients with advice & information on these medications.” The MediStori is an innovative tool, which assists patients to manage their medication safely in conjunction with their Community Pharmacist.”

ICAN: “We are delighted to be associated with MediStori as this tool will support our parents in keeping track of their various hospital appointments and also keep a record of medications their children on. It is a necessity in the lives of a family dealing with a long term chronic autoimmune disease.”
“Keeping a personal health record [PHR] has been demonstrated time and time again how it can improve service quality through the provision of accurate, timely information and user empowerment. However, if there is a lack of a national mandated, coordinated approach and resource constraints then this impedes personal records from being implemented in our health system.”

(Department of Health, HSE, 2010)

The preferred implementation model that was developed for the MediStori is based on delivery to all patients and carers who use public and private health services, rather than just a commercial model for those who could afford to pay for it (e.g., through pharmacies or online). Even though the public system model is the preferred model, it is important to note that many patients and carers do not use public services and so the resource was to be made available through as many avenues as possible upon validation of same. The MediStori aims to tackle the issues of medication adherence, communication of health information, appointment management and so forth. The design of the MediStori was grounded in quality improvement, lean and used co-design methodologies, employing feedback and advice from patients, carers, organisations and health care professionals. The initial stage of the development process concluded in early 2014 producing a minimum viable product of the MediStori toolkit.

Affiliation with the HSE

In 2014 Olive engaged with Mr. Tony O’Brien [Director General of the HSE], Mr. Brian Murphy [National Primary Care Manager HSE], and Dr. Philip Crowley [National Director Quality Improvement Division HSE]. This led to the HSE agreeing to trial the MediStori in hospitals in two national hospitals and various charities. Based on a positive evaluation, the further roll out of the MediStori in public services was to be viable from November 2015. Meetings also initially took place with Mr. John Kenny [Quality Improvement Manager, HSE], Ms. June Boulger [National Lead for Public and Patient Involvement Acute Hospitals HSE] and Mr. Greg Price [Director of Advocacy, Quality Improvement Directorate HSE] to identify key stakeholders in acute hospitals and voluntary sector organisations. The pilot study of the MediStori in hospitals and voluntary sector organisations began in April 2015, supported by research ethics approval, information leaflets, contingency plans, the training of health care professionals and other preparatory work. The study aimed to evaluate the feedback from patients, carers and health care professionals regarding 1) the MediStori itself 2) their health services and 3) their health care needs. Links were made with two hospitals, eight voluntary sector organisations, and a researcher.

- Mr Charlie Meehan ([General Manager, Mayo University Hospital] and Ms. Blánaid O’Connell [Chief Pharmacist, Mayo General Hospital]. Ms O’Connell agreed to help coordinate the study.
- Ms. Grainne Dowdall [Child Health Information Coordinator, Temple Street Children’s University Hospital], who agreed to be a coordinator of the trial in her hospital.
- Eight charities (with active patient and carer members) agreed to be part of the trial: Irish Dysautonomia Awareness, Dyspraxia Ireland, EDS Awareness Ireland, Irish EDS and HMS, Irish Children’s Arthritis Network [ICAN], Marfan Syndrome Support Group, Jack and Jill Children’s Foundation, Arthritis Ireland.
- Dr Pádraig MacNeela, Lecturer at the School of Psychology at NUI Galway, collaborated in survey development, research ethics approval, and the MediStori survey evaluation.
The MediStori Toolkit Description

Objectives
The objective of the MediStori is to keep an entire family's past and present medical information, from birth right through to end of life, in one unit with the capacity to accommodate new information as it is received. This creates a medical data portal containing all of a patient's most accurate and up to date information, which can be accessed at any one time, by any of the carers or health care providers associated with that patient. The example of attending an after-hours GP can be given: many patients are misdiagnosed, diagnosed too late or not diagnosed at all because fundamental information was not accessible at the time of the consultation.

Aims
The MediStori aims to provide the patient directly with the tools to provide these key points of data to ensure not only a speedy diagnosis but an accurate one too. Patient empowerment is the key to changing our system as we know it, and it also helps relieve the strain on staff and carers within public and private health sectors. Therefore usability of the MediStori is critical. As the MediStori is a paper based personal self-management toolkit and health record organiser it helps patients and carers keep all of their own and their loved ones' health records in one unit. With the Medicine Memo, the patient does not have to re-write the medications over and over again, as the completed "log time taken" section can be changed and stored away for future reference. Paramedics can see the exact times and types of that patient's last medications and to identify current medical status by reviewing medications. Taking the form of a versatile, personal medical "filo-fax" style organiser enables not only single person use but builds into a complete medical record of each child, adult and grandparent in a family.

Features
From a design aspect, the MediStori is a two-fold folder which can be can also be stood up like a flip chart to ensure regularity in use, therefore making the A5 refill pads (called Memos) habit forming. These Memos are designed to suit a range of daily medical issues (e.g., medicine intake, asthma, diabetes, arthritis etc.) and will help people suffering from these ailments at present. They aim to reduce the proven risks, anxieties and confusions for a patient/carer that can be associated with mismanagement of medications, appointments, diets or symptoms. The MediStori and Memos helps doctors and nurses in hospitals/primary care centres better communicate with patients and carers about medications. The same benefit can be achieved by community pharmacists to supplement/compliment the use of “blistering”. Blistering has been a proven method to combat medication non-adherence, but is not relevant to medications in liquid, inhaler, injection or patch format.
Design, Development and Delivery

The MediStori’s design is simple – it helps store hospital letters, medical cards and prescriptions and also helps record and manage medications, health records, symptoms for diagnosis or even questions and answers for doctors.

It is useful because it –

- Provides real time up to date information for emergencies
- Can help accurate and speedy diagnosis and treatments
- Can reduce readmissions, retesting and miscommunication
- Can be used from birth or started at any age – for life
- Non-disease, age or gender specific
- Helps increase social prescribing, medication adherence
- Increases patient safety and quality in healthcare

With respect to specific intended purposes, MediStori can:

- Be used to manage all health care information
- Aims to focus on the individual needs of a person
- Different members of the family can use same folder
- Developed by all stakeholders together
- Builds up to be personal unique patient passport
- Improves communication with healthcare teams
- The folder can free stand for visibility
- The diary can be hung up, making it habit forming
- Charity / information leaflets can be stored in it
- Helps with medication management

The MediStori aims to enable better communication regarding medication adherence. Communication about the medication regime is important to address problems in non-adherence, including:

- Forgetting to take/give them in first instance
- Forgetting when or if they took/gave them
- Patient feels better and doesn’t feel need for them
- Patient doesn’t know why they are taking medications
- Patient doesn’t know how to take medications properly
- Patient doesn’t like side-effects of medication
- Patient consumes too much medication (pain relief)

Using the refill Memos means a person can know about side effects, why they are taking their medications and monitor all medications – not just their pills.

Delivery

The MediStori is intended to be given to patients and carers at the point of care through public acute, primary and private care settings by health care professionals. It will be recommended that users bring back the MediStori to clinics and or appointments to help encourage its use and increase better communication of medications, symptoms and appointments. It will also be available through commercial avenues as many people do not use health services but want to manage their health.
Components of the MediStori

1 x Medicine Memo^{24} + Pen
- A daily management diary for all medications, for patients and carers
- Easier to remember when and if patients and carers have taken/given medications
- No need to rewrite medications over and over again due its simple design
- Log doses, times, requirements and information about medications
- Easier for family, carers and health care professionals to see what medications were taken/given

1 x Emergency Household Booklet
- Allows the patient/carer write down directions to their house from where the nearest ambulance would arrive. This information is extremely important to have if a nurse/childminder/carer/family member is in an emergency situation and they need to guide a paramedic to the scene quickly (also good to have if a child had to ring and the adult was in trouble)
- This booklet also allows a patient/carer write down any possible medical risks for people in the house in which a carer/sitter may need guidance with quickly. Information about the symptoms and/or where to find the location of emergency medications (e.g. inhalers/ adrenalin etc.) is put here with details of next of kin.
- There are pages in this booklet to help remember such things as neighbour’s phone numbers; health professional contact details; hospital bag check lists and so on.

1 x Medical Diary
This pre-lined diary is to help patients and carers write down any concerns or issues they want to remember to tell their GP/ health professional. It has space for questions and answers and is essential in times where they may be finding it difficult to cope with a diagnosis or even get a diagnosis. This diary can help increase engagement, communication and increase informed decision making processes.

1 x Appointment Calendar
This small but simple calendar allows patients and carers to track medical appointments along with everyday life such as birthdays, extra-curricular and so on – it can be helpful to see at a glance, when they were last appointment and when rebooking new appointments.

2+ Personal Health Record Booklets
- Important Contact Details (Next of kin; health professionals etc.)
- Full Medical History (long-term illnesses; past accidents etc.)
- Personal Care Guidelines (Such as fears, risks, likes, dislikes, comforts etc.)
- Allergies/Reactions (Medications, foods; cosmetics etc.)
- Vaccinations and Infectious Diseases (Chicken Pox, TB, Measles etc.)
- Medical Investigations (MRI’s, X-rays, Bloods etc.)
- On-going Illnesses (For antibiotics, diagnosis etc.)
- Outpatient Appointments (Questions and answers for doctor; care plans)
- Your Family Medical Tree (For parents, siblings, family medical history)
- Birth Records and Developmental Records (First time development stages)
- Optical, Hearing and Dental Records (Eye tests, hearing tests, dentist etc.)
- Social and Living Records (Track of education, employment, therapies)
Rationale for a Pilot Study

By 2015 the MediStori was already being used and tested by patients and families in different parts of Ireland. The pilot study was the first occasion to utilise it within specific hospital services and charities. The overall study explored usability and ease of use of the MediStori through feedback and further suggestions from patients and carers on how well suited it is to their specific needs.

The primary objectives of this pilot study were to:

- Obtain user feedback so that the MediStori could be amended to best meet end-user needs.
- To analyse pilot study responses from the MediStori users with respect to factors such as patient satisfaction, motivations for use, and perceptions of usability.
- To identify how MediStori could be best integrated with systems and processes of health care.
- To establish whether patients/carers find the MediStori to be a useful tool in helping to manage their own or their loved ones health and treatment needs, including medication compliance.

Methodology

Initially a target of 200 patients and/or carers was deemed a satisfactory number to be recruited. By October 2015 this target was exceeded, with a total of 251 people participating.

- Recruited through Charities/Online: 61 participants responded through their charities on online surveys – these were adult patients and carers. 3 of these participants responded through online surveys but did not specify a charity they used.
- Recruited through Hospitals: 190 participants responded through paper based questionnaires given to them in outpatient clinics. All participants in hospitals were parents/guardians.

Duration

This 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 is 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 can be given during this time. There were two questionnaires to be filled out by all participants; namely Time 1 and Time 2 Surveys. Time 1 survey was to be filled in by the participants just as they received their MediStori and Time 2 surveys were to be filled in by participants six weeks after receiving the MediStori. This period was chosen on the basis of initial discussions with clinicians in acute hospitals as repeat visits (which are an opportunity to provide follow-up data on MediStori use) can occur within a six week period. Within the total time frame [April – November 2015] the Time 1 Surveys received 251 responses and Time 2 Surveys received 61 responses (24% Response Rate). It is important to note that follow-up with the Time 2 participants is still on-going as many are still returning their questionnaires [a further 19 have since been received bringing the response rate to 28%]. Reasons for non-completion of Time 2 surveys within the six-week timeframe in acute hospitals were identified by the Temple Street Children’s Hospital study coordinator a) a number received the MediStori prior to a surgical procedure b) further received the MediStori shortly after receiving a diagnosis of an illness and c) the second data collection period overlapped in many cases with returning from summer holidays and with return to school.
Procedures

Ethics Approval
Research ethics approval was obtained from Mayo University Hospital and Temple Street Children’s University Hospital before commencement of the study. The procedure for the Pilot Study comprised: (a) participant recruitment and orientation to the MediStori, including pre-Pilot Study questionnaire completion (Time 1), and (b) after a period of use of six weeks, the participants were prompted to return the post-Pilot Study (Time 2) questionnaire. For those recruited online, approval was sought from the charity organisers prior to commencement. The MediStori team provided information, videos and instructions to which the charities could forward to service users to request engagement.

Survey Tool
The survey tool was designed on the basis of the conceptual framework outlined in the introduction to this report – it included sections on demographics, the nature and characteristics of the patients/carers/parents with respect to caring responsibilities, familiarity and prior use of systemic means to record patient information, perceptions and first impressions of the MediStori, evaluations of its characteristics, and for further context, two validated measures of patient/parental satisfaction and difficulties with health care were included. The findings section to this report provides a descriptive analysis of the responses given (MacNeela 2015).

Pilot Study Representatives and Coordinators
The coordinator of the pilot study at Temple Street Children’s Hospital was Ms Gráinne Dowdall. Ms Dowdall coordinated the MediStori pilot study across different clinics at the hospital, and the MediStori introduction was carried out by a number of staff at the hospital. Time 1 survey completion took place in Temple Street from April 2015 and continued for approximately 2 months. Recruitment in Mayo University began in May 2015 and continued for six weeks. After six weeks the participants were contacted in turn to request completion of the Time 2 survey (MacNeela, 2015). The Pilot Study Representative at Mayo University Hospital was Olive, who introduced the MediStori to all of the study participants, while Ms Blánaid O’Connell coordinated the nurses and teams in the hospital to assist in the study. The reason an “expert patient” was used to recruit participants in this study was to be able to see if non-healthcare professionals could be trained and upskilled to this work (e.g. patient volunteers).

Inclusion Criteria
- The inclusion criteria were for participants to possess literacy and fluency in the English language as these were considered to be important characteristics for use
- The study was for any patient, carer or parent - irrelevant of disease group, locality or gender
- All participants had to be over the age of 16

Requirements
Requirements for taking part were that the parent/guardian/patient:
- Completed the initial questionnaire and used the MediStori as best they could for six weeks
- Brought the MediStori with them to as many health appointments as possible
- Filled in the second questionnaire (which was posted or emailed out six weeks later)
Referral & Protocol

Introduction
The following procedure was used to inform patients/carers about the study in acute hospital settings:

- The parent would present to outpatient department clinic with child for scheduled appointment.
- In the outpatient department leaflets and posters were available informing patients/parents of study.
- The Pilot Study Representative introduced themselves; the MediStori; the study and nature of the study upon arrival.
- When the child was triaged for blood pressure, weight, height etc., the nurse ensured that the parent/carer had adequate levels of literacy and English language use before briefly showing them the MediStori and informing them again of the study.
- After reading the information, and if the parent wished to learn more about study participation, s/he could go direct to the pilot study representative who was in the clinic area.

Instruction

- The pilot study representative would demonstrate the MediStori and show how to use it.
- If the parent/carer wished to proceed, they would be given an information leaflet and a consent form to be filled.
- The Pilot Study Representative would again ensure that the parent met the inclusion criteria prior to informed consent being filled in.
- Informed consent was then taken.
- The Pilot Study Representative explained how each questionnaire was coded and that no personal identifiable information would be put next to their answers.
- The parent first filled in Section 1 of the Questionnaire (Contact Details). They handed this back to the Pilot Study Representative, who wrote down the reference code at the bottom of the sheet and filled this code only into each page of Section 2 of the Questionnaire.
- A sticker was put on the inside of the parent’s MediStori pack with this code in case they needed to ring the helpline and use it as a reference.
- The Pilot Study Representative then (in front of the parent/carer) put Section 1 of their questionnaire into a sealed envelope and put it into a safe box. This ensured that no identifiable information was stored with the personal data.
- The parent filled in the remaining questions in Section 2 of the questionnaire.
- When the questionnaire was filled in fully, the parent received their MediStori. They also received relevant contact information for support services.

Content of Questionnaires

- The questions in the survey were compiled from analysing issues that arose from previous focus groups led by the study team and with support from NUIG and healthcare professionals.
- Each participant was given a code at the beginning of the study of which they used to ensure no personal data would be shared and also to ensure no duplication of answers to questions.
- Questions asked were to collect both qualitative/quantitative values.
- Not all questions had to be answered by all respondents as topics may not have been relative.
- Each questionnaire took on average of 35 minutes to complete in full.
Collection and Analysis of Questionnaires

- All collected paper based questionnaires were left on each hospital site, in locked cabinets in staff offices. These were all collectively sent via courier to NUIG.
- Any online surveys were distributed by the Pilot Study Representatives and received by NUIG.
- All surveys were analysed by Dr Pádraig MacNeela in NUIG.
- Online surveys completed by participants through charities were submitted to the MediStori team through the website - this data was coded prior to being received and so was anonymised.
- Surveys were collated, sent to NUIG and analysed by Dr Pádraig MacNeela.

Services and Supports

A telephone helpline was available to all participants to contact, for support and advice from a trained coordinator regarding the MediStori pack. During the six-week period of participation in the pilot study the participants could contact the MediStori helpline at any point. There was also a specific email address.

Contingency

In the event that a patient, carer, parent or child experienced emotional or physical distress a contingency plan was in place, to avail of support staff from the hospital itself. Participation in the pilot study was to cease at that point. No instances of this needing to happen were recorded.

Completion

At the end of the six-week period, the participants were prompted to complete the end of Pilot Study (Time 2) questionnaire pack. The participants that were recruited through hospitals received a pre-paid envelope in the post to return their questionnaire or had the option of completing an on-line version of the questionnaire. A reminder was sent to all participants via email / phone to complete the questionnaire if they had not done so, by the Pilot Study Representative. Participants recruited online were sent an email with a link to the survey. The Time 2 Questionnaire required approximately 35 minutes for completion. All participants could be sent a summary report on the findings if they wish. 27

Report

This document includes material from Dr Pádraig MacNeela’s report as submitted to relevant parties of the HSE in November 2015 [Evaluation Report of Pilot Study of MediStori in Two Paediatric Centres – Part One] and this will be referenced accordingly throughout. Dr Pádraig MacNeela is a lecturer at the school of psychology, NUI Galway. He is co-leader of the community-engaged research in action research cluster at the institute for Life Course and Society. He co-directs the PhD in Child and Youth Research and is Director of PhD studies at the School of Psychology. Dr MacNeela has worked with community and voluntary sector groups on participatory research studies since 1999 and has a long standing track record in nursing and medical decision-making research. He has expertise in survey design and qualitative research methods with patients and practitioners.
Demographics

Participants recruited online were not from any specific age, disease or geographic group – additionally they could be carers or patients. The study took place over a number of healthcare sites.

Charities and Organisations

Participants were asked which charity they signed up to do the trial with online; these were as follows - Arthritis Ireland, Irish Dysautonomia Awareness, Dyspraxia Ireland, EDS Awareness Ireland, Irish EDS and HMS, Irish Children’s Arthritis Network [ICAN], Marfan Syndrome Support Group, Jack and Jill Children’s Foundation, Brittle Bone Association and MS Society [the latter were mentioned by participants but were not recruited by the study team]. Three participants were not associated with any charity. Nearly all (95%) of these respondents said they also visited hospitals and other primary care services as named above to help them with their condition.

Participants included parents, guardians, carers and adult patients. While some of these groups are disease specific, others aren’t – e.g. Jack and Jill Children’s Foundation provides nurses in the homes of families where children have life limiting conditions. Additionally, in many of the charities some diseases would have higher incidences of comorbidity meaning that other conditions/symptoms could be present.

