HEALTH AND SPORT COMMITTEE

Additional information from Chaloner Chute, Digital Health and Care Institute following the Primary Care Inquiry - Technology and Innovation evidence session on 5 November 2019

The Committee asked for analysis on personal ownership of data undertaken to be shared with them following the meeting on 5 November.

Two Reports are attached:

- Experience Lab Project Report
- Advancing Digital Health & Care: Exploring the infrastructure required for citizen-centred services

Lastly, the link below is to our lessons learned from actually integrating systems in a way that gives the user full control over their own data. The first half discusses some of the trends in personal data / clinical integrations. The second half showcases our practical work.

https://strathprints.strath.ac.uk/68135/

Chaloner Chute
Chief Technology Officer,
Digital Health & Care Institute
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Exploring how people living with Multiple Sclerosis would like to manage their own personal information in order to improve the experience of accessing services, and understand the potential of a person-owned data store (or digital ‘Backpack’) to support health and care professionals to deliver more integrated and person-centred care.

Participants: 9

Lab Team:
- Gemma Teal
- Dr. Tara French
- Dr. Jay Bradley

Methods:
- Focus Group
- Experience Mapping
- Paper prototyping
- Digital prototyping
- Prototype iteration

Tools:
- Backpack prototyping tool
- Personas
- Experience map
- Service mapping tool
- Scenarios
- Digital prototypes

Academic Output:
- Report
- Video

Facilities:
Mydex CIC / University of the Highlands and Islands
NHS Grampian / Moray Council / The Glasgow School of Art

2016

Two Exp.Labs + 1 Mini-Lab
Lab Location: Elgin

Participants:

Participants: 9

Methods:
Focus Group
Experience Mapping
Paper prototyping
Digital prototyping
Prototype iteration

10 Hours Experience Lab time
+3 Hours Mini-Lab time
Executive Summary

The Personal Data Store (PDS), herein referred to as the Backpack, was proposed as an opportunity to improve the experience of accessing services, enabling integrated and person-centred care potential solution by the project partners: Mydex CIC, a community interest company who specialise in personal data management, together with NHS Grampian and Moray Social Health and Care Partnership. This report describes the Experience Lab research activity for the Backpack project and presents a detailed set of findings, concepts and scenarios of use.

The overall aims of the research project were to explore how people living with Multiple Sclerosis (MS) would like to manage their personal information in order to improve the experience of accessing services, and understand the potential of the Backpack to support health and care professionals to deliver more integrated and person-centred care. To meet these aims, design researchers at The Glasgow School of Art led a participatory design process with people living with MS and health and social care professionals. People living with MS were identified as highly knowledgeable co-design participants, due to the complex and progressive nature of the condition, requiring wide-ranging interactions with statutory services. Participants living with MS were involved in a Mini-Lab to explore current experiences of accessing services and managing information and an Experience Lab, which used design-led activities to map key moments of data sharing
and developed paper-based prototypes of the Backpack. A second Experience Lab involved health and social care professionals in testing prototypes of the Backpack, identifying user requirements from the perspective of service providers, and understanding how access to person-owned data stores would change current working practices.

Analysis of the conversations, maps and prototypes led to: i) a wealth of insight about the current experience and challenges of service users and providers; ii) the identification of a set of overall principles to shape the development of the person-owned data store; iii) synthesis of the main ideas for functionality as four overarching but complementary concepts that describe how the Backpack could manifest; and iv) a number of scenarios of use to describe how the principles and concepts could support person-centred and convenient access to services. A roadmap for discussion is presented to explore how the different concepts interrelate, and how the Backpack integrates with other statutory and commercial systems. Presented alongside this are a number of questions, challenges and opportunities raised through developing and testing the Backpack concepts: intended to support a discussion around the next steps for person-owned data stores.
Experience Labs

The Experience Labs were developed by the Institute of Design Innovation at The Glasgow School of Art.

The Experience Labs offer a safe and creative environment where researchers, businesses, civic partners and service users can collaborate on innovative solutions to the health and care challenges facing our society.

Researchers use current and emerging design research methods to engage with our partners and participants, who are encouraged to share their own experiences. Real-life practice is often replicated to allow new technology, services, processes and behaviour to be trialled rapidly.

Researchers, partners and participants are supported to co-create potential solutions to achieve a preferable future. The resulting ideas become candidates for further research and development, allowing them to achieve their full potential.

It is a central element in the Digital Health & Care Institute (DHI), a Scottish Innovation Centre funded by the Scottish Funding Council, in partnership with Scottish Enterprise and Highlands and Islands Enterprise.

The Digital Health & Care Institute

The Glasgow School of Art is a founding partner in the Digital Health & Care Institute, which is a partnership between NHS 24, Scottish Enterprise and Highlands and Islands Enterprise.

The DHI Innovation Centre creates an open community where industry can collaborate effectively with academia, health, care and social partners on innovation opportunities that will create societal and economic benefits in Scotland. The DHI will co-create sustainable economic growth through new products, services and systems. These solutions will generate high value health and social care solutions to the benefit of the people of Scotland and further afield.
Experience Labs Project Team

Gemma Teal Research Fellow, The Glasgow School of Art
Dr. Tara French Research Fellow, The Glasgow School of Art
Dr. Jay Bradley Research Fellow, The Glasgow School of Art
Ree Barthels Innovation Designer, The Glasgow School of Art
Rebecca Phipps Design Intern, The Glasgow School of Art
Cate Green Production Manager, The Glasgow School of Art
Jane Candlish Content Editor, The Glasgow School of Art
Louise Mather Photographer and Videographer, No Middle Name

Project Partners: Backpack

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Dr. Jamie Hogg Clinical Lead for Modernisation, Associate Medical Director
NHS Grampian
Prof. Grant Cumming University of the Highlands and Islands
Lorna Bernard Moray Council

Acknowledgements

We would like to thank all of our participants for giving up their valuable time to take part in the Experience Labs.
Project Background

What if all your personal records, including your relevant personal health and care records were held in one place that you control?

Every person just has this one space, one number, one folder, which we call here your personal ‘backpack’. Your backpack content can be whatever you want and can be shared with whoever you want. It works like a protected folder from Dropbox*: invite doctors and services to view your folder and connect with you or with each other. The backpack connects with you by helping you to create a plan of action, specially designed for your personal situation. In this way it can make care more personal and embedded in your daily life.

The Personal Data Store (PDS), herein referred to as the Backpack, was proposed by the project partners, Mydex CIC, a community interest company which specialises in personal data management; NHS Grampian and Moray Social Health and Care Partnership.

Development of a PDS was regarded as an opportunity to improve the experience of accessing services, and as a potential solution to enable integrated and person-centred care.

In order to ensure the concept was tested and developed to meet the needs of people who have complex and wide-ranging interactions with statutory services, the health and care partners wished to explore the Backpack from the perspectives of people living with Multiple Sclerosis (MS). People living with MS were identified as likely to benefit from the introduction of the Backpack as it is a very complex and progressive illness, and no two people’s experience of living with MS is the same.

* Dropbox is a file hosting service that creates a special folder on the user’s computer, the contents of which are then stored remotely on Dropbox’s servers, and other users can be given shared access to the folder. The folder is synchronised via the Dropbox server, keeping the same files up-to-date on all devices.  
https://www.dropbox.com/about
Project Aims

The overall aims of the research project were to explore how people living with MS would like to manage their own personal information in order to improve the experience of accessing services, and understand the potential of the Backpack to support health and care professionals to deliver more integrated and person-centred care. The key goals were to test the concept with end users (both people living with MS and health and care professionals), develop a low fidelity prototype to embody the users’ requirements for the system, and understand how this concept would alter the working practices of service providers.

Some of the key questions the project aimed to answer were:

- **Understanding current experiences:**
  - What are the personal behaviours, journeys, stories and access points (administration, services) of someone living with MS?
  - What types of information and personal data are required to navigate the system and access services?