Acute Hospitals (Outpatient Departments)

Those recruited through acute hospitals were asked which hospital they were linked to (Mayo University Hospital or Temple Street Children’s University Hospital). Paediatric outpatient clinics were chosen because it was identified that there were not many studies on medication adherence with parents and their children. The Paediatric clinic was the most frequently cited clinic type mentioned in survey responses (36%), followed by Craniofacial (26%), Cleft Palette (9.4%), Diabetes (6.9%), Asthma (6.9%) and Spina Bifida (5.7%). Several other specific clinics were mentioned, each by a small number of respondents (e.g., Early Intervention, ADHD, Heart, Inpatient Neonatal, Neurology and Skin). The type of clinic cited was related to the hospital attended. Over half of the children attending Temple Street were with the Craniofacial clinic (58%). Cleft Palette (21%) and Spina Bifida (13%) made up a further third of the children attending this hospital. Nearly two-thirds of the children attending Mayo General were with Paediatric (65%), followed by Diabetes (13%) and Asthma (13%) clinics.

Family and Home Life

A total of 78% of those recruited online said they had children both over and under the age of 18. The children were attending a range of clinic types. Approximately one-third of the families taking part in the study through hospitals had one child, two children, or three (or more) children aged 18 years or younger. Five per cent of the families had children aged 18 or more. Half of the children were attending the hospital for a check-up for a diagnosed condition at the time of the survey. One-fifth of participants were attending to seek a diagnosis. Nearly one-quarter indicated ‘other’ (e.g., ‘pre op plan’, ‘to organise surgery’, ‘to meet new consultant’). (MacNeela, 2015) Nearly all (91%) of the participants who were recruited online said they had a diagnosis of a condition or an illness, although 23% said they were currently experiencing symptoms and were yet to be diagnosed with a new condition.
Chronic, Acute and Undiagnosed Conditions of Participants

Over 60% of those surveyed online said they had a pre-existing diagnosis and were awaiting another diagnosis for other symptoms.

“I have a diagnosis, but I am awaiting an extra diagnosis.”

“I have a pre-existing diagnosis and have received a further diagnosis since getting MediStori.”

“My wife is currently experiencing symptoms of a diagnosed chronic illness.”

Fifty-nine per cent of the participants recruited through hospitals said their children already had a diagnosis of a condition or illness, compared with 41% of children who did not have a diagnosis. Two-thirds of the children who had yet to be diagnosed were experiencing illness symptoms at the time of the survey. Fifty three percent of participants said they didn’t have anyone else in their home with long-term conditions, leaving 47% saying that they did have other family members in their household with long term conditions. Nine per cent of parents indicated that they had caring responsibilities for another child with a long-term illness, and 8.5% had caring responsibilities for another family member in the household (such as parent or spouse).

Initial Speculations of the MediStori

The MediStori was perceived initially very positively by all of those who took part in the study. Nearly all of the participants through acute hospitals rated the MediStori positively on these dimensions: 97% liked the size of the MediStori; 96% liked the colour of the MediStori; 96% thought that the MediStori was a good idea; 96% liked the way the MediStori was demonstrated to them; 96% thought it might help them with their specific needs; 100% thought it was a good idea to have it promoted in the hospital setting; 78% said upon initially receiving the MediStori that they would like to see an electronic version also.

All of the participants who were recruited online said they thought MediStori was a good idea.

“My first thoughts were wow they really thought of everything. The attention to detail and time that went into this to date must be huge.”

“Lovely size very organised”

“It’s a great idea but some areas are not big enough.”

“I thought this is just what I need. I have never missed an appointment but I have arrived a day early. I wish MediStori was available when my child was initially diagnosed as I am sure at times there was information I did not take in from doctors and information I have forgotten over time.”

“It is going to make our life as a family much easier especially attending clinics where my husband or I may not of attended the last clinic with one of the children we have record of what is going on for the other attending and also been able to relay information that may have effected one child in the past as two children have the same condition.”
Positive Impressions

Taken together, first impressions of the MediStori were of utility, originality, positivity, and accessibility. A number of other positive statements were given besides the keywords noted already. For instance, one person wrote that the MediStori is a “small and comprehensive record keeping system” (also “well put together”; “would be great when visiting other hospitals e.g. Crumlin”). A number of items were included in the survey with reference to specific aspects of the MediStori. Keywords from those recruited online included – “Love” (10), “Nice” (4), “Impressed” (6), “Organised” (2), “Record” (7), “Useful” (8), “Compact” (4), and “Excellent” (2). A large majority (87%) of the respondents who were recruited through hospitals gave a written response. These responses were grouped by keyword for analysis. The most common was “Good”, followed by “Helpful”, “Useful”, and “Great” (all referred to in 19 or more comments). Four other keywords were cited less commonly (“Organised”, “Fantastic”, “Brilliant”, and “Excellent”).

“It is a brilliant organiser, so helpful, thank you for sending this to me.” “Well done, great idea.” “Would have been so useful in the path to diagnosis and management of condition.”

“It’s great to have a quick look over on the last appointment before going into the hospital to refresh your memory and if my daughter takes I’ll in a family members they can show the MediStori to a doctor so they know the child’s background.” “It is the best organiser that I have ever seen and easy to use, thank you again for sending it to me.”

“The presentation is certainly professionally designed, its compact enough not to be overwhelming, and seems to have some useful info. As it is set up similar to a filo-fax/day-planner, I would expect that some sections could be added as needed. The binder is not enough to hold my records that I bring with me to appointments, such as diagnostic and consultant letters or MRI discs.”

“My first thought was at last. Years ago a health nurse was in our house checking on our daughter when I saw her notebook I did say to her now that’s what I need is there any way I could get one and she said no sorry only nurses have them. Now that was 19 years ago. So it is brilliant to have one in my hands now. It’s a great size to fit into bag or side of car door. It is very well thought out and I would strongly love to see every parent, carer to be able to have a MediStori if possible to everyone that needs one. Our daughter was a premature baby 13 weeks early and our son 6 weeks early. So it would be a great help.”

“Nice colour! Very tidy and compact, love the added pen! Then when I opened it I was very impressed with all the sections given.” “Really comprehensive, loved the size of it. Really liked that it had a plastic pocket also for prescriptions etc.” “Well organised easy to use.” “Looks nice. Seems comprehensive but a bit full of pages I might not use.”

“Very impressed. I can tell that it is well manufactured and is durable and will last a long time. Very impressed with the layout of pages inside it too.” “Small compact excited to record all info in the one place.” “Easy to use, comprehensive and useful.”

“It’s a fantastic idea. Not sure about the non-medical aspects of its content e.g. Shopping lists etc. I like the idea of having one location for all day to day and life records but I’m not sure the pack is big or versatile enough for that catch all approach. That said, I like the holistic approach to managing all aspects of your life and in turn normalising/de-stigmatising the medical segment.”

“It is one of the most useful medical devices I have ever seen! - I presently have a full large drawer of hospital notes which would not fit into one lever arch file and this is superb in condensing what is important and a great size to carry around when required! It would fit in my handbag. I like the fact u can remove the relevant sections as required to take with you - for e.g. the questions for consultants section. Perhaps one small clear folder per file would be helpful to include to aid in carrying one section around to protect it in your handbag.”
Design Aspects of MediStori

After using the MediStori for six weeks positive appraisals from those recruited in hospitals were made of the MediStori size (95% liked the size), colour (97% approved), whether it is a good idea (100% agreed), and whether it was well demonstrated (91%). Similar positive appraisals were made through those recruited in charities: (90% liked the size), colour (93% approved), whether it is a good idea (100% agreed), and whether it was well demonstrated (87%). Just over half (51%) said there were changes they would like to make to it [noted further in document] and 36% from the charities further commented about the MediStori.

“Quite sturdy to stand the test of time and small to bring with you. Well done.”

“I think this is a brilliant imitative but would love to meet as a group to hack out areas for improvement also have a lot more to report back on pros and cons initial survey could have been a little smaller or more an idea in email on information looking for in it as then could have been ready to go with a list.”

“It’d be good to have a section where you can write all previous interventions and medications tried and what effects and side effects they had so you don’t have doctors repeating meds you tried before esp. if they were unhelpful.”

“I would definitely like an electronic version of the MediStori. I think it is a necessary part of the product to ensure it is used and not lost. I recently travelled to the UK with my daughter and despite having filled her MediStori - I forgot it! I was very annoyed with myself but it would have been great to have online access to the record.”

“I was delighted. I was expecting it to be a lot bigger and more cumbersome, but it’s the perfect size. It’s a good strong folder and seems quite durable. I also love the colour of it because we love pink and purple in our home, so the aqua colour stands out straight away. I genuinely can’t believe all the information in it. I can’t figure out how the team came up with everything. Even down to a section for the GPS co-ordinates. I cannot say enough good things about it and I am sharing it with everyone I know who I think would benefit from it. Also I can’t believe the speed of dispatch. I ordered it on the Thursday and it arrived first thing on Tuesday morning. And in that time I actually got an e-mail apologising about how long it was taking. It was the best service I could ever imagine and can’t talk highly enough about it.”

An organiser is essential. Particularly in the Irish health care system where the ability of hospital teams to communicate effectively is highly questionable, it is extremely important to keep track of and take charge of your own health records. I answered no to the size and colour questions as I think it should be bigger and different colour like light blue or green. White is a little cheap and clinical (in my opinion).”

“I think it is fantastic for at home or in the car to be able to get it if they require so much information but I find the medical profile I have done to be extremely useful and easy and compact to use but I feel it is way too bulky to bring with you and use"

“It means I won’t forget info when at doctor.”

“It’s great. I am a much organised person and like to have everything in its place that’s important to me and it’s a brilliant idea.”

“It’s very practical.”

“It is a very good idea. At this stage in my life I feel some of the information unfortunately might not be wholly accurate due to poor recall (dates etc.)"

“Yes I think it’s a great idea especially for children and older people to help them remember everything.”
Reasons for Participating in the Study

Participants recruited through hospitals were asked why they wanted to be part of the study. The most common keywords in their responses were “Help” (or “Helpful”) (cited 23 times), followed by “Good” and “Information” (both cited 18 times), “Medical Records” (15 times) and “Interesting” (13 times). This reflects the emphasis respondents had on managing information and records more effectively and perceiving the MediStori as having the potential to help them achieve this. Three related primary keywords were noted (“Easy”, “Benefit”, “Medication”). These continue the theme of effective management and an expectation that MediStori could be easy to use and that it could benefit them. Several participants responded by saying they had been given information about the study (“Asked”, cited five times).

“...My wife has a chronic illness and I also have health issues. I wanted to use MediStori to help us keep track of our appointments, medications and symptoms. “I wanted something that would help me and my wife to keep track of our health issues in order that we could improve our quality of life and future prognosis.”

“I was already formulating my own medical profile for my child and had started using it, I had shown my liaison charity nurse so when she came across MediStori she showed it to me and then when you started doing the trial she asked would I like to do it, I was delighted to do it and give the pros/cons in using it.”

“A lot of the time your everyday life gets in the way of keeping on track of all hospital related issues but since I have the MediStori book I feel a bit more in control am confident with everything.” “I thought the idea was brilliant, and I’m very much a paper diary type person, so it suited me!” “To help me keep track of meds, appointments, ailments.” “I need to organise health info for me and son.”

“Our family has a number of health conditions with lots of appointments. We also keep a medical diary for my daughter to keep track of symptoms and side effects.” “I was interested in trialling the MediStori as myself and two children have complex medical needs.”

“Because I thought it was a wonderful idea and would be a great help in trying to keep on top of my daughter and my illnesses. I have been finding it difficult to keep track of our medications so I felt this would be the perfect thing to help us keep on top of everything.”

“It was very interesting and I felt it could benefit us as a family.” “To see how helpful a written record of everything would be when I attend consultations.” “I thought it would be helpful in managing my conditions and medications.” “I needed something to help me keep track of the many medications and doses of same that my daughter has to take, also for anyone else looking after her needed to have all information in one place for her.” “To find a good way to organise our medical history and medicine intake diary.” “All of our family have medical conditions and attend different clinics which help us keep track of appointments and medical history all in one place.” “To help me keep track of my son’s meds and appointments.”

“I loved the idea of having a way of recording both mine and my family’s medical history. For me my investigations are ongoing and it is vitally important that the outcome is stored as this is a hereditary disease and it appears my son may have it.” “I was looking for something to keep all my medical info, appointments etc. together.”

“I was looking for a way to keep medical information together. I have up to now used a daily diary and often have difficulty finding information when I could not remember the exact date.” “I have multiple long term illnesses and this seemed like a tool that could be useful to me.” “I want to help make this product as usable as possible for other patients. I’m so delighted to see something developed to help chronically ill people manage their health care.”
Reasons why patients and carers became involved in study

<table>
<thead>
<tr>
<th>Keyword</th>
<th>Number of references</th>
<th>Illustrative comments (Patients and Carers Voice)</th>
</tr>
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</table>
| **Help/Helpful** | 23                   | “I feel that a system like this would be very helpful for my family”  
“I have three girls and it would be a good help to keep all their records as they grow up”  
“To help me organise my baby’s appointments”  
“To help the HSE run that bit better”  
“To help the study and I feel it’s a fantastic idea” |
| **Good**         | 18                   | “I have a new born and even from being pregnant I have seen so many different doctors and lost or forgotten information on the way or have forgot to ask question so I think the books sound like a very good idea”  
“Seems a good way to keep all medical details handy” |
| **Information**  | 18                   | “After reading the information and had an explanation of the aim of the study it sounded beneficial to me and my child”  
“I choose to take part as I feel it is a great way for me to have my child’s information in the one place and all together” |
| **Medical Records** | 15                   | “Anything that helps me keep track of my child’s medical history and ongoing treatment is a great idea”  
“Having a child that will be receiving care in a hospital setting for 18 years comes with a lot of referrals, appointments, prescription with changes and medical details. It is hard to arrange all of this paperwork and have it to hand” |
| **Interesting**  | 13                   | “Three children, one with asthma interested in keeping all medical information together”  
“Interested in storing my daughter’s medical data in one safe place and may make it easier to remember” |
| **Easy**         | 8                    | “I think this MediStori is a brilliant idea and would make life much easier for me” |
| **Benefit**      | 7                    | “It will be beneficial to me and my child as less likely to lose documents” |
| **Medication**   | 6                    | “To safely manage medication and appointments” |
| **Asked**        | 5                    | “One of the very nice nurses asked me to take part” |
Expectations of Patients and Carers

Besides the keywords, references were noted to specific conditions (for instance, “I have a child with special needs”; “Have a child with asthma”; “I thought it would be of benefit to my day to day routine when looking after my son who has spina bifida”; “My son has a complex and ongoing medical condition”). These suggest an association between such conditions and an additional need for information management systems. Other important reasons for taking part included the need for continuity between health care professionals (e.g., I “have had experience with doctors who have no idea of the history of my child so this is a great idea to organise me and inform the doctors”; “It’s a great idea to be able to communicate results, etc. between the different health care professionals, partners and family”). The most common keywords from participants using the online survey tool were Appointment”, “Medical”, “Medications” “Brilliant”, “Benefit”, “Accessible” “Organise”, “Chronic Illness” and “Record”. Others wanted to “be part of the research” and “track health information”. Nearly all (98%) of participants said that they felt the MediStori could help in the future with their specific needs. Some of the areas which were helpful were:

“I needed a way to record medicines and keep history.”

“The meds and appointment’s sections I use all the time to help me keep track of everything It will help me keep her current records in one place.”

“I like the daily record.”

“Since starting to use MediStori my daughter has been diagnosed with two new conditions it is helpful to have somewhere to keep all appointments etc. all together and record when she started certain meds, side effects if appropriate and dates of MRI, scans etc.”

“It was good to be able to check appointments, keeping prescriptions, medical reports all in one place so I always know where I can find it.”

“I’ve often needed to leave my info behind... Sometimes copies of consultant letters, or other details. The MediStori isn’t set up for easy printing now... But I understand that’s something in the works. I don’t need to keep track of taking meds, as no one else is administering them, and my pill boxes do the trick. It isn’t adequate for storing documents, CD’s or receipts (finding the sleeves too small and too difficult to use with limited use of my hands plus my literacy condition). “

“I do like the fact the paper quality is thick enough and matte so that pencil marks erase cleanly and pen doesn’t show through. The forms are adequate size for someone with difficulty writing or vision problems (within reasonable margin).”

“A diary or booklet with lots of room to write a short explanation of the patient’s condition and medical history over a few pages would be very handy.”

“We have a rare condition I would never expect to find that sort of thing anyway and each person with the condition is different too so it would be huge work.”

“My child has yearly major tests and I would like to be able to compare year on year results. Most of the children in our charity have these annual major tests.”
Did MediStori Meet Specific Needs?

Post use, over ninety per cent (93%) of those recruited through hospitals responded to say that the MediStori had met their specific needs during the six week period. Over eighty per cent (87%) of those who responded through charities said that the MediStori had met their specific needs. Some comments were made which could help them more specifically:

"Yes I especially like the preparation for appointments, and the calendar for appointments - excellent. It will help in all my medical history and help me to keep track of any changes with my tablets and how each hospital appointment went."

"I will be able to use it as reference to medication taken, any allergies from previous medications taken and other allergies, keep track of vaccinations. "It should help me monitor my health."

"Both yes and no. I will be adapting my own system with some things you've thought of -- especially keeping better records between appointments. I don't think I will be using the book though, as it's not appropriate for the information I want at the ready in consultations. Specifically, I rely on my consultant letters quite a lot, as my condition is not well known or accepted in Ireland. These letters validate what I'm trying to communicate. They give me the credibility I've lacked for years with doctors."

"A lot of it was irrelevant to myself and my conditions but would be very helpful for others I am sure Yes it is very helpful to have a lot of his medical information on hand in one folder I do feel there are ways to improve it a lot and no on a daily basis going in and out of hospitals I feel my medical profile very useful Keep us more organised. Remember appointments easier, time dates etc."

"It will help me keep my child's medical information in one place and will be invaluable to him when he is old enough to attend appointments on his own."

"Without a doubt. It's helping us already. We had an appointment with my daughter's specialist and we were able to keep track of all of the questions we needed answered, the prescriptions given, her peak flow diaries, etc... In stressful hospital situations."

"Will help organise things."

"It has a diverse range of information on each family member and is quite concise."

"I would like to have all my info in one place in the event of illness where I am not able to care for myself or in the case of death as I wish to donate my body to science."

"Without a doubt. It's helping us already. We had an appointment with my daughter's specialist and we were able to keep track of all of the questions we needed answered, the prescriptions given, her peak flow diaries, etc..."

"I have so many appointments, medications and letters to keep track of that now they are in one place it has already helped me through one hospital admission just last week!"

"I would use this book again."

"I don’t think I could do without it now it comes with us to every appointment if we are asked about bloods meds physio OT etc. It's all on hand IN OUR MediStori I would be lost without it now I wouldn't be able to find anything."
Participants Perceptions of Charities

Ninety three per cent of participants recruited online through their charity said their charity was not promoted through their health care professionals or service. This was even though 86% of participants said they felt like their charity was an additional health service to them. Those that did recommend were cited as “public health nurse”, “social worker”, “physiotherapist” and “health care team”.

“I feel it is like an additional health service as they provide information which some medical professionals are not aware of.”

“Much more relevant day-to-day information about living with condition”

“I learn much more from the online groups than anywhere else. There are no specialist for my condition Ireland. Most of the doctors admit they know very little. Treatment is trial and error, non-existent or very dismissive from professionals. The group often finds reputable info, alternative treatments to try, and share names of doctors who are clued in / compassionate and receptive.”

“They help me to get specialist medical treatment for my condition.”

“If you have any questions about diagnosis or symptoms or just need to vent to somebody, they are always there to help.”