- **Exploring and developing the backpack concept:**
  - Would the PDS be useful and of interest to people living with complex long-term conditions to help them navigate the system and access services?
  - How would people and their care network want to interact with such a personal data store?
  - Who would they want to share their personal information with and how would they want to achieve this?
  - How would this change the working practices of their health and care professionals?
Methodology

MINI-LAB
Focus group with people living with MS to explore current experiences and identify key moments

LAB 1
Involving people living with MS
- Mapping key moments
- Packing the backpack
- Focus group

INTERIM LAB FINDINGS
Collecting, analysing and presenting for discussion with partners

DEVELOPING PROTOTYPES
Translating the participants’ paper prototypes into a digital and paper prototype for testing

LAB 2
Involving health and social care professionals
- Mapping the current system
- Exploring the prototype backpacks
- Focus group

KEY FINDINGS, REQUIREMENTS AND DESIGN CONCEPTS
Collecting and analysing

OUTCOMES
Backpack Report and Video
MINI-LAB

What we did

A focus group was held with five people who live with MS, recruited through the local MS Society support group. The focus group aimed to gain insight into current experiences of living with MS, in particular the challenges of and strategies for managing personal information and accessing support from statutory services. We aimed to identify several key moments of data sharing between people living with MS and health and care services to be explored in more detail during Lab 1.

Topics for discussion included:

- Technology usage;
- Circles of care: the formal and informal networks of support;
- Preferences for access to personal health information;
- Online data management and security;
- Paper-based data management and security;
- Experiences of accessing statutory services.

Audio from the Mini-Lab was recorded and transcribed in order to gain rich qualitative data on the user experience.

Key moments

Three key moments of data sharing were identified for further exploration during the subsequent Experience Lab:

1. Applying for disability benefits;
2. ‘Building your own team’: navigating the health system, understanding what help is available and finding the right people within the system who can help following diagnosis;
3. Transitions: coping with the progression of MS and changes in the level of support needed.
**EXP LAB 1**

**What we did**

Experience Lab 1 was a half-day session with people living with MS (three participants). Design-led activities mapped key moments of data-sharing and developed a paper-based prototype of the PDS, followed by a focus group to get feedback on the PDS concept and elicit issues around personal control over personal data.

Activity 1 aimed to explore the key moments of using and sharing data (identified through the Mini-Lab) to map out the experience in order to gather insights and identify opportunities for innovation in current services. This was a group session, facilitated by the lead researcher who mapped the key moments along a timeline (e.g. showing people, information flow, activities, places etc as appropriate).

Activity 2 aimed to explore:

- The types of information that participants would want to store in a personally held record;
- Who they would want to share their information with and how they would want to achieve this;
- How they would want to securely access their record and any other general requirements for the personal data store.

This was explored using the ‘backpack’ metaphor, with participants building up a paper file with cards representing the kinds of information currently held by health and care professionals, and held online (e.g. social media profiles) using connectors to allow the participant to indicate who they would like to give permission to see the information contained. This tool enabled us to introduce the concept of a ‘digital backpack’ or PDS. Finally we discussed options for securely locking/unlocking their digital backpack. The activity was facilitated 1:1, with participants prompted to explain their thinking, which was recorded directly on the prototype or in the facilitators’ notes.

Audio from the Labs was recorded in order to gain rich, qualitative data to support the map, prototypes and facilitators’ notes. The data gathered was analysed thematically in order to reveal emerging and recurrent themes. An annotated sketch was made of the structure and content of each of the prototypes. The prototypes were compared to identify common concepts and features, and points of variation in terms of e.g. the types of information they would want to store and or share, how it would be organised and how they would use the Backpack.
PAPER prototype
DIGITAL prototype
EXP LAB 2

What we did

Experience Lab 2 was a half-day session with health and care professionals (four participants). The aims of the Lab were to test the Backpack concept with service providers, gather user requirements from the perspective of service providers, and understand how access to a PDS would change current working practices.

Activity 1 aimed to explore the current health and care service for people living with MS, and identify the professionals and services the person might be supported by, the information they would require and generate, and the connections between the different services. Participants formed two groups, with each group receiving a paper prototype Backpack (see page 15). They were asked to explore the information in the Backpack, and get to know the owner (a persona: Andy or Laura) and how they currently manage their life with MS. Following this, participants were asked to describe all the different health and care professionals this person might engage with, recording each professional or service, the information they would require, the information they would generate about the person, and the services they might refer on to. Each professional or service was recorded on a folded card. Finally, the paper Backpack and folded cards were arranged on a large sheet of paper with the Backpack in the centre, and the connections between the persona and the different professionals and services were mapped. The output was a map of all the different services, interactions and information that represented their personas access to health and care services.

Activity 2 aimed to gain feedback on the digital and paper prototypes through practical use. The participants were given a chance to explore and interact with the digital version of their persona’s Backpack. Following this, participants were asked to use the digital prototype and the paper prototype they created in Activity 1 to help their persona to access services when they went through a challenging situation (i.e. when their partner and carer is unwell; to prepare for discharge from hospital following an illness). Participants were asked to highlight any missing information, and talk the researchers through the steps required to access the support services required.

The session ended with a focus group to invite the participants to reflect on their experience of using the Backpack prototypes and explore additional requirements and implications for their working practices.
Overall Findings

Analysis of the conversations, service maps and prototypes led to:

i) a wealth of insight about the current experience and challenges of service users and providers;

ii) the identification of a set of overall principles to shape the development of the person-owned data store;

iii) synthesis of the main ideas for functionality as four overarching but complementary concepts that describe how the Backpack could manifest;

iv) a number of scenarios of use to describe how the principles and concepts could support person-centred and convenient access to services.

The findings are structured with the next phase of development of the Personal Data Store in mind: overall principles are foregrounded, followed by the four illustrated design concepts presented alongside the insights and rationale that informed them. Finally the design concepts are illustrated through four scenarios of use from the perspectives of people living with MS, health and care professionals and family members.

Overall Principles to guide the development of the backpack

The concept of a person-owned, digital file store that would allow the person to securely manage and share their personal information was positively received by both people living with MS and health and care service providers.

Service Qualities

People living with MS highlighted a number of characteristics that support positive interactions with people and services, which can be translated into design principles for the structure, language, look and feel of the Backpack.

Service interactions should be oriented around their personal goals and needs, and should seek to offer convenience to make everyday life easier for people living with MS. Participants valued services and places that felt safe and welcoming; and professionals who showed understanding about the challenges of living with MS, and were knowledgeable about the people and services that could help.

“There’s a lot to be done online that makes life easier.”

“…to get a hold of all of these powerful things that are in the room takes understanding and skill and compassion and it needs somebody to make it safe.”

Equity and Depth of Information

Participants living with MS would value the ability to access their own health information, with equitable access to the information their health professional holds about them.

“I’m always wanting my liver function tests because I want to see how things have changed… I’d like to know what the actual results are and once or twice I’ve had print outs but it’s never been complete.”

“…I’m often very worried about what they actually have put on my account rather than what I’m living through… I haven’t been able to scrutinise them to the level that I would like… It’s very disempowering…”

They also highlighted disparity of access to health information between different professionals (i.e. across health boards and services), and suggested that the Backpack would allow them to ensure their health professionals had access to all the relevant information.

“I want them all to have access to the same information but they don’t always, within different systems…”

“I would be empowered to answer the Doctor’s questions.”

While participants appreciated the need to have access to
detailed test results to share with health professionals, many would not want to see impenetrable medical jargon. The Backpack prototypes proposed high level summaries, with more detailed information available if required. This echoed the health and care professionals’ suggestion that the Backpack would only be required to hold high level information, with an indication of who to contact (with contact details) if more in-depth information is required.

→ Security

While security of online information is a concern, participants were pragmatic about the benefits of having access to a shareable digital data store, versus the risks. The Backpack must make use of familiar and trusted security measures, with awareness of the needs of some people living with MS who have diminished capacity to recall passwords.