“I would not have able to care for my child at home without their help”

“Any worries or concerns you have no matter what hour of the day it is someone will have some advice. It’s very reassuring”

“I feel it’s important to have a holistic approach to my children’s conditions”

“Seeing as appointments can be so far apart with specialists it’s good to talk to others in between”

“Source of info, experience, solidarity, collated experience of medical professionals which means can be a helpful short-hand when dealing with a creaky and insubstantial health service. I have gotten a lot of peer support, advice on which specialists are tuned in to the condition (as it is rare), and it has helped me”

98% of participants said they did think it was a good idea to have the MediStori promoted through charities online. They also commented on other areas in health services where it should be promoted:

“Pharmacies.” “Maybe in hospitals.” “Doctors surgery and hospitals.” “Maternity Hospitals”

“I think community paediatricians as they seem to have the most complex kids - paediatric PHN for the same reasons.” “Hospitals, GP waiting room posters maybe.”

“Doctors surgery so my go thought it would be very helpful especially when relaying information from consultants to GP.” “Hospitals/ doctors’ offices/ disability organisations like Enable Ireland/ county disability teams etc.” “Downs syndrome Ireland and Cystic Fibrosis Ireland.”

“If we had a disability advocate or clinic for our disease, then that would be an excellent resource to be given on diagnosis or suspicion of diagnosis. I believe you should advertise the availability in every brochure/info section possible -- at GPs, hospitals, clinics, citizen’s info, pharmacies, etc. -- and your audience could be anyone that has chronic symptoms, difficulty remembering medical information, many children/patients in the home…. (I’m sure you’ve already given this adequate thought, but appreciate the “ask!”)”
Reasons for Choosing Charity

Participants were asked how they first learned about their charity.

- 34% found their charity through Facebook
- 10% found their charity through leaflets in waiting rooms
- 17% found their charity through friend/family/word of mouth
- 17% found their charity through Internet searches
- 9% found their charity through other support groups
- 7% were referred to their charity through health professionals
- 6% had various other ways in how they found their charity (trial and error etc.)
- 2% found their charity through the newspaper
- 2% found their charity through media coverage

There were multiple reasons why participants recruited online said they chose their selected charity.

- 74% wanted to connect with others in similar circumstances
- 62% wanted to communicate with others regarding concerns they have
- 60% wanted to find out more about their condition
- 60% wanted to be involved in conferences/talks regarding conditions
- 45% wanted to ensure they met other people with the same condition
- 40% wanted to raise funds to help support their service
- 9% were unsure as to why they chose their selected charity

“I feel I am not alone with this journey.” “They provide essential respite to help care for my child.” “They give me a break by having a qualified nurse looking after my child so I can spend some time with my older child.” “To get help and support and a few hours off to myself.”

“To keep track of doctor’s appointments and medications I’m taking also to keep note of my symptoms.”

“Joined to talk to other people with the same condition as me and to get support, information and advice and be part of the growth of awareness.”

“To connect with other patients with similar conditions in our country. To find out local info in regards to professionals who were helpful. Keep up to date with new studies and their findings.” “Support for my condition, and my son.” “To meet other patients my age with similar circumstances.”

“It is to keep up to date with events etc. which may relate to my condition.” “Other patients can give help and advice when going through similar experiences!” “I can ring or post any time with a question about meds, symptoms, services & nearly always get a reply.”

“I’ve learnt more about our condition from other members than I have from any doctors/consultants.” “Emotional support that is not provided by health care professionals.” “Learned about other services my child could benefit from home tuition; excellent dental care she was entitled to because of her condition.”

“Our charity have been so much help regarding information about our condition, information that’s no health professional has offered.” “Access to multiple levels of support via annual conference, online resources, contact with other families. Very helpful to read others experiences with the disease and medications.”

“I get information and support from other parents in similar situations, this can help especially if out of hours and on call medics are not familiar with my child’s condition.” “Without our charity we would be so worried and also feel so alone. To know other people are going or have gone through the same worries and concerns you are is just so comforting. And they give great advice on how to get the best out of the services.”
Demonstration of the Toolkit

Nearly 92% of those recruited online said they felt they were given enough information from the team. Twenty-five per cent said that would have found it easier to use however if it were shown face to face, with 69% saying they wouldn’t; leaving 6% unsure.

“Headings very self-explanatory.”

“I actually received the MediStori without speaking to the team, it was very self-explanatory and when I phoned it was explained what I had to do.”

“I found it easy to understand and easy to use.”

“The girl I was dealing with on the helpline was very nice and very helpful person she explained everything to me thoroughly.”

“It’s straightforward enough.”

“The video and one sheet card were more than enough to get started. The forms should be self-explanatory -- which they are. (I can’t stand to see a separate instruction sheet for filling out a form!).”

“Good info and good video info.”

“It is very self-explanatory and easy to use.”

“The YouTube example was excellent.”

“Very wordy sections.”

“Would have preferred more detailed written instruction.”

“Yes the team were great and everything is pretty self-explanatory.”

“The video explanation for using the medication chart was necessary. There were good, brief cues to help those who need it, yet the MediStori is usable without that instruction -- which a lot will skip. And really, a form shouldn’t require an instruction sheet!!! It should be self-explanatory. I’m pleased that this is. I do think the medication chart is quite overwhelming and probably your biggest design challenge. I’m impressed that the solution thus far allows for a varied level of input -- not requiring extensive record keeping, but allowing for it should the user want it. For some people, they need to be shown in person, and practice using it with a follow up assessment. The one-colour design I believe is always a good choice for costs and for simplicity. I don’t believe more would help -- rather could become too busy. As a former designer/art director myself for 24 years, I am big on using colour appropriately and to aid usability. I hope that input helps. I can just imagine some of the conversations that might have happened in developing this.”

“Yes the sheet that came with it explained it perfectly and also as you go through the MediStori itself it is pretty self-explanatory on how to use it.”

“I think it was really self-explanatory really I didn’t have any problems.” “Very intuitive and usable.”

“Simple to understand.” “Instructions were superb.” “Worked well.” “It was very well explained and easy to follow.”
Implementation Model

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: [GP was cited 7 times; hospital cited 5 times]

“Perhaps a GP could tailor a pack of templates, choosing relevant sections in MediStori, depending on circumstances.”
“Doctors surgeries, crèche’s I think it would be fab for mothers and father to keep track of all the family’s medical needs.”
“Pharmacies; doctor’s surgeries; hospital.”
“ICU for premature babies, A&E, CRC. Carers looking after elder parents or people with Alzheimer’s, health centres, chemists, heart, also genetics, metabolic units.”
“I feel it should be promoted in hospitals, with consultants and maybe GPs.”
“Doctors could offer them to patients with high visiting needs, to keep better records and make appointments more efficient.”
“I think it would be helpful to most patients with complex/rare conditions. I am a complex case as I have other controls also and a very long and full medical history.”
“Had our charities awareness page not promoted it I would never have heard of it.”
“Through hospitals / health care professionals.”
“Through medical centres/hospitals.”
“Hospital websites hospital noticeboards pharmacies GP surgeries.”
“GP offices, hospitals and physios.”
“Chronic pain seminar, doctors, hospitals.”
“ICU for premature babies, A&E, CRC. Carers looking after elder parents or people with Alzheimer’s, health centres, chemists, heart, also genetics, metabolic units.”
“Doctors could offer them to patients with high visiting needs, to keep better records and make appointments more efficient.”

MediStori from Birth to End of Life

After using the toolkit for six weeks, several participants wrote that the MediStori would be most effective for families if provided at birth (“wish I had since birth of each of my children. Love the idea. Can be hard to back fill information should be given out in maternity wards”).

“Wished I had it from when my children were born. Should be given to every new mother in maternity hospitals. Would have been so useful in the path to diagnosis and management of condition.”
“Antenatal clinics.”
“Your personal health, development and social record should be given to parents when a child is born.”

“Wished I had it from when my children were born. Should be given to every new mother in maternity hospitals.”

“Because my children are 12 and 19 years old it took a while to fill in all the details and I wouldn’t have a lot of the details for pregnancy i.e. bloods, ultrasounds etc. I don’t have dates of childhood illness. Maybe modify MediStori according to age. If MediStori was available at antenatal clinics then you could use the version you are using now, to give mom’s to be the chance to keep everything together and fill it in as you go along. As it is both of my kids development section are empty as I don’t have that level of detail recorded.”
Recommendation of PHRs & Types Used

Only 15% of participants through charities had reported having received any kind of personal health record booklet from a health professional. Just 6% reported that a personal health record system had been recommended by a health care professional yet 20% of the participants said that they maintain a personal medical record for themselves or family members.

This survey question asked for details on the record kept. A range of strategies was cited, and these were quite informal. For example: “A manila folder of all the official letters and records”, “Copy book”, “I have made my own document to log medicine dose and time given”, “Notebook”, “Notepad”, “Plastic folder”, “Box file”. Two electronic examples of organisation were given (“full record on laptop”, “in phone”).

Only 11% of the participants from hospitals reported having received any kind of personal health record booklet from a health professional. Just 13% reported that a personal health record system had been recommended by a health care professional yet 33% of the survey participants in hospitals said that they used a more organised system for managing relevant information, such as a diary.

This survey question asked for details on the record kept. A range of strategies was cited, and these were the same as reported in the hospital study.

“I had to start an A4 folder to keep all appointment letters, results, copies of feedback etc. as things were getting out of hand with so many consultants.”

“Use a diary to record appointments, meds, physio etc.”

“Just notebook, writing down how many infections I had for my lung consultant because I was getting so many it was hard to keep track. Nothing official though.”

“Created an excel spreadsheet listing meds, reason for taking, dosages, times and hospital ref # for my parents. Also extra notes as needed for ambulance. Handed it to crew any time we called them. Paramedics appreciated it. Hospital had record in file by the time family got to the hospital each time.”

“I used a diary to keep note of his time in ICU but once he came home after 5 months I stopped taking notes every day.”

“Temple Street developed a prototype ‘Spina Bifida passport’. 

“I have 5 folders with medical letters/ reports for each of my children. Not vaccination info though but most other medical things.”

Additionally 42% of the participants said that they maintain a personal medical record for themselves or family members (such as given by health professional; e.g. vaccination record).
Usability and Completion of Record

Thirty seven per cent of those recruited through charities had filled in the personal health record for themselves and 57% had filled it in for someone they cared for (a total of 94%), leaving just seven per cent who did not fill it in.

Nearly half (47%) had filled in directions on how to get to their house for a carer or babysitter so they can tell emergency response units how to get there. Eight-one per cent of those recruited through hospitals had filled in the personal health record for their child, and nearly half (48%) had filled in directions on how to get to their house for a carer or babysitter so they can tell emergency response units how to get there.

About half of the Time 2 participants from hospitals filled in all of the sections of the MediStori (52%). Reasons were given from some of the participants as to why they couldn't complete it: “Some of the stuff doesn't apply to me. My kids are older.” “I didn’t have access to my maternity file so some info regarding the births etc. was not available.” “Just filled in what was relevant to our family.” “Most of it but I need to take time to fill in vaccinations section.” “I find writing a lot very difficult and painful so need to fill it in bit by bit. Will get there eventually. Filled in the calendars and questions I had for doctors and have started completing each section but by bit.”

Impact on Self-Management

For nearly two thirds, the MediStori had had an impact on how they felt in their ability to manage their child’s condition (24%: Large impact; 41%: Some impact) and 83% recruited through charities said the MediStori had had an impact on how they felt in their ability to manage their own or their loved ones condition. The majority of respondents recruited through hospitals perceived the MediStori as having a positive impact on their ability to manage their child’s illness or condition during the six week period. The majority of respondents from charities similarly perceived the MediStori as having a positive impact on their ability to manage their own or their loved ones illness or condition.

Eighty per cent of those recruited via charities said the MediStori had helped them keep track of symptoms, with a similar proportion of those recruited through hospitals (77%) saying it had helped them keep track of symptoms.

Linking and Storing Information

After six weeks of use, seventy five percent of those recruited through hospitals indicated that the MediStori had helped them link between all of their child’s health care professionals, with seventy per cent from charities indicating similar. An additional question was also asked of those in charities and 93% said they thought it was important to keep all family members’ medical and health care information together in one place.
Medication Adherance and Management

Eighty six percent of participants who were recruited online said they were either taking or giving medications to themselves or the ones they provide care for. These same participants were asked if they had ever been given a method / device in the hospital to help them manage their own or others medications. Nearly 82% said they did not receive a medical device in a hospital setting to help them manage their own or someone they provided care for medications.

Positive Experience:
“The biggest help I got was by the hospital pharmacist in Crumlin who sat down with me and went through all of his medications and told me the best times to give them to prevent him getting sick i.e. on full tummy empty etc.”

Negative Experience:
“Are you joking? The hospitals have been useless at supporting me, and certainly not very interested in care outside their legal obligation! (Please excuse the cynicism. I’ve had very difficult experiences with the services!)”

These included pillboxes, medical diaries, peak flows and conversations with pharmacists. Very few of those recruited through hospitals survey respondents were given a method or device to help manage their children’s medications. Two reported having been given a diary for medications and one said they had received a timetable of what medications to give and when they should be given. Over 40% of the participants recruited in hospitals in the survey said that they wrote down a note of the medication name and the time it had been administered. Over 54% of participants recruited online agreed that they sometimes write down a note of the medication name and the time it had been administered.

“Years ago in A&E a lovely nurse gave me a syringe to give our daughter her meds cause she didn’t like taken any. It helped a lot. I think they are a lot easier to give then with a spoon when they are young and refuse to take liquids meds.”

“A peak flow metre and record book by the respiratory specialist.”

Eighteen per cent of the participants recruited through hospitals said their children were taking one medication at the time of the survey, and 16% were taking more than one medication (a total of 34%). The parent completing the survey responded to a set of items on difficulties or problems with medication use. Over half (57%) found it difficult to remember what time to give a medication and 52% found it difficult to remember if a medication had been given or not. Nearly sixty per cent (59%) acknowledged having forgotten to give their child a medication on time, while one quarter (24%) had forgotten to give their child a medication altogether. Prevalence rates were lower for the other medication-related difficulties recorded in the survey: 9% had gotten confused about how to give medication, 8% had given a wrong dose, 2% had given the wrong medication, and 5% were confused why the medication was being given.

Ninety five per cent of those who said that they were taking/giving medications recorded one or more difficulties with the management of medications.
Practicality, Understanding and Knowledge of Medications

Of those participants who signed up through their charity 25% thought they might have taken or given too much medication to themselves or someone they were caring for and 51% felt they may not have given/taken enough. Nearly 60% thought others couldn’t administer medications correctly to themselves or their loved ones. Of the families who reported having a child currently on medication, 12% reported thinking that they may give their child too much medication and 14% reported thinking that they may not give their child enough medication. Nearly six in ten (58%) reported thinking that other people looking after their child may not be able to give their medication correctly.

“When I've been in hospital or recovering from surgeries and others are in charge of my meds, they have gotten things wrong -- frequently (mainly in hospital). I now give them printed info, and yet it's still often wrong. From reviewing the previous survey and the MediStori system, I can see much thought has gone into this specific area.”

“That I did not administer her medications correctly in particular her injections.”

With regards to those recruited in hospitals, responses to the items on medication-related difficulties were summed to identify how many families experienced at least one difficulty. 74% reported one or more difficulty, with four in ten (41%) having experienced three or more difficulties. Some of the parents of children not currently on medication also reported medication-related difficulties, presumably in relation to previous experiences of medication use. The most prevalent difficulty reported through both groups of participants was in regard to remembering what time to give a medication – nearly six in ten (57%) said they had found it difficult to remember the time to give a medication through the acute hospital site with three quarters (75%) through charities saying the same. A smaller but still significant proportion had forgotten to give medication on time (H - 24%, C - 54%)

Medication Management – Pre Use of MediStori

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<tr>
<th>Participants were asked had they ever…</th>
<th>Charities</th>
<th>Hospitals</th>
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<tr>
<td>Found it difficult to remember what time they took/gave medications at</td>
<td>75%</td>
<td>57%</td>
</tr>
<tr>
<td>Forgot to take/give medication on time</td>
<td>75%</td>
<td>59%</td>
</tr>
<tr>
<td>Found it difficult to remember if they took/gave medications or not</td>
<td>72%</td>
<td>52%</td>
</tr>
<tr>
<td>Thought that other people may not give the medication correctly</td>
<td>59%</td>
<td>58%</td>
</tr>
<tr>
<td>Forgot to take/give medication altogether</td>
<td>54%</td>
<td>24%</td>
</tr>
<tr>
<td>Thought that they may not have taken/given enough medication</td>
<td>51%</td>
<td>14%</td>
</tr>
<tr>
<td>Got confused about how to give/take medication</td>
<td>27%</td>
<td>9%</td>
</tr>
<tr>
<td>Thought that they may have given themselves/someone too much medication</td>
<td>25%</td>
<td>12%</td>
</tr>
<tr>
<td>Got confused as to why they were taking/giving medication</td>
<td>21%</td>
<td>5%</td>
</tr>
<tr>
<td>Gave the wrong dose of medication to themselves or someone else</td>
<td>19%</td>
<td>8%</td>
</tr>
<tr>
<td>Mixed up medications with one another</td>
<td>9%</td>
<td>0%</td>
</tr>
<tr>
<td>Gave the wrong medication to themselves or someone else</td>
<td>8%</td>
<td>2%</td>
</tr>
</tbody>
</table>
What reasons were given for not giving/taking medications properly?

“The brain fog, fatigue, changing doses, and so many things to remember, of course these scenarios have happened over my life. Even when I only had 2 pills to take, I could be forgetful! I’ve many systems in place now to help, but nothing is perfect.”

“When the children are only on a medication for a short time e.g. antibiotics when they last had one or if they had a reaction to a certain medication been able to record and date this information helps when attending the next clinic or to mention when another family member is prescribed the same medication at a later date.”

“I find it difficult to remember all of the meds/dosage when asked. So I have made a typed document with details like this, that I can update as meds are often changed, and I give this medical info document to all my doctors for their files. This has helped most of the time to get my records more accurate, and saves a lot of time in communication, especially in hospital. It helps me recall info as needed too. I do not use this for recording daily stuff. I made a chart when I was not able to take care of myself and relied on someone else monitoring my meds and time -- as well as using phone alarms." “I am always forgetting to take meds at the right time our forgetting completely.”

“Personally I think it’s a wonderful idea. I know that this will actually save lives. When my mother passed away the doctor said I hadn’t given him vital information about her health which is what led to her being given the wrong medication. Had I had the MediStori I would have been able to prove that he had all the information he needed. It would not have been a case of my word against his. There would have been proof.”

Did MediStori help with the Management of Medications?

Three quarters (75%) of those recruited through hospitals said that it had an impact on their management of medications (11% said it was a large impact, 64% said it had some impact). Over three quarters (80%) recruited through charities said that it had an impact on their management of medications. Over half (55%) of the participants at Time 2 as recruited in hospitals reported that their child was on medications in the last six weeks. All of these 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. At Time 2, 82% of the participants recruited through charities reported that they or the person they cared for was on medications in the last six weeks. Seventy three per cent said they had used the Medicine Memo to write down their own or their loved one’s medication and the times the medications were given. Nearly all (93%) thought that it was a good idea that their charity offered them the MediStori to help manage medications.

“I found the MediStori has helped me to keep a great record of all medication I give my son.”

“MediStori has hugely improved all issues above that I would have previously had.”

“Had no issue since using MediStori.”