“The thing about health information for me is availability trumps confidentiality.”

Mini-Lab Participant

“I see my grandchildren and they’ve bought whatever they want, no problem, I just think that is the way the world is going, the information highway and

I think, health-wise, there will be security measures in place like Paypal… so if it meant it was easier to get from one thing on your list to something else… that would be great.”

Mini-Lab Participant

Participants acknowledged that others might have more reason to be concerned about protecting their health information, for example people who choose to keep their condition from their employers or insurers, therefore security measures should seek to reassure people who have a heightened fear of hacking.

“If someone could get into that (the backpack), they would have everything, so it would be great fun for identity theft. I’m quite an optimist normally and think they wouldn’t do that…”

Mini-Lab Participant

Participants acknowledged that others might have more reason to be concerned about protecting their health information, for example people who choose to keep their condition from their employers or insurers, therefore security measures should seek to reassure people who have a heightened fear of hacking.

In addition the Backpack should be adaptive and anticipate the needs of person as their health and care requirements change. For people living with MS, coping with the progressive nature of the condition and thinking about the future is emotionally challenging.

“I can only cope emotionally with the next stage of my progression, not the stage after that. If I go to the stage after that then… it’s too much.”

Mini-Lab Participant

The Backpack can overcome this using an asset-based approach, arming them with the strategies to cope with the next stage of their condition and highlighting eligibility for other forms of support.
DESIGN CONCEPTS
1) Mapping Interactions

Overcoming the challenges of navigating a complex system

This concept maps the care interactions around the person, providing high-level information to make visible the complex network of professionals supporting the person.

Health and social care professionals expressed frustration at the lack of information about what care is already in place. This often leads to duplication in effort and disconnected care, with instances of multiple referrals made for the same person. This is compounded by the complexities of MS, and the many different professionals who may be involved in supporting this person. In addition issues around capacity, in particular due to cognitive impairment associated with MS, can make it difficult for the person to remember who is involved in their care and what referrals have been made. Smaller regions such as Moray allow professionals to partially overcome this through close networks and known points of contact. This points to the need for new ways of mapping the services that currently support the person, and the resulting interactions that occur. Mapping the services in this way has the potential to overcome the lack of integration between health and care systems.

"And also we said about having the care package – how much care is coming in and what times they are going in, because often we’d be the same – we do joint visits with carers and you are running around trying to find out what times carers are coming in."

Lab 2 participant

"I think the good thing about this is the speed you can find stuff at rather than having to trawl through all the information and email people, if you just click…"

Lab 2 participant

Similarly, people living with MS spoke about the need to maintain and manage many different professionals to meet their current and changing needs. This relies on a proactive and motivated approach to ‘building your own care team’, which was challenging and emotionally demanding. In many instances finding the right person at the right time was considered serendipitous. Simple tasks like finding contact details or knowing who to call were barriers to accessing services. Sharing information about their care team with other professionals, and their current and past interactions would be preferable. Continuity of care was important, highlighting the need for handover when staff moved roles, since much of the valuable knowledge of the service and people move with them.

"So there’s a team of support there but I kind of needed to hold in my head that these are all people that can be accessed. But I’m quite motivated and articulate so I have pieced together the system that works for me and the journey has meant that different people have taken centre-stage at different times."

Mini-Lab participant

“I have given up looking for this care team and (I’m) realising it’s got to be a virtual one.”

Mini-Lab Participant

“I wouldn’t know who to contact or even if you phone the MS nurse, you leave a message and they’ll get back to you but even that gets lost in translation… I do tend to write things down…I must get a book because bits of paper just go missing, I know it’s my biggest problem.”

Mini-Lab Participant

Key Ideas

Mapping interactions

Information is presented as a timeline (Figure 1) or circle of care (Figure 2), showing the professionals involved, their contact details and agreed actions from their most recent interaction. This could also be presented as a diary showing the schedule of care and support already in place across the week, so that the professional can plan their visit to coincide or avoid other
appointments. The circle of care visual can also function as an address book for the person who owns the Backpack, making it easier to contact the person they need at the time.

⇒ **Shared decision-making**

For home visits, some social care professionals prefer to make their notes back in the office, rather than during the visit. They would not wish to make notes in the Backpack directly, and therefore the Backpack should be flexible to support this way of working and avoid duplication of recording. This has implications for how the interactions get into the Backpack and would require bi-directional access. However this presents an opportunity to make the service more equitable, by mutually agreeing the actions, thereby enhancing shared decision-making between the person and the health or care professional (Figure 3). The physical act of recording and agreeing the plan together during the visit changes the dynamic to empower the person. This would rely on a ‘publish subscribe’ model with the PDS owner giving permission for the professional/service to publish data to their PDS.
2) Health Story

Foregrounding people and their stories

This concept is core to person-centred care ensuring the person’s needs and wishes drive their care. It offers a way for people to tell their own story in their own way, and communicate what is important to them.

People living with MS described having to recount their ‘story’ every time they connect with a professional or service, which is frustrating, emotionally draining and time-consuming. The complexity of living with multiple long-term conditions made this story even more challenging to tell.

“So to be able to have a once and for all, okay, it’s not going to be once and for all because it’s changing all the time, but a template for my story of MS with all the awful bits remembered but without having to keep on doing it with each agency you engage with, having to prove yourself.”

Mini-Lab Participant

Participants were frequently surprised by the lack of basic knowledge held by the system, resulting in inappropriate appointments.

“I’m in a wheelchair, I don’t walk sometimes because I feel like it. But yet the NHS doesn’t seem to have this information.”

Lab 1 participant

Participants wanted this to contain relevant jargon-free health information, with links to more detailed test results that could be shared with their health professional if required. This would overcome the current challenge of services not sharing health information across regional boundaries.

Health and social are professionals could see the value of this type of information, as “ways in” to understand more about the person and the things that are important to them. This type of information would be particularly helpful in advance of meeting the person for the first time. It was also highlighted that having an awareness of the home environment and informal circles of care would help to prepare.

“(Anticipatory Care Plans) are incredibly useful when you are working out of hours because you don’t know anybody but you can read it in the car as you are going to the house so at least you have some real idea about the family set-up and who is involved and how you could help.”

GP participant, Lab 1

Key Ideas

‘Health story’ provides a space for the person to share their story in their own words, using video or written narrative, supported by key dates and facts.

“… it would be really nice if there was a little bubble with my story there without me having to say it again and again.”

Mini-Lab Participant

The story can be regularly updated showing recent interactions and high level test results, with an option to include a video of their home environment.

“…a video of what their home environment looked like and the access, particularly for hospital discharge and knowing what you are going out to, it would make it a lot easier for us because we would be able to progress what’s going to be needed.”

Lab 2 participant

The story can be shared privately with each new service interaction, or publicly as a way to support others in similar situations through personal experience. Where this information already exists online, e.g. in blogs, video diaries, there could be an option to upload this content to health story avoiding duplicated effort.
Andy Green

> Living with MS (diagnosed 2005)
> Living with type 1 diabetes (diagnosed 1980)
> Uses a wheelchair (from 2011)
> Weakness and difficulty moving limbs
> Numbness

In 2001 I began to have an achy feeling from the knees to the ankles, and found that I had to go to the toilet more frequently. This worsened over a few years but I was generally healthy and fit. In 2004 I completed a triathlon and staggered after crossing the finishing line, I knew something was wrong. After a year of visits to an assortment of specialists, the neurologist told me I had Primary Progressive Multiple Sclerosis and that there weren’t any treatments. Since then I have declined and can no longer walk any significant distance, I feel as if hundred pound weights are strapped to both legs. The problems with my bladder have also worsened. I can still walk, but not very far, so I use a wheelchair which gives a wonderful sense of liberation from lumbering around leaden-footed. I also have type 1 diabetes and have an insulin pump. My control is pretty good, and I have a reasonably healthy diet. I’m quite motivated and find I can usually find a solution for problems that come up, I have pieced together the system that works for me. I just want to stay as well as I can with the functioning I’ve got.