“This was not due to MediStori, as I did not use it to its full potential.”
Participants were asked how they managed medications PRE and POST use of MediStori

<table>
<thead>
<tr>
<th>Participants through Charities</th>
<th>Pre MediStori</th>
<th>Post MediStori</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Found it difficult to remember what time you took/gave medications</td>
<td>75%</td>
<td>17%</td>
<td>-52%</td>
</tr>
<tr>
<td>Found it difficult to remember if you took/gave medications</td>
<td>72%</td>
<td>10%</td>
<td>-62%</td>
</tr>
<tr>
<td>Forgotten to give/take medication on time</td>
<td>75%</td>
<td>40%</td>
<td>-35%</td>
</tr>
<tr>
<td>Forgotten to give/take medication altogether</td>
<td>54%</td>
<td>13%</td>
<td>-41%</td>
</tr>
<tr>
<td>Given/taken the wrong dose of medication</td>
<td>19%</td>
<td>0%</td>
<td>-19%</td>
</tr>
<tr>
<td>Gotten confused about HOW to give/take medication</td>
<td>27%</td>
<td>0%</td>
<td>-27%</td>
</tr>
<tr>
<td>Gotten confused as to WHY you are giving/taking medication</td>
<td>21%</td>
<td>20%</td>
<td>-1%</td>
</tr>
</tbody>
</table>

It was interesting to see that there was no real change between pre-use and post-use of MediStori in relation to WHY someone didn’t know they were giving or taking medications. This is not a practical issue but an educational and awareness matter. This shows how important it is that healthcare professionals communicate effectively with patients and carers about their medications.
Vaccinations

Nearly all of the participants (92%) recruited through hospitals reported having received a vaccination booklet for the child. Of these, 85% still had the booklet, yet only 65% of those still used the booklet. Over half (58%) kept all of the family’s vaccination records together, but 33% had occasion to contact a GP or Public Health Nurse to recall past vaccinations. Approximately one quarter (27%) had a vaccination booklet to record flu/tetanus/travel vaccinations for older children and adults in the family.

Over 72% of those recruited online reported having received a vaccination booklet for themselves or someone they cared for. Of these, 49% still had the booklet and 26% of those still used the booklet. Thirty four per cent of these kept all of the family's vaccination records together prior to using the MediStori, but 46% had occasion to contact a GP or Public Health Nurse to recall past vaccinations. Approximately one quarter (25%) recorded flu/tetanus/travel vaccinations for themselves and other people in the household.

Post use, sixty per cent of those recruited through hospitals had put their child’s vaccination record into the MediStori, and 31% had used the vaccination section to log flu/tetanus/travel vaccinations. A smaller proportion of those recruited through charities put their child’s vaccination record into the MediStori (37%), based on 70% having a record of same. 53% had used the vaccination section to log flu/tetanus/travel vaccinations.

Appointments, Recording and Storing Health Information

A large majority of participants who were recruited through hospitals said they wrote down questions to bring to the next appointment (61%) and kept information together on hospital / GP letters, test results, appointments or receipts in one place at home (67%). However, the majority of the respondents (89%) reported it was difficult to recall information about previous medication prescriptions, visits to the GP or hospital, or information about medical history. Over 96% of participants who were recruited online said they write down questions to bring to the next appointment with ninety per cent keeping information together about hospital / GP letters, test results, appointments or receipts in one place at home. However, 67% reported that it was difficult to recall information about previous medication prescriptions, visits to the GP or hospital, or information about medical history. However, only one quarter of the survey participants said that they used a more organised system for managing relevant information, such as a diary, as demonstrated in the first table. Two thirds (66%) said that they found it hard to manage and remember the child’s health care appointments with three-quarters of participants recruited through hospitals saying they found it hard to manage and remember the child’s health care appointments.

After six weeks of use, eighty per cent said it had some impact on how they managed health care appointments (30%: Large impact; 50%: Some impact) and similarly 80% as recruited said it had an impact on how they managed health care appointments.
Eighty per cent in total initially said they would like to see an electronic version also. At Time 2 83% of the participants recruited from hospitals said they would like to see an electronic version of the MediStori. Similarly, 73% of those participants at Time 2 recruited through charities said they would like to see an electronic version of the MediStori also. Some comments were made: [App cited 12 times.]

“As useful as the paper version is, I will take notes and store emails electronically.” “An app on the phone so information is always on hand, stored on an iCloud or other so is backed up and also maybe be accessed by health professionals.” “Cross platform.” “Laptop + smartphone.”

“It would be easy for young adults to access family medical history quickly in an emergency.”

“Unsure but one you can share with your GP/consultants/physios etc. somehow so they can log into it to read (only!!) from their own office so you don’t have to remember to carry it around. It’d be good if any professionals could log into this system once you provide them with your details which would be convenient if you ended up in A&E or some unplanned appointment where you didn’t have a chance to bring your MediStori with you. But keep the ’real’ version also cos it’s good and I prefer to have my own physical one.”

“This may in fact be more helpful. Most people do so much online nowadays although it would not be easy for healthcare providers or carers to review then.”


“A MediStori app that would notify you of when you’re to give/take certain medications. Or one when you’re next hospital appointment is due.”

“I myself am content with a portable log but my husband is a techy.”

“Something that is completely compatible with Android as well as Apple and Microsoft. I think having it on a tablet would be easiest because it is more portable.”

“I believe it must be accessible on all devices -- as some people don’t have access to a pc, only their phone. So an app or website that stays backed up, accessible anytime, anywhere, by any device would be ideal”

“Something you can log into and edit and professionals can too from anywhere as long as they have your permission and you get sent info on what they’ve written to verify and speed up waiting on their results/comments/conclusions/interpretations.”

“I would be worried about losing the hard copy so an online backup would be great.”

“Perhaps an app? Maybe for prompting reordering meds, appointments to attend, when next dosage is due.”

“I think there is a need for a paper booklet MediStori as is, especially for information that does not change, so everything is in one place. Electronic version would be useful for accessing this information on the go. (Like in PDF form) electronic symptom monitoring could be useful, like other apps.”

“A database type to fill in all information with a daily calendar to update symptoms and medications. To be available on phone. An option to have an alarm reminder to take medication and also reminders regarding appointments to remind a few days before appointment. A daily diary for symptoms is very important for me to track symptoms. Maybe a monthly summary if possible. To be available on laptop also. Like a medical Facebook that is private.”
Family Perceptions of Health Care

Two validated measures were included in the survey in order to assess the context in which the families experienced health care for their children. These measures relate strongly to parental satisfaction with care, which is seen as a critical outcome of the care process.

Multidimensional Assessment of Parental Satisfaction - Hospitals

The first measure presented in the survey was the Multidimensional Assessment of Parental Satisfaction (MAPS) for Children with Special Needs (Ireys and Perry, 1999). This is an 11-item measure where each aspect of health care is rated on a five-point scale from ‘Excellent’ to ‘Poor’.

The responses from those surveyed in acute hospitals suggest that families perceived health care providers as giving expertise and excellent levels of care with respect to ‘managing my child’s chronic condition’, ‘providing general health care’, in the ‘ability to answer questions about your child’s condition’, and ‘referral to other providers as needed’ (i.e., 70% or more of respondents rating these elements of care as ‘Excellent’ or ‘Very good’). A second tier of items received between 62.4% and 69.7% of responses in the ‘Excellent / Very good’ range: ‘Helping in coordinating care’, ‘effort to be flexible’, ‘sensitivity to background and beliefs’, ‘really listening to your opinions’, and ‘amount of information and guidance’.

Responses to two items fell below this level of perceived excellence: ‘Communicating with health care providers’ (58.5% rated this in the ‘Excellent / Very good’ range) and ‘putting you in touch with other parents’ (31.3% rated this as ‘Excellent / Very good’ and 47.9% as ‘Fair / poor’). Using the same measures, below are the perceptions from participants who were recruited through charities:

<table>
<thead>
<tr>
<th>Excellent, Very Good or Good</th>
<th>Perceptions of Health Services</th>
<th>Fair or Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>75%</td>
<td>Sensitivity to background and beliefs</td>
<td>25%</td>
</tr>
<tr>
<td>68%</td>
<td>Providing general health care</td>
<td>33%</td>
</tr>
<tr>
<td>60%</td>
<td>Managing my child’s chronic condition</td>
<td>40%</td>
</tr>
<tr>
<td>60%</td>
<td>Really listening to your opinions</td>
<td>40%</td>
</tr>
<tr>
<td>55%</td>
<td>Ability to answer questions about your child’s condition</td>
<td>45%</td>
</tr>
<tr>
<td>50%</td>
<td>Referral to other providers as needed</td>
<td>50%</td>
</tr>
<tr>
<td>49%</td>
<td>Amount of information and guidance</td>
<td>51%</td>
</tr>
<tr>
<td>44%</td>
<td>Help in coordinating care</td>
<td>56%</td>
</tr>
<tr>
<td>44%</td>
<td>Effort to be flexible</td>
<td>56%</td>
</tr>
<tr>
<td>30%</td>
<td>Communicating with other health care providers</td>
<td>70%</td>
</tr>
<tr>
<td>18%</td>
<td>Putting you in touch with other parents</td>
<td>83%</td>
</tr>
</tbody>
</table>
MAPS: Implications for the MediStori

The MediStori is relevant to the aspect of care concerning ‘communicating with health care providers’ as it is possible that having a personal health record for a child or patient will enable themselves or their parents to achieve better communication and retain information from communications from health care professionals and administrators. It is also relevant to the item concerning ‘really listening to your opinions’ as the MediStori could enable patients/parents to collate and present information back to health care professionals. Finally, the MediStori is relevant to ‘amount of information and guidance’ as it can be used to store information and retain guidance notes.

Items on Communicating about the Illness

Given the age profile of the children being referred to in acute settings, it is not surprising to see that 66.9% of respondents ‘never / rarely’ speaking with their child about the illness. By contrast, a quarter (24.4%) speak ‘often / very often’ to family members about the child’s illness. This is a similar proportion to those who speak to a doctor ‘often / very often’ (23.5%), and a larger percentage than those who speak to a nurse ‘often / very often’ (16.1%). The greatest degree of difficulty arising from speaking to others about the illness was in relation to speaking with the child (22.2% experienced difficulty ‘somewhat / very much / extremely’) and with family members (30.1%). These figures were considerably higher than for the medical or nursing staff (17.0% and 9.0%, respectively).

Items on Conflictual Communication

In relation to unsatisfying and conflictual communication, 51.6% of participants argued with family members ‘sometimes / often / very often’. By comparison, 39.9% felt misunderstood by family / friends and 31.1% worried about how friends and relatives interacted with the child. These figures were reflected in the percentage of participants who experienced difficulty arising from these issues (43.1% of participants found family arguments difficult, 35.9% found feeling misunderstood by family members to be difficult, and 30.1% worried about friends and relatives interacting with the child).

With regard to conflictual communication arising in the health care context, four in ten of the respondents felt confused by medical information ‘sometimes / often / very often’ (40.6%). Nearly three in ten (29.4%) experienced this as a source of difficulty (‘somewhat / very much / extremely’). Just 10.9% disagreed with a member of the health care team to that same degree of frequency, and 13.1% saw this as a source of difficulty. Participants who were recruited through their charities were also asked had they ever experienced unsatisfying and conflictual communication, and again there are slight differences of opinions.
Paediatric Inventory for Parents [PIP]

The second measure was the Communication Domain items from the Paediatric Inventory for Parents (PIP; Streisand, Braniecki, Tercyak, and Kazak, 2001). This measure is used extensively in studies of health care utilisation and perceptions of satisfaction in paediatric services internationally. The PIP presents nine events that parents of children who have (or have had) an illness sometimes face. The parent records how often the event has occurred in the past seven days. Several of these are inherently difficult (e.g., ‘arguing with family members’). Others are not necessarily difficult but have the potential to be difficult (e.g., ‘speaking with doctor’). The PIP frequency ratings are made using a five-point scale, from ‘Never’ to ‘Very often’.

The percentage of respondents making each response is recorded in the first three columns in the table below. In a second rating task, the parent re-rates each item on a five-point scale in terms of how difficult the event was (or generally is) (‘not at all’ to ‘extremely’). The last column presents the proportion of survey respondents who considered the items a source of ‘somewhat / very much / or extreme’ difficulty, as a percentage of those who answered the first part of the PIP measure.

<table>
<thead>
<tr>
<th>Results from Participants Recruited Through Hospitals</th>
<th>Sometimes, Often, Very Often</th>
<th>Never, Rarely</th>
<th>% Experience Difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arguing with family members</td>
<td>51%</td>
<td>49%</td>
<td>22%</td>
</tr>
<tr>
<td>Speaking with doctor</td>
<td>48%</td>
<td>52%</td>
<td>30%</td>
</tr>
<tr>
<td>Feeling confused about medical information</td>
<td>52%</td>
<td>48%</td>
<td>17%</td>
</tr>
<tr>
<td>Talking with the nurse</td>
<td>52%</td>
<td>48%</td>
<td>17%</td>
</tr>
<tr>
<td>Disagreeing with a member of the health care team</td>
<td>11%</td>
<td>89%</td>
<td>43%</td>
</tr>
<tr>
<td>Feeling misunderstood by family/friends as to severity of illness</td>
<td>52%</td>
<td>48%</td>
<td>36%</td>
</tr>
<tr>
<td>Speaking with my child about his/her illness</td>
<td>40%</td>
<td>60%</td>
<td>30%</td>
</tr>
<tr>
<td>Speaking with family members about my child’s illness</td>
<td>51%</td>
<td>49%</td>
<td>29%</td>
</tr>
<tr>
<td>Worrying about how friends and relatives interact with my child</td>
<td>69%</td>
<td>31%</td>
<td>13%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Results from Participants Recruited Through Charities</th>
<th>Sometimes, Often, Very Often</th>
<th>Never, Rarely</th>
<th>% Experience Difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arguing with family member(s)</td>
<td>95%</td>
<td>5%</td>
<td>54%</td>
</tr>
<tr>
<td>Speaking with doctor</td>
<td>85%</td>
<td>15%</td>
<td>33%</td>
</tr>
<tr>
<td>Feeling confused about medical information</td>
<td>79%</td>
<td>21%</td>
<td>39%</td>
</tr>
<tr>
<td>Talking with the nurse</td>
<td>73%</td>
<td>27%</td>
<td>22%</td>
</tr>
<tr>
<td>Disagreeing with a member of the health care team</td>
<td>73%</td>
<td>27%</td>
<td>34%</td>
</tr>
<tr>
<td>Feeling misunderstood by family/friends as to severity of illness</td>
<td>67%</td>
<td>33%</td>
<td>61%</td>
</tr>
<tr>
<td>Speaking with my child about his/her illness</td>
<td>63%</td>
<td>37%</td>
<td>37%</td>
</tr>
<tr>
<td>Speaking with family members about my child’s illness</td>
<td>49%</td>
<td>51%</td>
<td>43%</td>
</tr>
<tr>
<td>Worrying about how friends and relatives interact with my child</td>
<td>46%</td>
<td>54%</td>
<td>49%</td>
</tr>
</tbody>
</table>
**PIP: Implications for the MediStori**

In terms of implications for the MediStori, the PIP measure demonstrated that communication with family members and with health care providers is a source of difficulty for a significant proportion of the families who took part in the study. Of particular note are relatively high percentages of participants who found family arguments, misunderstandings and family member interactions with their children as difficult. In relation to communication with health care professionals, the most salient finding is that nearly 30% experienced confusion with medical information as a source of difficulty. These findings suggest the need to examine how the MediStori can be used to help with communication about illness and treatment within families as well as using it to dispel confusion and promote effective communication episodes.

**Perceptions of Health Care and Family Support**

Two internationally validated measures of parental satisfaction with health care and perceptions of difficulties were included in the survey. With regard to the MAPS measure, the items of particular interest were ‘communicating with health care providers’, ‘really listening to your opinions’, and ‘amount of information and guidance’. The MediStori could enable parents to engage in more satisfying two-way conversations and collaborations with health care professionals around children’s needs. The PIP measure demonstrated that communication with family members and with health care providers is a source of difficulty for a significant proportion of the families who took part in the study. Of particular note are relatively high percentages of participants who found family arguments, misunderstandings and family member interactions with their children as difficult. In relation to communication with health care professionals, the most salient finding is that nearly 30% experienced confusion with medical information as a source of difficulty. These findings suggest the need to examine how the MediStori can be used to help with communication about illness and treatment within families, alongside using it to dispel confusion and promote effective communication episodes with health care providers.

**Did MediStori help improve communication & engagement?**

Almost three in ten (29%) as recruited in hospitals indicated that the MediStori had an impact on how they felt asking health care professionals questions about their child’s health condition and / or medications, whereas 37% from charities indicated same. Nearly 80% in both sites indicated it had an impact on how they communicated health care information to health care professionals. Nearly three-quarters (74%) of those recruited in hospitals said that it was not hard to take the MediStori out in front of health care professionals. Fifty per cent of those recruited through charities said it was not hard to take the MediStori out in front of health care professionals, whereas 7% said it depended on who the person was; 3% said it depended on what the topic was about and 40% said they didn’t take it out in front of health professionals.

“I took the diary and also medication list.”

“I didn’t need to but would have no problem because it looks professional.”

“I think it showed them that I was prepared and had questions. They took me more seriously.”

“I use it with grateful confidence as I can look back on my notes.”
Decision Making Processes

Over half (57%) of those recruited through hospitals said that it had an impact on feeling part of the decision making process with health professionals, with 50% from charities saying the same.

“I could use my list of medication as the actual medication history as I am doing this task each day and a consultant may misread their record and having MediStori medication list to hand perhaps helps reduce risks due to miscommunications.”

“Because of the written questions I was given more detailed answers and respected more.”

“As I can track all symptoms and treatments it is easy to see what works and what doesn’t for my child’s condition.”

“At times I feel I am part of it and at times I know I have no control, this has not changed.”

“Before appointments I wrote down questions I had for doctors/physios so instead of trying to think what I needed to ask I had it written in front of me.”

“I've not been able to get to a decision making process with health professionals yet! It's very frustrating for me. I don't see where the MediStori would make any difference. It does save me time in appointments so there is more time for discussion vs. Transfer of info/history.”

These benefits were illustrated by examples given:

Here one parent discusses being able to be more active in decision-making due to being able to review their child’s treatment history:

“As I had results all in one place, when the doc suggested a new option I was able to fully inform myself on all previous steps and suggestions and be able to have a fully informed decision.”

This parent was able to use the MediStori as a prompt to ask questions and check on test results:

“Found it easier to remember when tests were going to be back. I’m currently pregnant and baby brain bad so I put a note in ‘tests back on such a date’ – asked this question last time so I remember to follow up on them more.”

This parent describes the effect of having access to information in one place as empowering:

“I have more communication with our doctor as now I can remember everything using the help of MediStori.”

In this example, the MediStori was used to build up information that was shown to the doctor for input:

“Keep track of the particular complaint of my child. I had a proper log to show the doctor.”

“When you use the MediStori it’s easy to make reference to previous appointments e.g. injection because it’s all together in one book.”

References to the utility of MediStori suggested that it helps people achieve the high level of organisation matching their personal preferences:

“I liked the idea of having a complete medical history etc., for my children at my fingertips along with something I could give to whoever was looking after my children and have all the numbers medicine/allergies there so everyone has some information.”
Quality Improvements

It was extremely important to learn what changes participants wanted made – and for the team to be able to action on this, in line with quality improvement PDSA good practices. All participants were asked what changes they would like to make to the toolkit, the way it was delivered to them or any other observations they had. The word “None” was cited 5 times, meaning participants would like no changes to be made to the MediStori. Singular comments said they would like it: bigger; different colours; smaller; use lighter materials; if used to store records A4 more appropriate; different colours for each section or tabbed for easy identification/access.

Observations of MediStori After Use
Irrelevant of whether comments, opinions and thoughts about the MediStori were good, bad or indifferent, or even if the participants used it themselves, nearly all of participants recruited in hospitals still said they would like to see the MediStori rolled out nationally (97%) and all (100%) of them would refer the MediStori to a friend. This recommendation remained the same with those recruited through charities with 100% wanting MediStori rolled out nationally and 100% of them referring the MediStori to a friend.

As at Time 1 responses, positive comments and evaluations of the MediStori were noted post use:

“I love it, it is an essential medical book for everyone. It makes hospital and GP visits a breeze”.