[update by Andy, 10th April 2017]

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3) Smart Form Filling

Emotional cost of navigating the system

This concept tackles the emotionally demanding bureaucracy of statutory systems. Intelligent forms permit fields to be automatically populated based on data saved in the Backpack and recognise eligibility for other appropriate services based on criteria.

“…when you come up against an obstacle you can also get fatigued by that so you decide ‘I’ll just not go there’...it’s a funny one because you have to face your emotions and that tires you out too.”

Mini-Lab Participant

People living with MS described the challenge and emotional cost of navigating complex systems to find the right information, people and services. Eligibility criteria and forms seem to be deliberately confusing, deficit-based and require significant energy to complete, which is already in short supply for people living with MS. Often this effort is wasted as the person does not meet the narrow criteria set for eligibility.

“…when you are invited to claim a benefit that’s related to your health and disability you are encouraged to describe yourself as a sick person.” And same person “(practitioners) are encouraging you to think as a well person, to be positive and we know that positive thinking helps... you want the benefit because it makes a huge difference to your life so you become that sick person and for as long as you are filling in the form you are that sick person…”

Mini-Lab Participant

Many applications to gain access to support require people to prove their level of need, which adds to the burden of filling out paperwork and can leave people feeling that they are suspected of cheating the system.

“...it’s proving that you are ill enough. It’s difficult enough coping with it without actually having to prove that you are... and you can vary so much too from day to day, you can feel reasonably well one day and feel absolutely wretched the...(next)”

Mini-Lab Participant

The need to “make yourself known” to the many different parts of the system is an unnecessary and invisible barrier participants face when trying to access the care they are entitled to.

“…the MS Nurse… suggested getting in touch with (local) Council and the phrase she used was ‘I think you should make yourself known’ because I don’t get any services from the (local) Council

Homecare department… then in case of emergency or sudden change of circumstances I’d have a safety net.”

Lab 1 participant

Participants had strategies in place in case of emergency, such as car accidents or cognitive decline, storing practical information and wishes to support their next of kin. Similarly health and care professionals raised the issue of capacity and the importance of power of attorney to be in place.

“I’ve got a file in my ‘misc’ folder on the desktop of my computer which is basically an ‘in the event of my death file’, so that’s all my passwords, all my details.”

Mini-Lab Participant

Health and care professionals queried how the Backpack would handle issues around the possibility of editing or removing information they recorded, given that the Backpack would be a person-owned data store.

“Just one wee negative - I’m thinking on is...could (I put in..) ‘could the client then change that slightly’? – ‘I’ve never seen that for two years’, so would it need to be something that’s locked”

Lab 2 participant

Key Ideas

Gradually filling up
Rather than requiring a large amount of data entry prior to use, the Backpack could gradually accumulate information as the person completes forms and could automatically draw in data from existing sources.
In Case of Emergency

Andy Green
> Last updated 1st Mar 17

Emergency Contact

Amy Green
Wife
(Next of kin)

- **Power of Attorney** in place for Amy Green
  Registered with The Office of The Public Guardian (Scotland) - 12/12/2016

- Transfer access of my Backpack to **Amy Green**
  including:

  - **Access All Areas**
  - Restricted View (specify)
  - Restricted Share (specify)

“I’m excited about the idea of this Backpack but the excitement diminishes when I think about having to key in all the information myself…”

Mini-Lab Participant

→ **Suggesting appropriate services and verifying eligibility**

The Backpack could intelligently compare data against eligibility criteria, highlighting any appropriate services they may be entitled to access. Information could be verified through the Backpack (i.e. this person is on the MS Scottish Register) to automatically prove eligibility for services (i.e. Blue Badge).

“Once (the GP) has made a diagnosis that someone has MS, that can be represented by a letter or it can be represented by a digital letter or it can be represented by a digital token and the person could carry that with them, as they do, or it could be live with (local) Council that when this person rings there’s a token that comes up to say that this is who they are.”

Lab 1 participant

Information could be locked, dated and attributed to the person who added it so only mutually approved information is saved in the Backpack (i.e. a professional’s notes can’t be changed at a later date).

→ **In Case of Emergency (ICE)**

ICE and power of attorney rules can be set up in advance to allow the person to transfer ownership of the Backpack and give access to their nominated person.
4) Tools for the Specialist MS Nurse

Overcoming the challenges of supporting people to live well with their condition

This concept is a staff facing view of the Backpack, designed specifically with the needs of the specialist health professional in mind. It responds to the insight that the MS nurse would want to use the Backpack in a different way from their health and social care colleagues.

The role of the MS nurse is such that they cannot discharge patients, and therefore case load only ever increases, with one person managing a high number of people. While they run clinics with scheduled appointments, they also offer support over the phone as and when needs arise, and in case of emergency. This differs from other health and care professionals who only require to access information about the particular patients they are scheduled to see that day.

Changes relating to the patients are not communicated to the MS nurse, to the extent that they are not informed of, e.g. hospital admissions, outcome of referrals or even death.

“That’s the thing. I never get anything. I get nothing from OT, I get nothing from physio, I get nothing from the GP, the only person I ever get anything on and it’s very sporadic, is from (Leisure Centre Trainer), from the GP referral scheme to say somebody has completed their course. I really get no feedback from referrals that I make, nothing. And that’s honest – I don’t.”

Lab 2 participant

In an empowering role, the MS nurse aims to support patients in self management in sharing news and updates of available services and treatments. They currently have no means of providing patients with this information collectively, with all communication on a one-to-one basis.

People living with MS greatly appreciate the support of the MS nurse, but are aware their time is limited. They suggested that having a designated person would help them with the challenging task of navigating statutory systems.

“I feel we could do with a designated social worker, care worker, health worker — somebody you could phone and say ‘this is what I need right now, how do I get it?’”

Lab 1 participant

Key Ideas

The specialist nurse would be able to see an aggregate view of all patients in their caseload. With permission from the Backpack owner, the system would notify the nurse of any changes in their condition or circumstances recorded by the person or their health and care professionals. These patients would be shown at the top of the list to enable the nurse to better manage their caseload prioritising people who may need their support.

The nurse would be able to send out communications to all their patients via the Backpack (e.g. ‘email all’).
<table>
<thead>
<tr>
<th>Patient Name</th>
<th>Change (priority order)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andy Green</td>
<td>&gt; admitted to hospital May 9th 2017 (Dr Grays, Nurse J. Holmes)</td>
</tr>
</tbody>
</table>
| Esme Lime        | > referred to Physio (GP, Dr. Black)  
> appointment scheduled for May 26th 2017                                                                                                                                                                       |
| Rosie Smith      | > referred to Occupational Therapist (GP, Dr. Smith)  
> home visit scheduled for June 10th 2017  
Rosie needs to be assessed due to new symptoms of numbness and problems with balance. Home environment may need modifications to reduce risk of falls. |
| Jen Pink         | > Husband has been admitted to hospital (Jen Pink, May 24th 2017)  
> Home care support requested social work assessment pending                                                                                                                                                         |
| Jules Damson     | > Tonsilitus (GP, Dr Brown)  
> Antibiotics prescribed (GP, Dr Brown, May 24th 2017)                                                                                                                                                                               |
| Dan Forrest      | > Community Alarm requested (Joanne Forrest, May 23rd 2017)  
> Home assessment scheduled June 1st 2017 (Alarm team, Kay Jones)                                                                                                                                                           |
| Betty Blue       | > Community Alarm requested (Betty Blue, May 22nd 2017)  
> Home assessment scheduled June 1st 2017 (Alarm team, Kay Jones)                                                                                                                                                           |
The following scenarios were drawn from examples given by participants, and are intended to illustrate the benefits of the Backpack concepts through practice.

**Scenario 1**

**A person living with MS applying for disability benefits**

The Backpack automatically pre-fills the form with demographic information and unchanged data saved from previous applications, enabling faster completion by the person living with MS. Information such as health conditions and functional abilities verified by a health professional, and videos of the home environment (e.g. showing adaptations required) reduce the workload of assessors and ensure faster processing of claims.

**Scenario 2**

**A social worker preparing for a home visit to assess a newly referred person living with MS**

The social worker can review the Health Story, preparing themselves with information about the person’s interests and wishes to identify “ways in” to understand how they can best engage with and support the person. They can watch a video or view photos of the home environment, to ensure they bring appropriate equipment and are prepared for any needs or challenges it might pose. They can view the diary to choose the most appropriate time to schedule their visit, e.g. when a carer might also be present to support the assessment. They can also view the timeline or circle of care, to understand at a glance what other care is already in place, and any other recent referrals or equipment that has been ordered. With the person’s permission, data from the Backpack can be used to pre-fill the assessment forms to reduce the time required. The MS nurse will be able to see that the social work home visit is planned, and the outcome of their assessment to follow up for any further support the person might require.
Scenario 3

A person living with MS who requires additional care to be in place to support them to return home following a hospital admission relating to a progression in their condition

The Backpack will alert the MS nurse that the person is in hospital, with information about the reason for admission. Videos of the home environment help the ‘home from hospital’ team to assess any issues or modifications required to support them to return home. Their Health Story can provide the team with an understanding of their preferences, ensuring they are reflected in the care plan. The circle of care view can quickly show them what existing care and family support is in place, and identify any new services that might be appropriate.

Scenario 4

A person living with MS who has experienced a cognitive decline, requiring their partner to use power of attorney to make decisions about their care for the first time

The partner can access the information in the Backpack due to the instructions of the person living with MS saved in the ICE folder. The partner can see their care wishes within the Health Story, and use this to make decisions about their care. They have full access to the contact details of the different professionals and services that support the person using the circles of care view, and can see any scheduled appointments or care in the timeline and diary views.
Roadmap for Discussion

This visual is intended to explore how the concepts interrelate, and how the Backpack integrates with other statutory and commercial systems. In addition to generating awareness of the context and developing the concepts, the Experience Labs also raised a number of questions and comments for discussion to identify the next steps for the Backpack, presented here in the surrounding circles.

DISCUSSION QUESTION
Who is responsible for protecting the security of sensitive information within the context of risk-averse health and care systems?

DISCUSSION QUESTION
Could Backpack offer a person-centred way of integrating health and care services, and sharing information between professionals to overcome deficiencies in current IT systems?

DISCUSSION QUESTION
Should it sit outside the NHS so that the power remains with the user? How do we ensure access to services remains equitable?

DISCUSSION QUESTION
Who is responsible for protecting the security of sensitive information within the context of risk-averse health and care systems?

DISCUSSION QUESTION
Could these insights be transferable to other types of specialist nurses? Could this become a key tool in coping with demand due to the rise in LTCs?

DISCUSSION QUESTION
Who is responsible for protecting the security of sensitive information within the context of risk-averse health and care systems?

LAB 2 PARTICIPANT
"...you can’t just take information off that and put it into that, so there’s another thing about duplication of work. You find it hard enough to do your notes as it is without doing them twice."

How do we ensure the Backpack can interface with staff-facing systems if it is patient-owned?

Frontline health and social care

Health Story

Smart Form Filling

Mapping Interactions

Back office

NHS IT systems

External Providers

other statutory systems

third sector

CONFERENCE 2: Are these insights transferable to other types of specialist nurses? Could this become a key tool in coping with demand due to the rise in LTCs?
DISCUSSION QUESTION: Should it sit out with the NHS so that the power remains with the user? How do we ensure access to services remains equitable?

DISCUSSION QUESTION: Who pays for the Backpack?

DISCUSSION QUESTION: What is the business model?

DISCUSSION QUESTION: What are the options for developing the concepts as standalone or integrated products?

DISCUSSION QUESTION: Could this become a key tool in coping with demand due to the rise in LTCs?

DISCUSSION QUESTION: Are these insights transferable to other types of specialist nurses?

DISCUSSION QUESTION: Who is responsible for protecting the security of sensitive information within the context of risk averse health and care systems?

DISCUSSION QUESTION: What are the options for developing the concepts as standalone or integrated products?
Conclusions

The concept of a person-owned data store that would allow the person to securely manage and share their personal information was positively received by both people living with MS and health and care service providers. People living with MS highlighted a number of characteristics that support positive interactions with people and services, which can be translated into design principles for the structure, language, look and feel of the Backpack. Insights about security and data sharing suggest that participants were pragmatic about the risks of loss of privacy in exchange for the perceived benefits of convenience and equitable access to information, empowering them in their interactions with statutory services. Participants highlighted the importance of designing the Backpack to accommodate and reflect their personality and interests, facilitating everyday life and activities. Health and care professionals would also value this information, supporting them to understand what the person enjoys and tailor their care to their aspirations.

Health and care professionals could see how the Backpack would overcome many of their current challenges in: accessing information from other health and care professionals, better understanding the needs and wishes of their service users and managing increasingly large case loads.

The four design concepts presented offer insight into how people living with MS and health and social care professionals would envisage person-owned data stores working for them in practice, offering a fresh perspective to existing conversations between technologists and Government strategists. The benefits of involving citizens and health and care professionals in this conversation are highlighted by the innovative and practical nature of the proposed concepts. The ongoing participation of people living with long term conditions, carers, and health and social professionals is vital to ensure that any developments in this area meet the needs and aspirations of the people who will use them.
The idea of being able to hand this to somebody and say, ‘here, this will tell you about me, things that maybe you need to know’.”
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Advancing Digital Health & Care

Exploring the infrastructure required for citizen-centred services

Chaloner Chute, Chief Technology Officer, the Digital Health & Care Institute
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1. Executive Summary

The use of digital technology is advancing rapidly across Europe with many citizen’s including those thought to be ill equipped or excluded now accessing public services online. The UK is ranked highly (6th) for digital progress overall, but relatively poorly (18th) for accessibility and use of digital public services.

This pattern extends to digital health and care services. In the UK, like many European countries, there are successful infrastructures that have improved service delivery from a systems perspective – such as Electronic Health Records (EHRs) and Clinical Portals. These worked very well in a system in which the NHS was expected to control the dialogue and optimise clinical outcomes for citizens. As care is shifted towards more distributed, citizen-centred, and community-based models, these systems – which are largely centralised - can no longer handle the complexity and diversity involved in integrated and personalised care.

Health and care systems have attempted to remedy this through ‘Patient Portal’ platforms by giving citizens access to their EHR and by digitising transactions such as appointment and repeat prescription booking. This has had some positive impact from an administrative and workflow point of view but has as yet shown very poor uptake and retention of use and has shown no improvements in health outcomes for citizens. This is largely because this approach reflects only small changes within the existing patriarchal model of healthcare system and medical control, offering citizens only a small access point into the healthcare system as it already exists, rather than meaningful co-management functionality.

To learn from those countries topping the European digital public services accessibility and use rankings – Finland and Estonia – they have more radical approaches to citizen empowerment. Thinking holistically and with citizen access and empowerment in mind, these countries share common components around national identification, enforced database interoperability and consent driven, transparent control of data flows by the citizen. This simplifies access and builds trust in data sharing, which in turn creates a more seamless citizen experience. They are both also exploring personally held data capabilities that can adjoin the statutory record to personalise services more effectively. This approach is based on a national dialogue led at the highest levels politically and organisationally.

Scotland currently has taken a more cautious route. A mandated change around identity, privacy, citizen control and data sharing is difficult to commit to politically, and the benefits of doing so are not necessarily clear.