Benefits of using the MediStori were identified as giving a prompt to action:

“Good as it helps to remind you of things to do.”

Keeping records and having information available across different clinics:

“Found it brilliant that when my son received his medicine we marked it off so everyone knew what medicine he had been given and when also he has appointments next week in different hospital and have questions and notes done since it’s a new doctor so he doesn’t know my child.”

Offering support after becoming a parent:

“Fantastic idea especially for new born as it is hard to remember everything.”

There were a limited number of negative first impressions recorded. For instance, two respondents used the term ‘bulky’. These comments will help when redesigning the product. However there were more positive references to the size of the MediStori (e.g., “small to fit in handbag”). One person referred to needing more time to learn about the MediStori (“I don’t know much about it will have to read a bit more into it”). Another person suggested that, although “positive”, the MediStori “may be more appropriate from birth”, while a different person questioned “will you have it when needed for example to A&E”.

Minimate Limited©2016
Constructive Statements after Use

Future Health Information
Participants felt that MediStori could be helpful for future generations.

“As above, a super all in one medical record for the family, and a great way to pass on medical history to children as they grow up; particularly as they may have inherited the same rare disease.”

The Team
Person centred care shows through the support team

“The people behind this are very obviously extremely caring and experienced people with the patient’s best interests at heart.”

Persons Life Cycle
It was interesting that people thought of the MediStori as more helpful for a “family, child or older person” as it seems that they didn’t think the health records were about them regarding their own personal health history, or that these health records would benefit them personally as they got older.

“I think for older people and families it’s a great way to keep track of everything.”
“I think it is a good idea for some sections of the healthcare population, perhaps not for all.”
“I really like it except for the child/family sections which are completely unrelated to me.”
“There does seem to be a lot given over to children and babies that are not applicable so that makes it a bit bulky. Maybe that section could be separate and included with packs as an extra for those who want them.”

Confidence for Carers and Patients
The emotional, social and physical impact of having or caring for someone with a chronic condition can be just as hard as the management of the medications, appointments or symptoms.

“I am so glad I was accepted into this trial, the MediStori has allowed me to be more confident in keeping track of my daughter’s medications and appointments, rather than keeping bits of paper everywhere or having to double check with my husband or even daughter about medications and if she has taken them that day or about appointments. It has helped me feel more confident in my taking care of my daughter.”

Better Communication & Recall
Leaving a clinic appointment and forgetting what you asked can be frustrating.

“Very good to list medication and keep a log - plus prompt heading on asking questions at next appointments.”
“It will be good to be able to refer on past medical history when needs be.”
“I love it I still have not used all the sections yet I use the appointments notes and meds sections mostly but I will use the other sections in the coming months.”
“It is so easy to forget stuff and even length of time that you are on a certain medication etc.” “It’s great to have all the information stored together.”
Some thought there was too much detail in the MediStori...

“I don’t think I need something so detailed right now.”

“Very useful and user friendly - only issue is that it’s quite heavy to carry around.”

“Cut back on wording throughout - remove unnecessary information (i.e. things that are not related to health such as car things, packing lists, etc.) - keep some things in fixed booklet style, and other things that are expandable as time goes on.”

“A little easier lay out, when I first looked at it I was a little overwhelmed.”

“Not sure about person info e.g. CV I would not use this as a diary for everyday needs as I keep a Filofax. I would like it to be A4, I think it is easier for writing and reviewing. Also letters and reports could turn be stored within.

2 extremely minor things. It would be nice to have somewhere specifically to put a pen other than on the medicine calendar, as that’s not always in the folder. Also, with regard to the medicine calendar, it would be good if it didn’t go as far into the slot as it does, as when it slips down too far the clasps in the binder is scoring the bottom of the calendar. But that’s being really picky.”

Others thought there was too little detail in the MediStori...

“The size is not adequate for storing all the information I keep at hand for appointments. The plastic sleeves are a good concept but grossly undersized for someone with a chronic illness. (In just in one year, I have an A4 folder 8 cm thick -- and that doesn’t include CDs, receipts, photos or research.) I do see the MediStori as a good addition to my folder of records -- something for the day-to-day management of my care, but not as the tool I use for long-term-record keeping. I do like having everything in one place, prepared for any appointment. It is a good idea, but I found it too much to be writing in the medicine memo when three members of the family are taking medication a few times a day. It is very labour intensive to be writing up each of their meds every day. You also go through a lot number of sheets of paper.”

“I did not find it easy to use. I felt there was not enough room to document all of my history. I found it hard to recall my detailed medical history to put into it as I have had a lot of contact with healthcare and a lot of different tests in the both recent and distant past. It would be a good tool for someone beginning their medical history.”

“More space to write things like special requirements, allergies, risks, long term, chronic and past illnesses. In the vaccines section, name each vaccine rather than “6 in 1” because the vaccines given vary and so do the ages cos many users of this will have been born at different times and there was only the “3 in 1” when I was born and we didn’t get HepB, Pertussis or HPV jabs.” “More list space on the investigations, and diagnosis pages.”

“The sections to write in are quite small. (Medicine memo, mother’s health during birth etc.) The MediStori calendar is too small to actually input important information. Extra-curricular activities seems to take up a huge amount of space by comparison, and isn’t necessary. I have no interest in putting photos and ultrasounds in a medical notebook, as they are more like emotional keepsakes, but perhaps others find this suitable. Also: the plural of GPs does not have an apostrophe!” “A calendar book with more writing room would be great!”

“More list space on the investigations, and diagnosis pages.” “More room to write in information.”

“Perhaps maybe a section for an exercise diary write things like physio could be tracked and progression and improvements are easily visible.”

“Personally I find the meds part hard to use. There is not enough room for some of my info like investigations, are additional pages provided. I am not sure whether I like the person info being included like CV, employment history.”

“It should be available with extra tailored booklets that you can add to it as necessary and they should not be expensive.”
And many thought the MediStori was just right!

"Quite sturdy to stand the test of time and small to bring with you - well done."

"It is one of the most useful medical devices I have ever seen! - I presently have a full large drawer of hospital notes which would not fit into one lever arch file and this is superb in condensing what is important and a great size to carry around when required! It would fit in my handbag. I like the fact you can remove the relevant sections as required to take with u - for e.g. the questions for consultants section. Perhaps one small clear folder per file would be helpful to include to aid in carrying one section around to protect it in your handbag."

"Brilliant idea with all baby all milestones are huge and I love to keep dates etc. of milestones. Great for medicine and to hand over to our home care nurse."

"It provides an easy access to all my child’s medical information. I have their doctors and contact details from each hospital and all appointments in one place."

"It will make it easier to keep all family’s health information together to cross reference members of family health information especially with medication allergies, dates of clinics and family medical history."

"Great to be able to keep all the different info in the one place and have space for important letters and things which I tend to need to inform every professional of."

"For me personally to have all the important medical info in one folder is handy to bring to appointments/ have to hand when needed."

Privacy Issue
It is important all users feel that their information is safe.

"There is a privacy issue regarding all information collated in one place currently. I.e. mother’s maiden name is not essential for MediStori, but with this along with all other info is enough for someone to effectively steal your identity. Some sections were too small to write in effectively, which made me wonder about whether a bigger folder would be helpful. Depends on whether it is a source of info or something you carry with you. Overall I think it’s an excellent tool, and I can’t believe something like this hasn’t been done before."

Future of MediStori
As stated earlier, many would like to see an electronic version.

"Progress to a digital version."

Great idea, even better idea to go digital with it, but only if the hospital has a way of clicking into that information too so when you are admitted, they click on your name or chart number and all your information should be there at the touch of a button. The hospitals, GPs and pharmacies who have or are promoting this product should all have a linked computer system so they all have access to your medical information. any of the information you add to the app could be uploaded to the cloud and shared among the hospitals, GPs and pharmacists so all medical professionals have access to the information already on your medical file from the doctors side and the edited/added information you have added to the app. this would be in an ideal world, could be awesome to integrate the MediStori like this."

"I would definitely like an electronic version of the MediStori. I think it is a necessary part of the product to ensure it is used and not lost. I recently travelled to the UK with my daughter and despite having filled her MediStori - I forgot it! I was very annoyed with myself but it would have been great to have online access to the record."
Specific Add-Ons (Future Developments)

Additionally, 69% of participants said they would want specific diaries for their needs.

“A bigger calendar.” “E.g. a pain diary for my joints, a food and weight diary for my gastrointestinal problems.” “A few pages with space to put in your child symptoms/needs etc. relating to a diagnosis or medical condition. Blood results booklet. Physio diary.” “I don’t think these things need to be disease specific.”

“Pain charts for starters diet tracker digestive tracker (like IBS symptoms) tracking other symptoms carbon copy for doctor notes -- I take 2 lists of my questions to every appointment and give one to the doctor -- that way the record is more likely to reflect what was discussed, and the doctor can keep track of my concerns before rushing me out the door!”

“Good to have everything in the one place. Would need more blank pages to tailor the system to suit your own needs. Or maybe more columned pages that you could title your own way.”

“My daughter has cluster headaches and was only diagnosed two weeks ago. For the last six months I’ve been keeping a diary of symptoms. I had to use an A5 notebook as the diary from the migraine association didn’t have enough space for symptoms, duration of these, what meds taken and how often.”

“There are so many illnesses out there I do not think this would be possible. My daughter has regular high temps and have to record temps 4 times a day for rheumatologist. It would be great to have a temp charting sheet as well.” “E.g. pain diary, fatigue/energy diary, food diary.” “Great idea - a symptoms section would be nice.”

“Side effect tracker for meds and information on other related illnesses. For instance tummy pain or diarrhoea in the condition we have may indicate coeliac diseases as both are autoimmune diseases.”

“Our condition is effected by weather. Would be good to keep track of daily air pressure and humidity and what body parts are effected when it is raining, foggy, humid etc. At present using a diary to keep notes.”

“Pain location and type diary (mark an outline of a body and face) pain scale diary diet diary overlapping with symptom diary BP and heart rate diary periods/hormone diary temp medication diary??? Rough notes for upcoming appointments pages to guide appointment conversations (I have a sample somewhere) at -a-glance calendar of upcoming appointments.”

“It’d be good to have a section where you can write all previous interventions and medications tried and what effects and side effects they had so you don’t have doctors repeating meds you tried before especially if they were unhelpful.”

“It should be available with extra tailored booklets that you can add to it as necessary and they should not be expensive.” “Just a little one - to make the calendar space a bit bigger for writing in.”

“I would like more, clear plastic pockets in it.” “Do not feel the need for the living and social section, I will not use that.” “Make it a little but prettier maybe pink and flowers on the cover for a little girl.” “As mentioned above a section where diabetics can track their blood sugar levels.”

“Size, flexibility of adding sections as needed, reducing what’s in each book -- breaking that into multiple sections like a filo-fax, adding room for consultant letters, photos, daily records, pain trackers, things that prove what’s happening at home, vs. what’s seen in the clinic at that day.”

“I think there needs to be sub divisions in the diaries. The one in the pack is more suitable for babies and young children. Unless they are being given to everyone at birth, then a different one tailored for the older child would be more appropriate for lots of people like me.”

“I’d like a separate book, or dedicated section in the MediStori booklet (personal health record) for symptoms and a food diary. Medicine memo - step 6 says “column to the right under important notes” - this seems to be the column to the left rather than right.”
So What Did Health Care Professionals Think?

An online questionnaire was sent out to 62 health care professionals from various different fields, of which eleven responded within a six-week time frame (18% response rate). These participants all work in the public, private, business, voluntary and charitable arenas. Seventy three percent came into direct contact with patients as part of their main job role. Seven of these participants were based in Ireland, with four living outside of same – three of whom in the UK.

These health care professional job roles included:

- Nurses
- Pharmacists
- Superintendent Pharmacists
- Paediatricians
- Quality Improvement Coordinators
- Charity committee members
- Patient Organisations
- Advocates
- Managers
- Leaders
- GPs

Some gave information about their specialties:

- Paediatrics
- Organisational behaviour
- Long term conditions
- Midwifery
- Youth
- Overall health care strategy

Initial Perceptions of MediStori

Nearly half (45%) found out about MediStori through Olive making direct contact with them or their team; with 18% saying they heard of it through word of mouth; 18% saying it was at a conference or event and a further 18% saying it was through other means. All of the participants were very interested to learn more when asked about their level of interest.

Reasons given were:

“In my role I meet families all the time who when questioned do not know the names of people their child attends in other hospitals/community services etc. A tool that will enable parents to have all information to hand would be incredibly helpful for adequate communication.”

“I could immediately see the benefit of MediStori for patients.”
Paper vs Technology

Participants were asked upon initially learning of MediStori if they were surprised MediStori was paper based of which 18% said they were; 55% said they were not and 27% had not given thought about that aspect.

One relevant comment was that:

“Many older people would prefer paper.”

Participants were asked about their opinions on health records prior to learning about the MediStori. Thirty-six per cent said that paper-based health records should be replaced by electronic versions; 27% said they should still be used; 27% said they should be integrated or replaced with electronic versions - but only if evidence suggested such. Participants were then asked about their opinions on health records after learning about the MediStori. Dropping from 36%, only 9% of participants felt all health records should be replaced electronically with an increase from 27% to 36% of those stating it should still be used and an increase of 27% to 46% saying it should be integrated or replaced with electronic versions - but only if evidence suggested such.

“For healthcare institutions we should have resources to be electronic. Not all parents will have access to electronic or perhaps the knowledge/interest to use electronic & paper based will be preferable. I think both options should be offered.”

“Wi-Fi is not accessible to the public the hospital so patients would have to use paper while in the hospital as inpatient or for appointments.”

Nearly all (89%) of the participants said the MediStori should be made available in both electronic and paper-based versions, with 11% saying that it should be available as a paper-based version.

“It should be in the ‘control’ of the patient/carer so unless they have sole access to the electronic version, the paper version is probably best suited to most people (until we all carry smart phones for all our data recording!)”

“Many people do not want electronic formats, especially elderly. However they have a great advantage for people who are open to them in that data completion can be automated saving a lot of time.”

“Electronic and paper based for the next few years until we have the IT in place to roll out it effectively.”

“Some people prefer to go online. Ironically I am doing questionnaire because it is online and on my smart phone which I have on me all the time. I don’t think I would complete a paper survey and then send it back by post. So why would I want a paper based record. However I realise there are patients who prefer paper base versions too.”

Nearly four-fifths (78%) of participants said they would call the MediStori both a Self-Management & Personal Health Record System, with 33% saying a Self-Management Support System and 22% saying a Personal Health Record System.
Perceptions of the Promoter

Seventy per cent of participants had seen Olive give a presentation of her work.

"Excellent, very good communicator, personal story is a powerful way to show the value of MediStori."

"She is really excellent and speaks as a service user, a parent and also has the insight of a health professional from the point of view of how the health service works. She is very passionate about this PHR and the evidence available from the pilot studies of the benefit to patients."

Seventy per cent were very satisfied with how Olive demonstrated the MediStori to them when meeting her on a one to one with 10% saying they were satisfied and 20% saying they were somewhat satisfied.

"Olive is very passionate about MediStori and I understood her presentation as I have a pharmacy background. I think a simple, factual, short presentation i.e. perfect the elevator pitch for patients with no medical background, would be useful. Maybe this had been achieved now as it has been a long time since I was first presented with MediStori."

"Olive simply shines and emanates kindness - Her passion is palpable!"

All participants said that they felt Olive was very interested/interested to learn more about their work.

"Olive is very interested to know how MediStori may be adapted to meet the needs of patients in all different areas."

Sixty per cent of participants said that Olive was very open-minded about their feedback and suggestions with 30% saying she was open-minded and 10% saying she was somewhat open-minded.

"All comments made were taken on board and considered with the best interest of the patient and professionals always to the fore."

Ninety per cent said that Olive was very knowledgeable of the product and how best it could be used and delivered, with ten percent saying she was knowledgeable.

"How best to deliver still needs to be clarified, there needs to be a business model - either retail MediStori like a Filofax and market to hospitals and pharmacies, or try to get HSE to allow MediStori reimbursable status as a medical device."

"She is expert on this product and all the potential of it to support patient’s self-care and management."

All participants said that her personal experiences positively impacted on the development of the product

"She has developed the product from the service user point of view which is really excellent."
Perceptions of the MediStori Toolkit

All participants said that when they learned that the MediStori was developed collaboratively with patients, carers and health care professionals together that this was an appropriate method to develop a product, project or initiative.

“It is essential to develop with all stakeholders involved. It remains to be seen if pharmacies and wholesalers should be part of that stakeholder group from a sales and distribution perspective.”

“I think this is a template for how health care services and information systems should be developed.”

Ninety per cent said they felt patients, carers or service users should be involved in the design, development and delivery of projects, products or initiatives in health care with ten per cent saying it would depend on the project or initiative.

“It is important to involve patients and service users from the beginning so that they feel ownership of the development and can fully impact on the process of development which will lead to a more suitable end product.”

Fifty-six per cent found the MediStori and the way in which was promoted as very innovative; with 11% saying it was extremely innovative and 33% saying it was somewhat innovative. Two-thirds (67%) rated the design of the MediStori as high quality, with 33% saying it was very high quality. Fifty-six per cent said all sections of the MediStori would benefit persons they provide services to; 22% was not applicable and no one said any section would be of benefit to service users, for instance:

“Medication management and clinic appointment sections seem most beneficial.”

All of the participants said there was no part of the MediStori would have a negative impact, but some constructive comments were made:

“Detail may overwhelm some.”

“Patients do not need to complete all sections if they do not think that they are relevant to them.”

Forty-four per cent said they would like to see a specific section included for the people whom they provide services for, with 33% saying they would not; 11% saying they could not think of any further material to include or that it was not applicable to their work.

“I think you should offer chance for it to be modified for different children with different conditions.”

“Culture specific groups.”

“Have discussed with Olive that E-Health Promotion - screening information could be included.”
The participants were asked what they liked most about the MediStori:

“Comprehensive; convenient size; patient led; can be added to or reduced as per patient needs.”

“The medication history part, the overall look and design.”

“The level of detail in it and it’s a one stop resource.”

“Gives patients and carers control to manage their own health care.”

“Its simplicity - once people grasp what it is and what it could do for you, it becomes easy to use it.”

And what they liked least...

“I haven’t used it enough to be very familiar with its lay out yet.”

“Initially I think some people may see it as too much work.”

“Only one colour could be a problem if it takes off. Kids like to personalize things so maybe do a range of covers for them and places where they can put names on the outside.”

“It is a little big to carry hence the need for electronic options.”

“Wondering who is eligible for one.”

“Its size means it is quite bulky and could put people off.”

They were asked what changes most would improve it...

“Content is very good already.”

“Chance to make it adaptable to different circumstances.”

“Perhaps reducing the weight of it, if possible and a mini section to carry around in handbag on a daily basis.”

“As other healthcare information is developed documents should be A5 size to fit in the file.”

“It would be great to see it as an app - and simplified.”
Perceptions of Patients and Carers Needs

Participants were asked if they felt patients and carers have issues with...

- Storing their health information efficiently (56%)
- Recording their health information efficiently (67%)
- Communicating their health information to others and health care professionals efficiently (56%)
- Managing their medications efficiently (67%)
- Managing their health condition efficiently (67%)
- Managing their health care appointments efficiently (56%)

Related comments included:

"Healthcare professionals often do not consider the impact on patients and how they manage all their various care aspects. Most only see the interaction as one to one, that is their own interaction with the patient and fail to consider how many others may be interacting at the same time, or in the case of a mother or carer, how many interactions they are managing for other people too."

"We still have quite a lot of DNA's and medical errors so MediStori can help reduce these issues. Healthcare is very complex and people have less "free" time to manage their health. Many fall between the gaps. People rarely ask why - especially the patient."