To close the gap between Scotland and the European leaders, it is recommended that, at a minimum there is a national dialogue initiated around a Scottish e-society – focusing on effective delivery of citizen centred digital public services and therefore concerning identity, privacy and transparency around data sharing in the context of effective public service provision. Progress is slow because the public sector does not have a clear mandate from its citizens to transform services.

Realistic Medicine, as espoused by the Chief Medical Officer, can be achieved by enhancing our ability to share data in a consent driven fashion, allowing more seamless and personalised services, with diversity for citizen but built on a consistent core infrastructure and standards base. Key to this are three interlinked concepts:
1) If the citizen is to be empowered, then they must own their own data, must see the data held by others about them and must be able to limit how data is shared effortlessly and directly.

2) Care is distributed – so the digital infrastructure must not centralise power and access. If citizens feel they genuinely have this control and choice, then trust in the system increases and data begins to flow more effectively.

3) Personalisation is more than just customisation of generic services - permission-less innovation must flourish near the citizen, but within a governed set of standards and norms to protect quality of care.

A distributed care system supported by a distributed, but standards based digital infrastructure, is exactly what the Scottish digital health and care marketplace needs to flourish. The leading e-societies of Europe are now capitalising economically on their more open, distributed, data rich systems. Businesses are able to add value significantly quicker with far fewer barriers and can demonstrate benefits directly to citizens. This in turn then allows them to engage with global markets that are increasingly working to the same consumer focused, distributed delivery models.

So, in conclusion, it is recommended that Scotland begins with citizen-centred co-design activity to understand how to empower citizens in a digital era and then use this to start a national dialogue to secure a mandate for change. This could then initiate a distributed digital infrastructure that can then allow innovation to flourish in response to these diverse needs.
2. European Digital Progress

Europe’s Digital Progress Report (European Commission, 2017) identifies a rapid uptake of digital channels in the communication between citizens and public services. There has also been a decrease in digital exclusion as private and public services develop methods of improving access. Internet use for elderly people has also expanded greatly in this five-year period (48% to 65% of the population).

**Figure 1: Preferred channel for submitting forms to public authorities by EU citizens**

Looking then to comparative indicators, the UK is placed sixth for overall digital progress in Europe.

**Figure 2: Digital Economy & Society Index**

However, the UK only ranks 18th when looking at only the use of digital public services.

**Figure 3: European Digital Public Services Dimension**

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1. The Digital Public Services dimension indicators: 1) % internet users who have completed an online public service form, 2) how much the form is pre-filled from existing public service data, 3) how many interactions can be performed completely online, 4) the government’s commitment to open data.
3. European Digital Health & Care (eHealth) Progress

Deployment & Adoption by Services

The UK is acknowledged to have good foundation eHealth infrastructure, ranking sixth in the European benchmarking exercises for deployment of eHealth services in hospitals, and seventh for primary care.

Figure 4: Benchmarking Deployment of Hospital eHealth Services (Maghiros & Sabes-Figuera, 2013)

Figure 5: European Index of Primary Care eHealth Adoption (European Commission, 2013)
Availability & Use

However, the UK does not perform as well, ranking 20th, when assessing how this eHealth infrastructure then translates into the use of digital services by staff and citizens (such as embedded clinical decision support, electronic communication with patients, and remote monitoring of patients).

Figure 6: Benchmarking Deployment of Hospital eHealth Services 2012 – Availability & Use (Maghiros & Sabes-Figuera, 2013)²

This paper will explore the disparity between the UK’s robust eGovernment and eHealth infrastructure and the relatively poor accessibility and use of digital services provided on top of that infrastructure.

Note that no separate data is readily available that compares Scotland with the rest of Europe in these terms. It is assumed for the discussion that follows that Scotland is broadly representative of the UK experience as a whole – that Scotland has great digital progress overall, but that it has struggled to capitalise on this through usable and accessible digital public services.

² Note the equivalent data was not available for availability and use in primary care.
4. Analysis

This section first outlines the common eHealth approaches across most European countries. It then goes on to contrast this with the emerging approaches that distinguish the countries leading in terms of accessibility and usability of these services. It finishes with a discussion of the broader requirements for eGovernment as health and care services integrate.

4.1. General eHealth Features

4.1.1. Existing eHealth Services

Besides basic ICT information and infrastructures, the key pillars of eHealth include (European Commission, 2013):

1) **Electronic Health Record (EHR)** - “Systems used by healthcare professionals to enter, store, view, and manage patient health and administrative information and data” – characterised by a spread of different, disconnected systems in primary, secondary and social care.

2) **Health Information Exchange (HIE)** - “The process of electronically transferring / sharing / enabling access to patient health information and data.” - characterised by:
   - **Point to Point Integration** - and data sharing between health and care providers, governed by information sharing agreements.
   - **Clinical Portals** – provides a web interface that draws together many disparate sources of patient information into one, usually read-only, view.

3) **TeleHealth** - “The use of broadband-based technological platforms for providing health services, medical training and health education over a distance.” - characterised by:
   - **Remote consultation** - replacing face-to-face with video conference or secure messaging.
   - **Remote monitoring** – either diagnostic or trend monitoring – most commonly for blood pressure and blood glucose control.
   - **Training and education** – using mainly video conferencing technology.

4) **(Tethered) Personal Health Record (PHR)** - “Electronic systems allowing patients to have secure access to, and manage, their health information.” - characterised by:
   - **GP Patient Portals** – that offer patients a read-only view of the Electronic Health Record (EHR) held by GPs on a practice by practice basis.
   - **National Patient Portals** – that draw information from across multiple health and care systems to offer a single web-based view of the citizen’s record and transactional services.
   - **Condition Based Patient Portals** – that offer patients a web-based view of pertinent information about their condition – usually a long-term condition such as diabetes.
4.1.2. Emergence of the Person Held Record

Due to the emerging nature of the Person Held Record / Personal Health Record (PHR), it is often confused or defined in overlapping terms with a Patient Portal, or Electronic Health Record (EHR):

- A “tethered” PHR is a means by which citizens can view the data held by a health and care system (EHR). This is often offered in the context of a Patient Portal offering secure login and collocating this information with educational resources and some transactional services such as appointment booking. The tethered PHR can sometimes allow for basic editing of demographic data by the citizen, or at least feedback on changes and errors.
- An ‘untethered’ PHR is an entirely citizen-controlled and edited data repository. Use of the data within it is driven by a consent model, ensuring that privacy is maintained (satisfying new General Data Protection Regulations (GDPR) for active consent to share data).

The ‘tethered’ PHR / Patient Portal concept has been discussed since the early 2000s and has now evolved to include transactional elements such as appointment or repeat prescription booking. It is important to understand what drives the uptake of tethered PHRs and Patient Portals globally. The patient portal concept is intended and often narrated to be a tool to empower a citizen and increase the ease with which they access services.

However, the main drive and uptake of this technology is found in the U.S. In 2009, the U.S. Congress passed the HITECH Act, which authorised incentive payments to physicians who demonstrated “meaningful use” of Patient Portals. Since 2015 those not adhering to this face penalties. Meaningful use at stage 1 required 5% of service users to register for and use a Patient Portal. Many practices have struggled to hit even this seemingly low level of adoption. Figure 7 below highlights some of the reasons for poor uptake.

Figure 7 – Main reasons for poor uptake of a patient portal (Softwareadvice.com, 2014)

These are the hallmarks of a system built for the service provider, not the user. The critique most often levelled is that the platforms are developed with a ‘build it and they will come’ mentality, focusing on satisfying the ‘meaningful use’ criteria and building to achieve transaction-based administrative savings for the practices, rather than focusing on value to the patient.
An unnamed patient portal vendor’s sales documentation captures this well:

“Beyond basic requirements of sharing health record information, portals should be a place for each provider to customize the patient interaction based on their specific practice needs and workflow.”

Outside of the U.S. some countries have adopted national patient portals, portals for individual conditions or patient groups, or practice-based portals at a local level. In most cases the value is the ability to channel shift people away from offline communication channels, reducing the service pressure and administrative burden on staff, with parallel benefits projected for patient empowerment and therefore improved outcomes.

However, despite some evidence to suggest some efficiency and administrative savings, actual adoption by patients remains very low. Global reviews have also found no evidence to substantiate the view that empowerment and improved outcomes follow Patient Portal implementation (Ammenwerth, Schnell-Inderst, & Hoerbst, 2012).

The key question is, are we perpetuating and forcing an industry-led service offering that citizens simply haven’t asked for? There is clear evidence that people want access to their records and want to book appointments and prescriptions online (Accenture Consulting, 2016). What isn’t clear is that citizens gain value from systems that are built predominantly to satisfy the transactional needs of health and care providers.

Patient Portals have a place in a broader digital health and care infrastructure, but the transactional efficiencies they bring should be the focus, with other elements of the infrastructure being developed to support a package of capability that can empower a citizen and improve their outcomes. Development must include untethered PHR functions that are built on the citizen’s terms, allowing them to co-manage their own care, rather than purely focusing on the Patient Portal functionality to involve citizens in the service oriented clinical and administrative workflow.

4.2. Lessons from the most accessible eHealth services

Estonia and Finland rank first and second in Europe for both overall digital public services and for the availability and use of eHealth services. The Estonian composite indicator for eHealth availability and use is double the EU average and triple that of the UK. This section explores the approach to broader digital public service delivery that enables such high levels of access and use.

4.2.1. Case Study 1: Finland

A National Personal Health Record

Kanta Services is the Finnish National Archive for healthcare information. They are now introducing an untethered Personal Health Record (PHR) that will enable citizens to enter their own health-related data (Hypponen, 2017). Third parties will be able to develop digital services and apps for citizens that produce, store and analyse this personal data. Health and social care professionals will be able to access the data only with the citizen’s active consent.
Sandbox development environments are currently available for early stage experimentation and development. The following elements are being developed to help govern this capability:

- Consent management standards and systems
- Authorisation and data security solutions
- Broader technical standards around identity, authentication and data sharing
- Certification criteria and process for PHR linked apps
- Legislation to allow, through consent-driven processes, for these apps to access official health and care data held in the main electronic health record.

Capitalising on this Infrastructure

The Finnish Digital Primary Care (ODA) project is a new approach to digital citizen monitoring, symptom checking and self-management. It builds upon this new Finnish National PHR approach. It is predicated on a digital-first approach to taking a person’s own data (Untethered Personally Held Record or PHR), combining it with the data from their Electronic Health Record or EHR and then using automated decision support systems to help them self-manage, make decisions and interact further with services if required.

This integration of records enables a citizen’s own data to auto-populate many of the data fields in the tool – significantly cutting down on the time and effort spent, while ensuring advice and self-management options are given in a personalised manner. This in turn then forms the first step in a dialogue with the health and care system, rather than a mere disconnected symptom check.

Technological Foundations

Sitra, the Finnish innovation fund, states that for the diverse provision and use of digital services such as this, there is a requirement for “the electronic identification of citizens and the exchange of information between databases in a unified manner. The existing databases of public organisations could be exploited for service production purposes, through the use of a common data exchange layer. Several types of registration data, such as health records or motor vehicle registrations, would only need to be stored in one place – the layer would enable the use of original, up-to-date data from its original source when, and where, needed. Together with an eID this also enables citizens to check and update their own data and to use a variety of public and private services online. A data exchange layer operates on the basis of standardised interfaces between information systems.” (Sitra, 2017) (emphasis added).

Cultural and Political Foundations

However, technological elements are only one aspect of the fully transparent, interoperable digital infrastructures required for the development of effective digital self-management services. The following are the broader key features required for effective eGovernment, as it relates to the Finnish experience (Korhonen, 2016):

- A culture of openness – that values transparency in the delivery of eGovernment and ensures broad-based support for transparent and effective data sharing. This includes a national dialogue in which everyone understands that owning your own digital identity enables this enhanced transparency and control on the part of a citizen.
- High level leadership - The Prime Minister chairs the Finnish Information Society Programme.
• **Legislation compatible with digital government** – acts that promote and ensure the secure and effective interoperability of information systems, electronic identification as standard, and openness of access to non-personal data while protecting personal data.

• **Proper base registers form the foundation** – population, company, property and other registers are core infrastructure for eGovernment and must hold comprehensive, accurate and up to date information, and protect against unauthorised changes.

• **Interoperability and cooperation within government** - Interoperability within government is a prerequisite for sophisticated e-service provision. Today, internet technologies dominate and typical technical interoperability problems can be solved quite easily. In the Finnish administration, the Achilles heel of interconnection between different systems usually lies at higher levels of interoperability. In some cases it is about semantics. The same concepts, sometime even simple ones, such as addresses and names, can have slightly different meanings and formats. In other cases, strict legislation may prevent the exchange of data between organisations. The Finnish government is continuously working on these issues to overcome the obstacles for smooth interoperability. If there is no proper interoperability, then there are no seamless digital services either.

• **Focus on the citizen** - Customers’ needs should be the main focus in service design. Digital services are not just forms on web pages and you should not rush to modify existing services to electronic ones. Some procedures (or services) might not be needed at all – either in traditional or electronic format.

4.2.2. Case Study 2: Estonia

A Distributed, transparent eHealth model

A legislative programme was developed that enforces the following foundation principles:

• All health and care providers must send data to the Health Information System (HIS).
• Access given only to licensed professionals and others permitted by law.
• ID card for authentication and digital signature.
• The citizen has the right to close their own data on the central database (opt out), access their own data (Patient Portal), declare their intentions and preferences and monitor who visits and undertakes activities with their data on the HIS – all actions leave a secure, permanent trail.

Capitalising on this Infrastructure

The Electronic Health Record is a nationwide system that integrates data from Estonia’s different healthcare providers to create a common record for each patient. Using the data exchange layer, X-Road, the EHR retrieves information from various systems, and presents it in a standard format. In an emergency situation a doctor can use a patient’s ID card to read time-critical information such as blood type, allergies, recent treatments, ongoing medication, or pregnancy. The system also compiles data for national statistics, so the relevant ministry can measure health trends, track epidemics, and make sure that its health resources are being spent wisely.
Patients have access to their own records, as well as those of their children. By logging into the Patient Portal with an electronic ID Card, the patient can review their past doctor visits and current prescriptions, control which doctors have access to their files, and even receive general health advice.

**Technological Foundations (E-Estonia, 2017)**

X-Road is the backbone of e-Estonia. X-Road is an integration layer that allows all public (and some private) databases to interact, making integrated digital services possible. Institutions are not locked into any one type of database or software provider. Databases are decentralised – every government agency or business can choose the software/hardware product that is right for them. All of the Estonian e-solutions that use multiple databases use X-Road. All outgoing data from the X-road is digitally signed and encrypted. All incoming data is authenticated and logged. National ID cards are mandatory in Estonia, giving digital access to all of Estonia's secure digital services. The embedded chip on the card uses 2048-bit public key encryption, making it a secure and definitive proof of ID in an e-environment. The ID card is regularly used in Estonia, e.g.:

- As a national ID card for legal travel within the EU for Estonian citizens
- As the national health insurance card
- As proof of identification when logging into bank accounts from a home computer
- For digital signatures
- For online voting
- For accessing government databases to check one’s medical records, file taxes, etc.
- For picking up e-Prescriptions

The six main security principles of the Estonian eHealth system are:

- Secure authentication - of all users with ID-card or mobile ID.
- Digital signing or stamping - of all health documents.
- Maximum transparency and accountability – actions will leave an unchangeable, secure trail.
- Cording of personal data – separating personal data from medical data.
- Encrypted database – that removes the confidentiality risks.
- Monitoring – of all actions together with corresponding counter-measures.