"Provides an ideal place to keep everything, perhaps an instructional YouTube video on how to incorporate using it into everyday routines would be useful. Getting people to use it is a great way to get them engaged and participating in their care and to give them more power and control."

Participants were asked did they feel the MediStori could help patients in a number of areas.

89% of health care professionals said that all of the below statements could help patients:

- Help patients and carers store their health information more efficiently (44%)
- Help patients and carers record their health information more efficiently (44%)
- Help patients and carers communicate their health information to others and health care professionals more efficiently (33%)
- Help patients and carers manage their medications more efficiently (22%)
- Help patients and carers manage their health condition more efficiently (22%)
- Help patients and carers manage their health care appointments more efficiently (22%)
- All of the above (89%)
Cost Savings

Ninety percent said they felt the MediStori could save money, with 10% saying they were unsure:

“Improved compliance with everything - appointment attendance, taking medications, vaccinations - all would save money. At admission to hospital, having it along with you could prevent medication error. 90% of patients have at least one error in their admission medication profile and 6% of patients have errors that are potentially harmful. A harmful medication error suffered while in hospital adds 4 days to length of stay and conservatively will cost an additional €1,800 per event. Having a MediStori to allow accurate history and admission prescribing could prevent this.”

“More efficient if patients take medication as prescribed and attend their appointments. Would save admissions and reduce waste of clinic slots”

“If used correctly it will reduce costs through a number of ways. Improving patient outcomes and giving more time to treat for doctors and health professionals - can see it being very useful and cost effective for chronic illness.”

All (100%) of participants said that they thought that if a patient or carer had a MediStori to hand it could potentially help health care professionals save time, resources or money:

“Staff in area like ED or Clinics could assess patients more accurately if they had all the patients’ up to date information in regard to medication and medical history. This would include investigations which may have been carried out at another hospital. This would save duplication.”

“It will save them time as they’ll have the record beside them so they can make a clinical decision based on factual evidence.”

“Giving the patient a better outcome while saving time and money.”

Thirty-three per cent said they felt patients and carers should pay for the MediStori directly with 44% saying they should not have to pay directly and 22% saying they were unsure.

“I think that people place more of a value on something that they actually pay for. Giving it for free could result in wastage which would be a shame.”

“I would give it free to PCRS card holders but charge DPS patients. Look for it to be allowable against the DPS monthly threshold.”

“Should be free.”

“I think this would be a barrier to its promotion and some people may not be able to afford it.”

“People value things more if they pay for them. It should not be a lot (so not full price) but we all benefit from sense of ownership.”

All health care professionals said they would recommend MediStori to patients.
Model of Implementation

All participants said it was important that the MediStori was given to patients and carer by health professionals (44% Extremely Important, 11% Very Important, 44% Important)

“It could be supplied direct but the advantage of engaging hospitals, doctors, nurses and pharmacies is that you have a better chance of it becoming integrated into the routines of care. This does not mean they all need to supply it, in fact as I said before I would suggest it be distributed through pharmacies and GPs could prescribe it on PCRS as a medical device – need agreement on this. I would use a large wholesaler to distribute and perhaps make a deal with one of them - this is normal commercial practice for medication supply. ”

“Much more likely to use it if given by Healthcare Professionals and full potential and reasons for each section explained. Also important that Healthcare Professionals ask the patient about it and encourage them to bring it to their appointments.”

Referrals & Recommendations

All participants said it would likely they would recommend the MediStori to their team, colleagues or peers (67% Extremely Likely, 33% Very likely). None had barriers to recommending it.

“I am promoting this actively with staff in my hospital group and feedback has been really positive.”

“I love the MediStori and there is no doubt in my mind it benefits patients. I would like to see it in app format and possibly simplified.”

Ninety per cent were likely for themselves or their team to recommend the MediStori to patients or carers.

“I can only speak for me and not my team!”

“Many CNS have indicated that the want to introduce MediStori and give it to their patients.”

Participants were asked what would make them more likely to recommend it:

“If there was widespread information on its benefits and it was readily available throughout the health system.”

“A clear system for distribution, pricing etc. - for an electronic version, integrated into national systems that are on the way - using national product catalogue, national health identifiers, etc.”

“Continue to Co-Design MediStori with users carer's staff etc. “

“Good patient participation.”

“Having it as an app.”

“If patients asked for it too.”
Who Would Benefit Most Using MediStori?

Participants were asked when they think about the MediStori in relation to the people they provide services for, do they:

- Think it could positively impact on managing their health condition & information (67%)
- Think it could negatively impact on managing their health condition & information (0%)
- Think it could positively & negatively impact on managing health condition/information (22%)
- Feel unsure if it would impact on managing their health condition & information (0%)
- Not applicable (11%)

Participants were also asked where they felt the MediStori would be best promoted:

<table>
<thead>
<tr>
<th>Setting</th>
<th>% of Respondents</th>
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</thead>
<tbody>
<tr>
<td>Hospitals - Acute and Chronic Conditions</td>
<td>100%</td>
</tr>
<tr>
<td>Maternity Hospitals and Units</td>
<td>89%</td>
</tr>
<tr>
<td>GP Practices and Out of Hours GP Service</td>
<td>89%</td>
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<tr>
<td>Pharmacies</td>
<td>89%</td>
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<tr>
<td>Nursing Homes and Respite</td>
<td>33%</td>
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<tr>
<td>Crèches and Schools</td>
<td>44%</td>
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<tr>
<td>Rehab and Rehabilitation</td>
<td>56%</td>
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<tr>
<td>Mental Health Facilities</td>
<td>67%</td>
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<tr>
<td>Charity &amp; Associations</td>
<td>67%</td>
</tr>
<tr>
<td>Supported Community Care</td>
<td>67%</td>
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<tr>
<td>Public Health Nurses and Clinics</td>
<td>89%</td>
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<tr>
<td>Primary Care Centre</td>
<td>67%</td>
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Nearly 80% said they feel the MediStori could benefit people with chronic conditions/health problems:

*I don’t think ‘healthy’ people would be bothered with recording events unless it was part of a national recording system/Healthcare record.* *Could include vaccines, health promotion and health screening.*

*Vaccine records, preventive health appointments etc. - but you should focus on those with need not spread your resources and your message too thinly.* *Health promotion.* *Creates self and family health awareness.*

*Facilitates research.* *Future health passport for individuals, families, communities and generations.*

*Too much information and recording of data can be a bad thing for some people.*

Health Care Professional Evaluation Summary

All of the health care professionals, across a range of backgrounds, thought that the MediStori could potentially help save time, resources or money. All felt that it was appropriate to develop the MediStori collaboratively with patients, carers and health care professionals together. All did not identify any part of the toolkit as negatively impacting on service users. All identified that it is important that MediStori is given to patients and carer by health professionals and would recommend MediStori to their team, colleagues or peers. When asked where health care professionals felt MediStori should be promoted to patients, carers and healthy population, all agreed that it should be in hospitals for those with both acute and chronic conditions.
Does MediStori Meet Needs and Expectations?

The first impressions of the MediStori were overwhelmingly positive.

The MediStori was initially perceived very positively by all of those who took part in the study. Nearly all of the participants rated the MediStori positively on these dimensions: 92% liked the size of the MediStori; 95% liked the colour of the MediStori; 97% thought that the MediStori was a good idea; 96% thought it might help them with their specific needs; 100% thought it was a good idea to have it promoted in the hospital setting. (MacNeela, 2015). 72% said they would like to see the MediStori available through outpatient departments in hospitals, GPs, pharmacies and charities at the same time, in that order of preference.

The keyword analysis of the reasons why families were taking part in the Pilot Study highlighted terms like ‘good’, ‘helpful’, ‘medical records’, and ‘interesting’. This reflects an emphasis on managing information and records more effectively and perceiving the MediStori as having the potential to help them. In addition, particular information management issues were associated with several of the medical conditions arising from complex care needs. The most common keywords were ‘good’, ‘useful’, ‘helpful’, and ‘great’. The positive tone in the qualitative free text comments made by all participants was continued in the ‘yes’ / ‘no’ survey items. Over 90% recorded that they liked the size and colour of the MediStori that it was a good idea that might help them with their specific needs, that the MediStori had been well demonstrated, and that it was a good idea to demonstrate it in a hospital setting. Nearly 80% said they would like to see an electronic (‘app’) version of the MediStori also – not instead of. In addition to the positive evaluations made of the MediStori, there were useful suggestions for revision and improvement. It should be noted that different levels of information management may be required depending on the complexity of a particular family’s health care needs. The number of children, type of condition, degree of complexity of medical care and medication regime are all likely to be influential factors in determining how many features of information management a family would need. The references to wanting to tailor the MediStori to an individual family’s needs were notable and highlight the potential to individualise the MediStori (in keeping with the person-centred philosophy).

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 child’s 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 child’s medication.
Information Management Needs and Practices

At Time 1 of the survey, just over half (55%) of all of those involved in the study, were either taking or giving, more than one medications. Sixty one per cent reported having had a difficulty remembering to give the medication at the required time. A similar proportion reported difficulty in remembering if the medication had been given and in forgetting to give a medication on time. In all, 81% of participants who were either taking or administering medications to others experienced medication-related difficulty. Additionally, the majority of participants (82%) said they did not receive a medical device in a hospital setting to help them manage their own or others medications. Of those that said they did, they included pillboxes, medical diaries and conversations with hospital pharmacists. Very few of those recruited through hospitals were given a method or device to help manage their children’s medications. Two reported having been given a diary for medications, one a peak flow device and another said they had received a timetable of what medications to give and when they should be given. (MacNeela 2015)

Forty three per cent said they wrote down notes on medication names and when it has been administered. A total of 84% of participants recruited in hospitals said they write down questions to bring to their next appointment, with 96% from charities saying the same. Nearly 90% in both groups kept information together about hospital / GP letters, test results, appointments or receipts in one place at home. Seventy five percent of all participants reported that it was hard to manage and remember health care appointments. Nearly all of the participants (84%) from the hospital sites reported having a difficulty in recalling medical information at times, such as prescriptions, visits to the GP or hospital, or medical history details, with 67% using charities reporting same. One third (33%) of all those recruited had occasion to contact a GP or PHN to recall past vaccinations. The vast majority (74%) still had a vaccination booklet and 56% were using the booklet. Over a quarter had logged other vaccinations (e.g., for flu, tetanus, or travel).

Just over a quarter (27%) were using a diary or other information management system for health care records, and just under 15% had received any kind of personal health record from a health professional. Current methods were usually hand-made and informal, such as keeping letters and appointment records in an envelope or folder. 25% of the participants said that they maintain a personal medical record for themselves or family members. Nearly 92% of those recruited online said they felt they were given enough information from the team. Twenty five percent said that would have found it easier if it were shown face to face, with 69% saying they wouldn’t; leaving 6% unsure. Nearly all (96%) liked the way the MediStori was demonstrated to them.

Over 80% in both groups said they would like to see an electronic version also. 98% of participants said that they felt the MediStori could help in the future with their specific needs. 69% of participants said they would want specific diaries to help with their needs. 51% said there were changes they would like to make to it and 36% further commented about the MediStori.
MediStori – Help or Hinder? Key Learnings

This paper has shown how 100% of patients and carers stated that they would all like to see this one project rolled out nationally in Ireland and that they would all refer it to a family or friend. All participants thought it was a good idea to have the toolkit promoted in the hospital setting, with 98% stating they thought it was a good idea to have the MediStori promoted through charities online too. Over 80% of participants said they did not receive a medical device in a hospital setting to help them manage medications, even though 95% of those who were taking/giving medications recorded one or more difficulties with medication management.

Over 90% of all participants rated the MediStori positively on the dimensions of size, colour and demonstration. Nearly all (93%) used the Medicine Memo to write down their medication and the times the medications were given, with 100% of those who responded indicated that it was a good idea to have the MediStori to manage their medication.

Prior to using MediStori 75% said they found it difficult to remember what time to take or give medications, while only 17% said the same after using the MediStori. Other encouraging improvements included the percentage of respondents who found it difficult to remember if the medications had been taken/given, medication administration medication on time, forgetting to give/take medication, taking/giving the correct dose of medication.

All of the health care professionals who took part in the study thought that the MediStori could potentially help health care professionals save time, resources or money, and that professionals should be involved in introducing patients or families to the MediStori. All of the professionals would recommend the MediStori to their team, colleagues or peers. Collaboration is the key to ensuring patients and carers use this, or any other type of self-management toolkit. The MediStori should be used in conjunction with other products/services to manage health.

The MediStori can (and should) be used in conjunction with many of the toolkits already available. The fact that the MediStori is paper based distinguishes it from medical apps already available, and the vision is to integrate self-management supports for end-users, through promotion of it in hospitals and primary carers. To achieve this, PHRs need to be recommended by health practitioners and support groups need to know what to recommend. It is important to work with key stakeholders within both public and private sectors to have the MediStori available at outpatient clinics, at discharge level and through pharmacies. The toolkit itself and the way in which it is delivered by health care professionals can help with all of the main issues as stated at the beginning of this document: Patient Centred Care; Informed Decision Making; Patient Engagement; Integrated Care; Recognition of Carers; Health System Objectives; Self-Management; Unhealthy Competitive Cultures; Health Service Reform; Poverty and Health Status; Digital Divisions; Disease Grouping; Medication Non Adherence; Cultures of Blame; Readmissions and Communication Breakdown.
MediStori as Patient Passport

Having information and questions to hand saves time and confusion for the end-user, as does it for the health practitioner also. Hospitals could put their own leaflets inside, as can charities or organisations such as the HSE. Having information to hand about your health may save on retesting and even readmissions – many people with chronic illnesses go between many different hospitals and many of these hospitals are not linked up and so do not have access to the patients chart. Knowing information such as when/what vaccinations your child had is often asked at the Emergency Department. If the parent does not know this information it may delay/make it more difficult for diagnosis, but other information is also often asked in these situations such as history about specific illnesses such as chicken pox or family history such as heart disease, etc. If a patient is more knowledgeable about when they last had bloods done, had an X-Ray done, or even know their results themselves, this may save on timely and costly retesting to be done.

MediStori and Emergency Situations

The MediStori is about being proactive, not reactive and having ALL of this information to hand, in particular in emergency situations could greatly reduce misdiagnosis, reduce stress and risks for all stakeholders and can increase patient safety and quality in healthcare. Emergency Departments are used a lot more at weekends and evenings normally and this then means the correct information can’t be received until the GP is in work. It is beneficial for the patient to have as much information to hand to help with a quick, and more importantly, accurate diagnosis.

MediStori and Medication Reconciliation

With regard to hospitals ringing GPs, there is also likely to be a requirement to contact the patient’s pharmacist. And this is because many people that end up in A&E either do not know what they are taking or are not able to communicate what they are taking at that time. The Medicine Memo aspect of the MediStori allows a patient or carer to note all medications that person is taking; the time they took them and the purpose of the drug. There are also handy wallets in the folder where printed versions from the pharmacy can be put also. This again, is beneficial to all end-users – the patient can get their medications written up quickly by the hospital pharmacists and it allows physicians have a quicker and more accurate insight into what that patient takes. Sometimes patients have to wait until the next day to get medications written up because the hospital cannot contact the pharmacy. There are countless reports of the many people who do not attend clinics – many of these cases are through people forgetting or not having information on who/where to cancel appointments. Additionally when patients are given a MediStori at point of care this can start the conversation about medication nonadherence and other areas of health care needs.

MediStori and Appointments

If people keep all their medical data in the one place then they have a higher chance of remembering or making contact. Both end-users and health systems benefit. If patients are also being taught to self-manage at the clinics, while waiting at appointments, then this time is being used more efficiently.
“Personal health records (PHRs) are a rapidly growing area of health information technology despite a lack of significant value-based assessment ...this PHR analysis shows that all forms of PHRs have initial net negative value. However, at the end of 10 years, steady state annual net value ranging from $13 billion to -$29 billion. (David Kaelber et al, 2008)

“The CITL cost-benefit model assumes 80 percent of the US population actively uses one of four emerging PHR architectures: payer-tethered PHRs, provider-tethered PHRs, third-party PHRs, and interoperable PHRs...the projected annual savings by model are: Interoperable PHRs: $21 billion; Third-party PHR: $16 billion; Provider-tethered PHR: up to $14 billion; Payer-tethered PHR: $13 billion.” (Dimmick, 2008)
### Can MediStori Save Money?

<table>
<thead>
<tr>
<th>Area of Issue</th>
<th>Estimation</th>
<th>Issues Across System – Waste Time, Resources, Money...and Lives.</th>
<th>Examples of MediStori Addressing This Issue</th>
</tr>
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<tbody>
<tr>
<td>A&amp;E, Readmissions and Hospital Beds</td>
<td>€800</td>
<td>There can be a higher rate of admissions to A&amp;E at weekends and afterhours because after hour GP’s may have no history on patients presenting to them and may not feel confident to treat/diagnose if they do not have enough information to make an accurate decision.</td>
<td>Nearly 80% in both sites indicated MediStori had an impact on how they communicated health care information to health care professionals. Nearly three-quarters (74%) of those recruited in hospitals said that it was not hard to take the MediStori out in front of health care professionals.</td>
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<tr>
<td>Medication Compliance and Adherence</td>
<td>€300</td>
<td>If a patient has a better understanding of their medications and has an aide to help them keep track of when they took them, as given to them at the point of care by health care teams, there is a major chance of increasing medication adherence and compliance. This has a huge cost saving as it will stop re-ordering of drugs that are not needed; help reduce readmissions to hospitals due to medication related illnesses and it can even help cure/treat the issue and prevent visits to the GP.</td>
<td>95% of those who said that they were taking/giving medications recorded one or more difficulties with the management of medication. 80% recruited said that MediStori had an impact on their management of medications. All who were on/giving medications had used the Medicine Memo to write down the medication and the times the medications were given. Similarly, 100% of those who responded indicated that it was a good idea to have MediStori to manage/their/loved ones medication.</td>
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<tr>
<td>Appointments</td>
<td>€100</td>
<td>Every year thousands of patients do not turn up to appointments costing public services millions. While there are many reasons for this, practical reasons may be down to forgetting, confusion or no transport. As patients end up in A&amp;E, readmissions and hospital beds, this can cost public services millions.</td>
<td>75% said that they found it hard to manage and remember health care appointments. After six weeks of use, eighty per cent said it had impacted on how they managed health care appointments.</td>
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<tr>
<td>Inappropriate Diagnostics &amp; Diagnosis</td>
<td>€300</td>
<td>When health professionals are unsure as to whether the patient has had appropriate/previous tests done, they can often re-test them “to be on the safe side”. This has a huge burden of cost, risk and time. This can be effectively reduced if a patient is able to tell a health care professional when and where they last had medical investigations done.</td>
<td>83% recruited said the MediStori had had an impact on how they felt in their ability to manage their own or their loved ones condition. Eighty per cent said the MediStori had helped them keep track of symptoms. About half of the Time 2 participants from hospitals filled in all of the sections of the MediStori (52%).</td>
</tr>
<tr>
<td>Phone Calls/No Link</td>
<td>€150</td>
<td>As patients end up in A&amp;E / being admitted the nurse needs a full up to date list of prescription or the patient. This usually ends up with a phone call (or 3!) to a GP or pharmacy. If the patient has their most recent prescription to hand they can reduce this wastage of time (costs of calls) etc. for both the nurse and the GP/pharmacy and can have their medications written up on time for themselves. It can prevent unnecessary admission and/or help speed up the discharge process.</td>
<td>89% of health care professionals said that MediStori could help patients/carers store their health information more efficiently; help them record their health information more efficiently; help them communicate their health information to others and health care professionals more efficiently; help them manage their medications more efficiently; help them manage their health condition more efficiently and help them manage their health care appointments more efficiently.</td>
</tr>
<tr>
<td>Communication, Decision Making, Person Centred Care</td>
<td>€100</td>
<td>It is proven that if patients are part of the decision making process; trained in self-management ; are more reassured, informed and medicine compliant then there is a high chance that they will not be readmitted for same reasons or kept in as long as a patient who is not.</td>
<td>Over half (57%) said that it had an impact on feeling part of the decision making process with health professionals. 94% filled in relevant sections of the MediStori to them and over half (52%) filled in ALL sections of the MediStori – meaning they valued this toolkit for these purposes.</td>
</tr>
<tr>
<td>GP Visits/Calls</td>
<td>€150</td>
<td>If a mother doesn’t have to ring a GP regarding vaccination records, this will save their staff time in having to do this. And reduces risks for the child. Additionally, many vaccinations are given for flu, tetanus, travel and these are often not logged anywhere by the patient or carer.</td>
<td>46% had occasion to contact a GP or Public Health Nurse to recall past vaccinations. 53% had used the vaccination section to log flu/tetanus/travel vaccinations. However, 89% reported it was difficult to recall information about previous medication prescriptions, visits to the GP or hospital, or information about medical history.</td>
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MediStori Can Save Money…and Lives.
Taking all of these separate issues into account and recognising that all patients, carers and health care professionals felt that MediStori had helped in at least one of these areas, at least once, shows that the benefit far outweighs the cost. If MediStori were to address all of the above issues for one patient a minimum estimated saving of €1900 per annum could be made. If MediStori were to address any two of these issues (of which it did for most participants) then a minimum saving for the health service of €200-€250 could be made, meaning MediStori would have paid for itself, a many number of times over.

Business Case
If MediStori helped reduce one hospital admission because relevant health information was to hand to help clinicians make informed decisions then this would be a saving. If MediStori helped increase one patient comply with a medication it could help prevent further diagnostics having to be done, another readmission and/or unnecessary use of primary care or community services - and this could be a saving. If MediStori prevented nurses and doctors from having to ring and contact GPs or pharmacies for up to date information about patients in A&E situations then this could be a saving of numerous hours every day and a saving of costs of phone calls. If MediStori could help people remember when they got vaccinations, for example, then this could reduce GPs, administrative staff and Public Health Nurses taking unnecessary calls to look up this information and this could be a saving. If MediStori enabled charities to be better promoted at the point of care by health care professionals then this could be a saving. This list goes on. MediStori has been proven to address many of these, plus more, issues.

Health care professionals discussed how MediStori could help save money:

“Improved compliance with everything - appointment attendance, taking medications, vaccinations - all would save money. At admission to hospital, having it along with you could prevent medication error. 90% of patients have at least one error in their admission medication profile and 6% of patients have errors that are potentially harmful. A harmful medication error suffered while in hospital adds 4 days to length of stay and conservatively will cost an additional €1,800 per event. Having a MediStori to allow accurate history and admission prescribing could prevent this.”

“More efficient if patients take medication as prescribed and attend their appointments. Would save admissions and reduce waste of clinic slots.”

“If used correctly it will reduce costs through a number of ways. Improving patient outcomes and giving more time to treat for doctors and health professionals - can see it being very useful and cost effective for chronic illness.”

All (100%) of health care professionals said that they thought that if a patient or carer had a MediStori to hand it could potentially help health care professionals save time, resources or money:

“Staff in area like ED or Clinics could assess patients more accurately if they had all the patients’ up to date information in regard to medication and medical history. This would include investigations which may have been carried out at another hospital. This would save duplication.”

“It will save them time as they’ll have the record beside them so they can make a clinical decision based on factual evidence.”

“Giving the patient a better outcome while saving time and money.”
Patients and Carers Show MediStori Works

Family Centred Care.

“It is going to make our life as a family much easier especially attending clinics where my husband or I may not of attended the last clinic with one of the children we have record of what is going on for the other attending and also been able to relay information that may have effected one child in the past as two children have the same condition.”

“My wife has a chronic illness and I also have health issues. I wanted to use MediStori to help us keep track of our appointments, medications and symptoms.”

“Our family has a number of health conditions with lots of appointments. We also keep a medical diary for my daughter to keep track of symptoms and side effects.”

“All of our family have medical conditions and attend different clinics which help us keep track of appointments and medical history all in one place.”

“I loved the idea of having a way of recording both mine and my family’s medical history. For me my investigations are ongoing and it is vitally important that the outcome is stored as this is a hereditary disease and it appears my son may have it.”

“It will make it easier to keep all family’s health information together to cross reference members of family health information especially with medication allergies, dates of clinics and family medical history.”

Appointments.

“I thought this is just what I need. I have never missed an appointment but I have arrived a day early. I wish MediStori was available when my child was initially diagnosed as I am sure at times there was information I did not take in from doctors and information I have forgotten over time.”

“It does save me time in appointments so there is more time for discussion vs. Transfer of info/history.”

“The meds and appointment’s sections I use all the time to help me keep track of everything. It will help me keep her current records in one place.”

“I especially like the preparation for appointments, and the calendar for appointments - excellent.

“I don’t think I could do without it now it comes with us to every appointment if we are asked about bloods meds physio OT etc. It’s all on hand IN OUR MediStori I would be lost without it now I wouldn’t be able to find anything.”

“It provides an easy access to all my child’s medical information. I have their doctors and contact details from each hospital and all appointments in one place.”
Medications.

“I found the MediStori has helped me to keep a great record of all medication I give my son.”

“I could use my list of medication as the actual medication history as I am doing this task each day and a consultant may misread their record and having MediStori medication list to hand perhaps helps reduce risks due to miscommunications.”

“I needed a way to record medicines and keep history.”

“I thought it was a wonderful idea and would be a great help in trying to keep on top of my daughter and my illnesses. I have been finding it difficult to keep track of our medications so I felt this would be the perfect thing to help us keep on top of everything.”

“I will be able to use it as reference to medication taken, any allergies from previous medications taken and other allergies, keep track of vaccinations.”

“Found it brilliant that when my son received his medicine we marked it off so everyone knew what medicine he had been given and when also he has appointments next week in different hospital and have questions and notes done since it’s a new doctor so he doesn’t know my child.”

Person Centred Care.

“I like the holistic approach to managing all aspects of your life and in turn normalising/de-stigmatising the medical segment.”

“I feel it’s important to have a holistic approach to my children’s conditions”

All needs catered.

“MediStori has hugely improved all issues above that I would have previously had.”

“I have had no issue since using MediStori.”

Symptoms and diagnosis.

“As I can track all symptoms and treatments it is easy to see what works and what doesn’t for my child’s condition.”

“My child has yearly major tests and I would like to be able to compare year on year results. Most of the children in our charity have these annual major tests.”

“Would have been so useful in the path to diagnosis and management of condition.”
Safe and organised.

“It is one of the most useful medical devices I have ever seen! - I presently have a full large drawer of hospital notes which would not fit into one lever arch file and this is superb in condensing what is important and a great size to carry around when required! It would fit in my handbag. I like the fact you can remove the relevant sections as required to take with you - for e.g. the questions for consultants section.”

“To find a good way to organise our medical history and medicine intake diary.”

“I was looking for a way to keep medical information together. I have up to now used a daily diary and often have difficulty finding information when I could not remember the exact date.”

“It was good to be able to check appointments, keeping prescriptions, medical reports all in one place so I always know where I can find it.”

Communication.

“Because of the written questions I was given more detailed answers and respected more.”

“Before appointments I wrote down questions I had for doctors/physios so instead of trying to think what I needed to ask I had it written in front of me. “

“An organiser is essential. Particularly in the Irish health care system where the ability of hospital teams to communicate effectively is highly questionable, it is extremely important to keep track of and take charge of your own health records.”

“It will help in all my medical history and help me to keep track of any changes with my tablets and how each hospital appointment went.”

“Without a doubt. It’s helping us already. We had an appointment with my daughter’s specialist and we were able to keep track of all of the questions we needed answered, the prescriptions given, her peak flow diaries, etc...”

“Great to be able to keep all the different info in the one place and have space for important letters and things which I tend to need to inform every professional of.”

“For me personally to have all the important medical info in one folder is handy to bring to appointments/ have to hand when needed.”

Save lives.

“Personally I think it’s a wonderful idea. I know that this will actually save lives. When my mother passed away the doctor said I hadn’t given him vital information about her health which is what led to her being given the wrong medication. Had I had the MediStori I would have been able to prove that he had all the information he needed.”
Future prognosis.

“I wanted something that would help me and my wife to keep track of our health issues in order that we could improve our quality of life and future prognosis.”

Confidence.

“A lot of the time your everyday life gets in the way of keeping on track of all hospital related issues but since I have the MediStori book I feel a bit more in control am confident with everything.”

Offered support.

“I was already formulating my own medical profile for my child and had started using it, I had shown my liaison charity nurse so when she came across MediStori she showed it to me and then when you started doing the trial she asked would I like to do it, I was delighted to do it and give the pros/cons in using it.”

Carers.

“I needed something to help me keep track of the many medications and doses of same that my daughter has to take, also for anyone else looking after her needed to have all information in one place for her.”

“Brilliant idea with all baby all milestones are huge and I love to keep dates etc. of milestones. Great for medicine and to hand over to our home care nurse.”

And the words which summed it all up.

Just, thank you.
Who, When, Where?

From my own (a patient’s perspective), and from the study results, the MediStori should be introduced to new parents when they have a new baby (as a lifelong health record); to the entire healthy population and to all who suffer with chronic conditions or symptoms - at every health care setting.

However, this may not be feasible to begin with and so patients with chronic illnesses (or their carers) should be given priority and should receive a MediStori in hospitals while on the ward before being discharged; at outpatient clinics at point of care; and through as many primary care settings as possible. Primary target groups should be those who have multiple chronic illnesses, are on multiple medications or have multiple health care teams. An estimated one in three people in Ireland (>1.3 million) (Balanda, 2010) have a chronic condition such the likes of high blood pressure, asthma, diabetes, heart disease, cancer, depression and so on. The five major groups in Ireland that need a PHR are estimated to be –

- Chronic Illnesses: 1.3 million+
- Disabilities: 320,573
- People with both Chronic Illness and Disability: 274,762
- Carers: 140,000
- Parents of new babies: 76,000

The reason why outpatients seems like a good opportunity is because the majority of patients wait between 45-90 minutes to be seen in a public clinic and this time could be used very effectively to educate patients on self-management and medication adherence. It can be given to patients via nurses, therapists, pharmacists, carers, patient advocates or consultants even. During this time the patient could also be referred to local relevant charities/organisations where they can get more supports specific to their needs - information leaflets could be put in the MediStori for them. It is through primary care service and charities where patients can be educated on the importance of self-management, adherence and their conditions. They can also meet with their peers for additional support. It should be recommended by all health care professionals/services that the MediStori is to be brought to all medical visits, such as outpatient clinics or GPs. The more that endorse it the better it will ensure it is reinforced and patients or carers can feel reassured that it is okay to engage with all of their health professionals. Patients move between many health services and teams and having one link between all can be of huge benefit – especially when living with multiple conditions. The National Carers Strategy highlighted that carers are extremely vulnerable and there is a major lack of resources for voluntary carers. Many carers are family or friends who have had to assume the role of carer quite suddenly or unexpectedly. Often there are fears of under/over dosing and the responsibility may lie with the carer if there is no paper trail of what the patient took last. All participants in the study agreed that, while it was important to have another adult contribute to child care, concerns arose about the other adult’s preparation or knowledge of the child’s medications, especially at appointments. It was also identified that it was difficult to remember reasons/dates of GP visits or outcomes of appointments. This applies to parents of healthy children in the study with regard to having a facility to record immunisations and general health issues. Upon speaking to paediatricians they felt it was critical to keep records to look back on for the future. MediStori is a standardised proactive toolkit, and should be recommended by all.
What are the Biggest Challenges?

As stated by the HSE in 2010:

"Keeping a personal health record has been demonstrated time and time again how it can improve service quality through the provision of accurate, timely information and user empowerment. However, if there is a lack of a national mandated, coordinated approach and resource constraints then this impedes personal records from being implemented in our health system."

For any personal health record system to work effectively, it should be integrated on a national level, to make it easy on any patient or carer to be able to share their information wherever they may be. Challenges may arise due to other systems or projects already in place, or lack of funds. Interoperable and integrated PHRs can save money – they should be seen as an investment. There are many solutions available to the market, but it is extremely important that vital components are not overlooked which could stop proceedings towards national implementation:

- **Risk Assessments:** Having everything "paperless" can be risky – what happens if a system crashes? Accessibility for paramedics/ED to access information in case of emergency can be restricted by passwords, electricity and so forth. Back up plans need to be in place.

- **Self-Management Supports:** PHRs are not just “booklets” they are practical aides which help with the management of health and medications - more education needs to be done on this.

- **Unhealthy Competitive Cultures:** Universal solutions mean everyone is on the same page – currently there is no one link in public or private health services – except that is, the patient. So many people are doing so many different projects and not linking them together that it confuses everyone. People think that “they’re project” is the best and they do not want to integrate it with others.

- **Easy Access:** It can be difficult to visually view files because information is stored in different files, unlike a book or chart where you can see everything at a glance (unlike apps)

- **Family Centred Care:** It is important to recognise the roles of family and friends to patients’

- **Proactive versus Reactive:** It is important to educate healthy population on self-care and self-management so they do not have to learn how to do something new before they get sick.

- **Individualised Health Care:** It is important to look at the all of one’s health issues together, not as separate issues. Seeing a person’s own medical story from chapter to chapter rather than pinpointing one or two aspects at different stages in one’s life depending on which hospital visited

- **Social Prescribing:** Charities and organisations for specific needs or conditions can be hugely beneficial to patients, carers, families and communities. It was surprising to see such a high number of health care professionals not recommending charities to service users. While this may look like this is on purpose or there are negative reasoning’s for this there can be numerous circumstances – forgetfulness, not knowing which to recommend and/or not knowing if charity is reputable or not.

- **Engagement:** What was interesting in these statistics was that those participants who signed up online seemed to have higher incidents of mismanagement of medications, and/or nonadherence. The only topic which remained nearly equal was that the patient or carer was worrying that others may not give medications correctly. This could be looked at in a few ways – 1) those using health care services were given the right education and information so they knew how best to self-manage 2) those filling out the survey online didn’t feel that any health care professional would see their answers and so weren’t afraid to be honest or 3) those in the hospital settings were currently “unwell” and so were more activated to better self-manage.
Implementation of new projects can seem difficult, but this is not necessarily so if it is broken down step by step. Every health service is unique in its offering, but are not all that different, and so processes can be adapted as required. Here are a few examples of various processes.

Example Patient Engagement Process

1. Ensure the patient or carer is able to read and write, and literate in English language. [Until or unless other versions are available in different languages]

2. Ask the patient [or carer] would they like to have a personal health record system to help them manage their own or their loved ones medications, appointments and relevant health information.

3. Show the patient or carer the MediStori and show them what each booklet is for, in particular, explain how the Medicine Memo works. Ask for readback along the way. Ask patient or carer is there anything they don't understand.

4. If issues arise concerning medication mismanagement, nonadherence or reconciliation discuss with patient and refer to medical/pharmacy team if necessary.
   - If you know of local services/charity that could be relevant to the patient, put any information or leaflets you have into folder at this time.

5. It is important that the following is said to the patient or carer -
   - Ask patient to bring the MediStori with them to each health care appointment
   - Ask patient to treat MediStori like their wallet or phone - there is confidential material inside, so only put in it what they're comfortable - but do try use it as best as they can

6. Log the patients details into your internal file so you can track who has received one - this will include their email address and phone number. Ask the patient for permission that additional educational material and information about the MediStori be sent to the patient. Assign a number to the patient, log this on internal file and write this down on the inside cover of their MediStori for the patients reference.

7. Explain to the patient or carer that there is a website that has extra supports, a helpline and videos online. If they wish to avail of these to log online and fill in the number that was given by you.

8. Tell the patient to let the team know if any health care professional/service is unsure to engage with MediStori. The team will contact them and reassure them of same.

9. Ask the patient or carer would they mind filling in a basic questionnaire before they leave to get an understanding of their current needs to ensure MediStori can meet their expectations for their future.

10. Pop this questionnaire into safe box in clinic, to be gathered and given to Lead Coordinator on site

11. At the end of the clinic/week/month, each promoter will fill in a short evaluation on how they managed giving out the MediStori. This data will all be collated by agreed data analyst and reviewed at agreed time frames. Changes can be made based on this information.
Example Project Initiation Process

Step 1
• Identify Service Users (Patients, Carers or Parents)
  • Decide on service users who would need it most - high risk groups, early adopters etc.

Step 2
• Identify Site
  • Decide on sites which deliver services to these service users

Step 3
• Identify Lead
  • Seek out person on site who wants to champion and lead on the project & take overall responsibility for communication, education and evaluation

Step 4
• Identify Promoters
  • Seek out health care professionals or trained volunteers who want to promote and educate service users on project

Step 5
• Identify Needs
  • Meet with team to discuss any issues, barriers or requirements that will be needed for the health professionals; their users and the site in question.

Step 6
• Discuss Plan
  • Decide on how best to implement the project taking on board the requirements of health professionals, users and site

Step 7
• Design Plan
  • Draw up an implementation plan based on all feedback gathered.

Step 8
• Deliver Training
  • Develop and deliver training programme in place for health professionals

Step 9
• Produce Promotion Pack
  • Provide literature for service users who will be using it; surveys for evaluation and posters and leaflets for the overall site

Step 10
• Review & Action
  • Go through everything with the team and ensure everyone is confident and competent. Change anything based on feedback. Start Implementing.
Review, Action, Review

Meet with the full team and ensure everyone is on the same page. Change anything based on feedback. Pick a start date and commence of project begins. Continual assessment will begin as soon as the project commences, through surveys, focus groups and one to one meetings. Change based on need.

Produce Promotion Pack

To design, develop and provide promotional resources, surveys and posters for the overall site. The same will be provided for service providers in the community and primary care for the same reasons.

Deliver Training

To develop and deliver training programmes for the team before project commences and to provide online resources for new staff members and for the wider hospital team.

Design Plan

Draw up an implementation plan, with the internal lead, based on all feedback gathered. To include timeframes, contingency plans and team contact lists.

Discuss Plan

Discuss a plan that will work for that site for implementation based on this information.

Identify Needs

Meet with those who will be leading on and delivering the project to learn about their service users needs and how many they see annually, for logistics. Learn about what are they limited in doing.

Identify Promoter

For every disease group there are specialist teams within the hospital that work together with patients. Within these teams there may be specialist nurses or therapist who provide one to one education with patients to help them better understand and manage their condition.

Identify Lead

Various people with lead roles have a keen focus on improving issues such as medication reconciliation, health information or communication throughout the hospital. These include Patient Advocacy Liaison Officers (PALS), Pharmacists or Health Information Coordinators, for example.

Identify Site

Acute hospitals have various multidisciplinary teams and specialists on site which can be beneficial when discussing treatments, medications specific to that patient.

Identify Users

Service users most at need are those who need to take multiple medications or attend multiple health professionals – they may be at risk of acquiring secondary conditions.
Consideration: PPI – Public Patient Involvement

One of the founding principles of quality improvement processes is that all stakeholders should be involved at every stage of the process, which is widely documented; an example of which is in the book “Patient Safety and Quality: An Evidence-Based Handbook for Nurses:

“Quality improvement requires five essential elements for success: fostering and sustaining a culture of change and safety, developing and clarifying an understanding of the problem, involving key stakeholders, testing change strategies, and continuous monitoring of performance and reporting of findings to sustain the change.” (Hughes, 2008)

However, this can often be a difficult undertaking when seeking out the most appropriate person(s) for this task. There are a number of reasons why this is so. Olive has contributed to many working groups in healthcare and she has had numerous reflections on same.

Often she feels that much of the time practical toolkits need to be in place prior to public involvement. These may include:

- **Needs Assessment of the Project and Intended Outcomes**
  - This may help identify what type of stakeholders are needed (or not!) and what experiences they should have. It may also help with how many should be available and what ratios of health care professionals to patients/public should be present.

- **Robust Terms of References and Guidelines (not just one pagers!)**
  - This co-designed document may be helpful so that everybody knows the “rules of engagement”. This can be used mainly as a proactive toolkit and may be particularly helpful to aide in:
    - helping everyone on the team to think collectively and clearly
    - situations where final decisions need to be made, for example, and it is difficult for agreement
    - reviewing the roles and responsibilities of each person in attendance
    - ensure the purpose of the project is being fulfilled

- **Confidentiality and Consent Forms**
  - Often when healthcare professionals, researchers meet with patients or the public in settings as working groups, there can be times when the conversation is not as open as it should be. This can be because both parties may feel vulnerable regarding the information they are sharing. There could be concerns in relation to sharing of information to third parties, for example. If confidentiality forms and consent forms are signed, by all parties at the beginning this can help to ensure the conversations are as open as possible which may allow for more valuable learnings.
  - Topics arising may sometimes bring up different emotions/memories for person(s) in attendance and so having an action plan for this occurrence is vital.

There are many other matters, including the above, which may need adjusting or thinking about prior to public involvement but this does not mean it should not be done. There are many benefits of involving all stakeholders in projects and initiatives. Two such considerations of same are shown hereafter.
Abstract and Poster Submitted to Department of Health’s Patient Safety 1st National Patient Safety Conference 2016

A study to show how collaboration and patient input at the beginning of the design, development and delivery of protocol, processes and products in healthcare can save money, time & resources, and potentially contribute to patient safety.

Authors: Dr Pádraig Mac Neela, Ms Olive O’Connor

Context

The development and delivery of innovative services and products is predicated on initial primary research. This principle applies to all complex systems, with healthcare being no exception. A complex healthcare organisation includes many stakeholders, but patients and clients are the stakeholders who experience the outcomes of the processes that link together all of the system stakeholders. In this paper we describe how patient advocate input was used to feed directly into the design, development and delivery of a paper-based personal health record system.

Objectives

A survey design was used to elicit patient and carer evaluations of the pilot version of the MediStori personal health record. Multiple surveys were deployed. One was community-based, through charity partner organisations between February and September 2015. The second was a survey of outpatients in acute hospital and paediatric hospital settings, between March and October 2015. Qualitative and quantitative evaluations were triangulated between the settings.

Methods

The study represented a unique collaboration involving Health Professionals, the Quality Improvement Division with the Acute Hospital Division of the HSE, a Chief Pharmacist and Child Health Care Coordinator, a General Hospital and Specialised Hospital, along with eight National Charities and an academic researcher.

This collaborative approach ensured that patient and carer perspectives, healthcare policy makers, healthcare organisations, NGOs, innovation developers and evaluation researchers could cooperate to achieve a key goal: to assess the need for support around medication compliance, healthcare utilization, and information management, and to appraise the MediStori as a paper-based system to meet those needs. Online and paper-based surveys were designed comprising core and specific sections.
Main Results

The survey took 35 minutes to complete and elicited considerable optional, qualitative feedback from patients and carers who used the MediStori personal health record on a trial basis. To give an example of the needs identified by the survey, patients are currently finding it extremely difficult to manage their own and family members’ medications (>95%); to communicate effectively with health care professionals on medication issues and recall information (>89%), or to manage or remember when vaccinations were done (>45%). All survey respondents evaluated the MediStori as making a positive contribution toward meeting their healthcare information management needs and capacity for accessing healthcare providers’ support to do this. A number of helpful suggestions were made to refine the MediStori before production, thus proactively saving time, money and resources. The study provides an example of involving service users in design and development as a proactive patient safety initiative, and of engaging multiple stakeholders around this as a mutually relevant and motivating goal.

Discussion/Perspectives

Despite the penetration of powerful handheld computing devices into the everyday life of almost all of our citizens through Smartphones and Tablets, healthcare information is still for most patients paper-based – in the form of prescriptions, appointment cards, vaccination records, and healthcare provider instructions. The MediStori appears to be a useful innovation that rationalises the management, accessibility, and utility of these paper-based records. It brings together the tools for achieving patient safety through medication compliance, healthcare utilisation, and useful personal and family medical information into one coherent package. There is much to be said for continuing the multiple stakeholder collaboration that has demonstrated its viability into a future phase of rollout and implementation.
Patient and Public Involvement in National Clinical Effectiveness Processes: A Systematic Review

Authors: Veronica Lambert¹, Anne Matthews¹, Riyad El-Moslemany¹, Olive O’Connor²
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Context

There is growing consensus that patient and patient involvement (PPI) is crucial in clinical effectiveness processes. However, difficulties can arise in making patient and public contribution effective as there remains uncertainty on how best to engage lay stakeholders in national clinical practice guideline development and clinical audit processes.

Objectives

To synthesise available evidence on patient and public involvement in the development and governance of national clinical effectiveness processes, including clinical guideline development and clinical audit processes.

Methods

A systematic review on published and unpublished evidence was conducted and reported in accordance with the Centre for Reviews and Dissemination (2008) guidance for undertaking systematic reviews in healthcare and the Preferred Reporting in Systematic Reviews and Meta-Analysis (PRISMA) criteria (Moher et al. 2009), as far as possible. A comprehensive search methodology was used to retrieve published and unpublished evidence nationally and internationally, including electronic databases, grey literature, clinical audit and guidelines organisations. Documents were included if they reported specifically on PPI in the development, and or governance of clinical guideline and audit development processes at a national, or equivalent, level. No study design limits were applied and we included primary and secondary research, descriptive pieces and reference manuals, toolkits, policies and strategies produced by national, government and/or other relevant organizations with remit for clinical guideline and audit processes. Titles, abstracts and full text (as appropriate) of potentially eligible documents were assessed independently by two reviewers with any discrepancies resolved by discussion with a third reviewer. Duplicate data extraction was also conducted by two independent reviewers with any discrepancies resolved by consensus with a third reviewer. Primary and secondary research studies were quality assessed using three quality appraisal instruments to take account of the diverse study designs including, the critical appraisal skills programme (CASP) tool for qualitative studies, a modified version of an appraisal tool designed by Tsimicalis et al. (2005) for quantitative studies and AMSTAR (A Measurement Tool to Assess Systematic Reviews) for secondary review papers. Results were summarised narratively according to the review objectives.
Main Results

From a total screening of 2,515 documents, we identified 41 documents as eligible for inclusion in the review. Of these 41 documents 13 were discursive/descriptive/opinion pieces, original 7 were primary research studies, 7 were toolkits/reference manuals, 6 were secondary review papers, 3 were evaluation studies, 2 were protocols, 2 were policy/strategy documents and 1 was a research briefing.

The results of the quality assessment of the 13 primary and secondary research studies found the majority of studies to be of moderately high quality, despite some limitations of the appraisal tools used. Robust empirical evidence on which PPI strategy or approach is most effective was limited. The majority of documents reviewed reported on PPI in clinical guideline development with a dearth of data on PPI in clinical audit processes.

Despite a general consensus that PPI should be integrated in clinical effectiveness processes, the added benefits of doing this has yet to be established empirically. Indeed, the difficulty, or perhaps impossibility, of examining the effects of PPI using randomised controlled trials was acknowledged, in addition to the fact that decision-making processes may need to be studied in different ways. Three main PPI strategies were identified; consultation, participation and communication.

While there was limited data available on evidence based outcomes of these three PPI strategies it was recognised that each strategy had its own strengths and limitations. It was acknowledged that effective involvement should begin with finding the best approach tailored to the specific PPI goal in any given context; and the level of involvement should be clear and transparent for all concerned.

As simultaneous potential barriers and facilitators to PPI, core issues to take account of included; the representation and selection process for patient/public representatives; transparency in terms of the roles and responsibilities of patient/public representatives; training and support mechanisms, being committed to and valuing PPI and working in a mutually respectful environment.

There was agreement that patient representatives should be trained, prepared, guided, educated, supported and compensated for their role. Limited reporting existed on the model, mode, delivery, timing, content, trainers, cost, evaluation of and effective impact of various training and support mechanisms.

There was a paucity of rigorous process and impact evaluations to determine the effectiveness of PPI approaches, and/or methods and systems to support PPI, in clinical effectiveness processes.
Discussion/Perspectives

This review provides baseline data and valuable insights into the process of integrating PPI into clinical effectiveness processes.

Some key principles identified include: the integration of PPI into clinical effectiveness processes to strengthen public participation in healthcare decision-making and to bring expert experiential knowledge to these processes; the three PPI strategies of consultation, participation and communication can be employed as required in each clinical effectiveness process, and full active public/patient participation should be explored where appropriate; the most appropriate patient and public representation should be examined for every case, drawing on public, patient, carer and other peer or lay representatives and while there is no evidence to recommend one approach to the selection and recruitment of patient and public representatives a transparent process is required; and comprehensive support is needed for patient and public representatives, specifically in terms of training, remuneration/compensation, physical, psychosocial and emotional support.

There are several international organisations (e.g. NICE, SIGN, G-I-N, HQIP) which have developed structured PPI programmes (PPIPs), with supporting resources, to underpin their clinical effectiveness approaches and these offer valuable models to examine further for a national context. There is a need for further research to establish the effectiveness of different approaches to PPI programmes as advanced evaluation of PPI in clinical effectiveness processes could potentially enhance the wider acceptance and development of PPIPs if found to be effective.

References for this Abstract:


Overall Learnings

"Keeping a personal health record has been demonstrated time and time again how it can improve service quality through the provision of accurate, timely information and user empowerment. However, if there is a lack of a national mandated, coordinated approach and resource constraints then this impedes personal records from being implemented in our health system."

As stated in a presentation regarding child personal health records by teams in the Department of Health and the HSE, PHRs are shown to be effective in improving service quality, but they also state that for them to work and to be implemented there needs to be coordinated, national, mandated approaches and investment in resources.

The purpose of sharing this publication was to give an overview of the benefits of having a standardised, universal personal health record system, as recommended at point of care by health care professionals and health care organisations to patients and carers. This paper has shown the benefits of such a system which focuses on the main needs of all patients, such as managing their medications, appointments, communication and the impact of having conditions. It has shown how integration of specific components regarding disease, age and socioeconomic backgrounds of an individual can be added as required throughout the life cycle of a person. It has demonstrated the difficulty and confusion for patients, carers and health care professionals by having too many different types of systems and/or care plans across a health service, while showing the need for technology and devices as enablers. This documents showcases the MediStori project as an evidence based working example of this type of system. It has discussed its promoter and the founding principles for which this work was done – which is based on one simple question – “Is it in the best interest of the patient, or even better, the person?”

Hopefully this research will mean that more people will start thinking of the “patient” more as a “person” – from birth to end of life, and not just as a person with a condition or ailment, or as a child or older person. Hopefully all charities, health care teams and leadership teams will be able to see the benefits of working collaboratively together; and involving patients, carers and front line staff in their work. Hopefully this paper will have shown patients and carers how to better store, record and communicate accurate health information, and self-manage their own or their loved ones medications and conditions.

This paper shows how we need to be Personalised, Predictive, Preventive and Participatory and that we need to be ensuring the patient safety agenda is always a priority, before Profit, Pride, Positions or Power. We need to prove what works, and we need to do it, together. Every stakeholder needs to be involved in design, development and delivery. And this is what we do, as a team, on a daily basis.
You see, the MediStori is more than just a personal health record or standardised self-management system.

It is an entire movement.
It is the **MediStori Movement**.

“There is an emerging revolution in healthcare that will lead to a kind of medicine with new dimensions—it will be predictive, preventive, personalized, and participatory in Medicine.”

Lee Hood, MD, PhD
PAMI Chairman and SB President

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Solutions Need to Be Simple.
Cultures Need to Be Converted.
Charities Need to Be Collaborating.
Initiatives Need to Be Integrated.
Patients Need to Be Participating.
Professionals Need to Be Proactive.
Policy Needs to Be Practical.
Projects Need to Be Personal.
Processes Need to Be Proven.

#sharingislearning
#whatsyourmedistori
Dr Pádraig MacNeela  Lecturer Psychology, NUIG

All the staff in the HSE, in particular:

Mr Tony O’Brien  Director General, HSE
Mr Brian Murphy  National Manager Primary Care, HSE
Dr Philip Crowley  National Director for Patient Safety and Quality Improvement, HSE
Mr John Kenny  Manager Quality Improvement Division, HSE
Ms June Boulger  National Lead Public Patient Partnership Acute Hospitals, HSE
Mr Greg Price  Assistant National Director Quality Improvement Division, HSE
Dr John Fitzsimons  Clinical Director Quality Improvement Division, HSE
Mr Liam Woods  National Interim Director Acute Hospitals, HSE

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Prof. Alf Nicholson  National Clinical Lead in Paediatrics

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Ms Blánaid O’Connell  Chief Pharmacist
Mr Charlie Meehan  General Manager
Dr Michael O’Neill  Consultant Paediatrician

Charities involved with study

Arthritis Ireland  Irish Dysautonomia Awareness
EDS Awareness Ireland  Jack and Jill Children’s Foundation
Dyspraxia Ireland  Irish EDS and HMS

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Up to the date of which this is penned, a vast number of persons impacted the shape of my thinking:

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Mr Rosaleen Doonan  Dr Johnny Walker  Mr Brendan Chambers  Mr Flan Hassett
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Of course there are many, many more people who have shared so much time, kindness, knowledge and cups of tea with me. You know who you are.

Thanks so much to you, and to all who have been helpful in any way.
My last word...

I believe in person centred care and so I finish off this paper with a few personal notes of gratitude.

Particular thanks to all of my friends and followers who have worked with me; inspired me; and motivated me to do this work - especially to my kind husband Fintan; my three beautiful daughters, Micaela, Nicole and Mackensie; my own Mum; my Mum and Father in law - and to all of my family.

A very important thank you also goes to Áine McManamon, Erin Cafferkey and Alice Butler – core members of the MediStori team, and of which also comprises of one other person who helps me achieve so much every single day:

Jill, our childminder.

Otherwise known as “Mom in Lieu”, without the care and kindness Jill gives to my children, none of this would have been possible. She keeps them happy, safe and healthy - and when they're okay, so am I.

Thank you Jill.

And finally.

The MediStori was created for the gentlest man I ever knew, and the man I called, Dad. He sadly passed away on 17th May 2014. I dedicate this, my first publication, to him. His name was Eoin Carroll. This was his MediStori.

So on a final note, I now ask you...
What’s your MediStori?
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[Including Citations, References and Links]


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Footnotes, Definitions and Explanations

1 Integrated health services are health services that are managed and delivered in a way that ensures people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and palliative care services, at the different levels and sites of care within the health system, and according to their needs, throughout their whole life. [http://www.who.int/servicedeliverysafety/areas/people-centred-care/en/](http://www.who.int/servicedeliverysafety/areas/people-centred-care/en/)

2 People-centred health services are an approach to care that consciously adopts the perspectives of individuals, families and communities, and sees them as participants as well as beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways. People-centred care requires that people have the education and support they need to make decisions and participate in their own care. It is organized around the health needs and expectations of people rather than diseases. [http://www.who.int/servicedeliverysafety/areas/people-centred-care/en/](http://www.who.int/servicedeliverysafety/areas/people-centred-care/en/)

3 A person receiving or registered to receive medical treatment.

4 Quality Improvement Process - PDSA (defining, success metrics and putting a plan into action; followed by the do step, the study step, and the act step which closes the cycle, integrating the learning generated by the entire process, which can be used to adjust the goal, change methods or even reformulate a theory altogether. These four steps are repeated over and over as part of a never-ending cycle of continual improvement. [https://www.deming.org/themany/theories/pdsacycle](https://www.deming.org/themany/theories/pdsacycle) (The Deming Institute, 2015)

5 Lean is a business methodology which aims to provide a new way to think about how to organize human activities to deliver more benefits to society and value to individuals while eliminating waste. [Womack, 1996]

6 Co-design is about engaging consumers and users of products and services in the design process, with the idea that this will ultimately lead to improvements and innovation. [Burkett, 2012] experience-based co-design (EBCD) is an approach that enables staff and patients (or other service users) to co-design services and/or care pathways, together in partnership. The approach is different to other service improvement techniques [www.kingsfund.org.uk/projects/.../experience-based-co-design-description](http://www.kingsfund.org.uk/projects/.../experience-based-co-design-description)

7 Social prescribing in primary care is a relatively recent concept describing the use of non-medical support to address the needs of people affected by depression or anxiety. [https://www.icgp.ie/assets/39/73cb962a.../social_prescribing.pdf](https://www.icgp.ie/assets/39/73cb962a.../social_prescribing.pdf)

8 National university of Ireland Galway [www.nuig.ie](http://www.nuig.ie)

9 According to the WHO – “What is meant by social gradient? The poorest of the poor, around the world, have the worst health. Within countries, the evidence shows that in general the lower an individual’s socioeconomic position the worse their health. There is a social gradient in health that runs from top to bottom of the socioeconomic spectrum. This is a global phenomenon, seen in low, middle and high income countries. The social gradient in health means that health inequalities affect everyone.” [http://www.who.int/social_determinants/thecommission/finalreport/key_concepts/en/](http://www.who.int/social_determinants/thecommission/finalreport/key_concepts/en/)

10 World Health Organisation


12 International Society Quality in Health Care [www.isqua.org](http://www.isqua.org)

13 National Adult Literacy Agency [www.nala.ie](http://www.nala.ie)

14 [https://www.youtube.com/watch?v=rgd1qaozgxa&list=1ie4oomwyc4tyu6oi6p1kwk&index=14](https://www.youtube.com/watch?v=rgd1qaozgxa&list=1ie4oomwyc4tyu6oi6p1kwk&index=14)

15 [https://youtu.be/a2dKc57p4Cc](https://youtu.be/a2dKc57p4Cc)

16 Institute for Healthcare Improvement [www.ihi.org.com](http://www.ihi.org.com)


18 Department of Health

19 Dublin City University


21 [http://www.nuigalway.ie/our-research/people/psychology/padraigmacneela/](http://www.nuigalway.ie/our-research/people/psychology/padraigmacneela/) See end of document for more works

22 A minimum viable product is that version of a new product which allows a team to collect the maximum amount of validated learning about customers with the least effort. (Ries, 2011)

23 This is the process of putting pills into organised containers called pillboxes on a weekly/monthly service

24 See demonstration video here: [https://www.youtube.com/watch?v=fdxfo5v3yda](https://www.youtube.com/watch?v=fdxfo5v3yda)

25 Confidence level of 93% as percentage of error just 7% per 200 participants [http://www.sciencebuddies.org/science-fair-projects/project_ideas/soc_participants.shtml](http://www.sciencebuddies.org/science-fair-projects/project_ideas/soc_participants.shtml)

26 Internal surveys will generally receive a 30-40% response rate (or more) on average, compared to an average 10-15% response rate for external surveys. [Fyrear, 2015]

27 Many questions were qualitative, and so the team were prepared for some personal data to come through. Where this occurs, references have been replaced.
28 In medicine, comorbidity is the presence of one or more additional disorders (or Diseases) co-occurring with a primary disease or disorder, or the effect of such additional disorders or diseases. The additional disorder may also be a behavioural or mental disorder.

29 H- Hospital C - Charity

30 Other works published by Dr Pádraig MacNeela

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<th>Year</th>
<th>Conference Publications</th>
</tr>
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