**Cultural and Political Foundations (the Estonian Information Society Strategy)**

The Estonian Information Society Strategy is built on the following foundations:

- the development of the information society in Estonia is a strategic choice with public sector leading a partnership with the private and third sectors;
- the public sector is a smart customer, ensuring that in public procurements there is as much freedom as possible for innovative solutions;
- the information society is created for all Estonian residents, although particular attention is paid to the integration of social groups with special needs;
- the information society must not undermine people’s sense of security. The protection of basic rights, personal data and identity must be ensured, and mitigation of non-acceptable risks in information systems must be guaranteed;
- citizens will have increasing control over the use of their personal data;
• the public sector employs the already existing technological solutions (i.e. the ID card, the data exchange layer X-Road) and avoids duplication of IT solutions;
• the public sector re-organises its business processes so as to ensure a one-off collection of data from citizens, entrepreneurs and public bodies;
• the public sector gives equal treatment to different hardware and software platforms and ensures interoperability of information systems by using open standards;
• the collection of data and the development of ICT solutions proceed from the principles of re-usability.

Some Dos and Don’ts based on Estonia’s experience:
• Do – Create a decentralised, distributed system so that all existing components can be linked and new ones can be added, no matter what platform they use
• Don’t – Try to force everyone to use a centralized database or system, which won’t meet their needs and will be seen as a burden rather than a benefit
• Do – Be a smart purchaser, buying the most appropriate systems developed by the private sector
• Don’t – Waste millions contracting large, slow development projects that result in inflexible systems
• Do – Find systems that are already working, allowing for faster implementation
• Don’t – Rely on pie-in-the-sky solutions that take time to develop and may not work

4.2.3. Discussion

There are common features adopted by the European countries leading on both the development of digital public services and the availability and use of eHealth services, from which lessons can be learned. These include a commitment to:

1) Think beyond health and care - Common needs and use cases for a citizen’s data already exist across the broader public service estate. Investment in health and care specific digital infrastructures and services will duplicate effort and limit the full power of data driven e-governance. A citizen’s health is very often intimately linked to transport, education, welfare, housing, etc. – and so should not be serviced in a silo.

2) Distribute services – all sectors are experiencing a distribution of information and capability as digital technologies democratise processes. Health and care is shifting into community settings and aspires to put the citizen at the centre. This requires a shift in mindset around how digital infrastructure is developed – it cannot be centralised if it is to meet these needs.

3) Partner with, don’t just procure from, industry – Industry are adept at designing for the customer. The entrepreneurial thought process demands that customer needs be met locally, and a marketplace can offer the choice that would be extremely onerous and costly for the public sector to provide centrally. Importantly, citizens may expect to engage through mediums they already use – almost always provided by commercial companies.
Interoperating with these capabilities will drive much greater adoption than building bespoke solutions and attempting to enforce use at great cost. This is linked to the need to distribute information and services to meet citizen needs flexibly. If the state attempts to provide centralised services through large scale ICT projects, this then reduces the opportunities to personalise and democratise access to care while also damaging the country’s ability to derive the local economic benefit (which requires an open marketplace based on standards).

4) Centre design on the citizen:

   a) Avoid enforcing centralised interfaces - Patient Portal and equivalent technologies tend to be developed for services rather than service users. This is also linked to the need to distribute services and use what already exists. Avoid forcing a citizen to interact with one centralised interface where possible.

   b) Avoid digitising existing paper processes – the chances are that digital tools could enable a completely different way of working, or remove the need for an interaction in the first place.

   c) Instead understand attitudes to data sharing and use - engage in research around the acceptability of modern digital systems and their requirements – such as identity, consent and privacy. Once this is understood, services can be developed that meet needs for service, but also for security and privacy.

5) Develop a common approach to identity

   a) National ID Card – this evocative notion has been resisted in the past in many countries. It conjures up fears for privacy and an overreach ing ‘nanny state’.

   b) We already have several IDs – There are identification numbers – such as the NHS CHI number, national insurance numbers, etc. The citizen does not ‘own’ these numbers at present – they are seen only as a means for the state to store and recall information on a citizen. There are also entitlement cards such as YoungScot and the National Entitlement Card (NEC). These numbers and cards have not been unified but the data sets behind them are already easily linked.

   c) Citizens cede much more privacy to businesses – such as Facebook and Google – often without knowledge or any transparency.

   d) A common identity can enhance ownership and transparency – in both Finland and Estonia, strict governance applies, with citizens now able to see who is using their data and query it. Citizens can withdraw their data from use or consent to its use by others. This is significantly better than public services exchanging and linking data sets behind the scenes from a privacy and transparency point of view – but this only works with a citizen owning their national ID.

   e) Develop in dialogue – as per the citizen-centred point, co-design can help identify the right balance and acceptable use cases and structures for identity in the context of consent, citizen empowerment and new service development. It is clear that this level of identification will only be acceptable with a significant increase in control and transparency of the data that links to it.
6) Develop a data exchange layer

a) **Create data once and then reuse it** - Critical to the citizen’s perception of seamless integrated care is the ability to only tell their story once, and for everyone to work to that story and keep up to date as it evolves. The Estonian Exchange Layer was estimated to have saved 7,182,262 working hours last year.

b) This interconnectedness is one of the critical measures for the European measures of accessibility and use of eHealth. However, “the use of inter-connected registers with the purpose of avoiding re-submission of data by the user is not yet widespread. Pre-filled forms are available, for half of EU countries, for less than half of the cases where this could be possible, and sometimes much less than that. Some notable exceptions are Malta, Estonia and Finland, with seven other countries following suit.” (European Commission, 2017).

Figure 8: Use of interconnected registers to auto-populate forms

The UK is third from the bottom on this particular measure.

c) **Use open standards and build for interoperability** – to take advantage of existing capabilities. Do not build bespoke infrastructure and avoid proprietary ecosystems.

d) **Exchange Layer** - Both (a) and (b) have been achieved in Estonia and Finland with the creation of a Data Exchange Layer. This is an open, secure and standards-based intermediary layer that all public service databases can connect to. It does not store data centrally or create new databases – instead it allows different databases to be called on to a portal for a unified view by the citizen’s data, and in turn to be shared with others via a consent model with the citizen in control. It allows citizens to track who uses their data, update their data once and then cascade this through public service databases, auto-populate forms from their existing data and, if desired, share this data with third party service providers to enhance their services for the citizen – all without a centralised database.
7) Develop a personally held record

a) True ownership – where the Exchange Layer allows a view of ‘tethered’ records (i.e. those held in public service databases), ownership and transparency would be further enhanced if an ‘untethered’ record was fully held and controlled by the citizen.

b) General Data Protection Regulations – the key test of ownership is three-fold – 1) active, not passive, consent to share, 2) the ability to withdraw consent at any time, and 3) the ability to delete your own information entirely. An untethered personal record would satisfy this requirement.

c) Choice – in Finland, Holland, and increasingly in other identity schemes such as for the UK Government’s Verify, citizens are encouraged to choose a third-party provider to exert their ownership at arm’s length from a central authority. A marketplace should be stimulated for the untethered personal record, in which citizens should be able to use government credits or their own funds to select a provider that aligns with their own needs – be it principles, ethics, data storage location, reuse of data for commercial return, or interface.

d) Shift the balance of control – over time, as it became clear that a privacy-concerned citizen was generating and holding better quality information on themselves, models of care would evolve to be driven from a personally held (untethered) record managed entirely by consent.

8) Capitalise on the infrastructure – demonstrate the benefits:

a) Develop systems to support decision making – the advantage of these sorts of open, interoperable systems is the availability of data subject to consent. This will have benefits purely from a citizen empowerment point of view – however the other main benefit will be in the ability to support decisions made by professional and informal carers, ideally with the citizen, about the best course of action for care or treatment.

b) Develop preventative approaches – powered by this shared data, care models could evolve that consider a more holistic view of the citizen and understand what events and trends may lead up to an issue. For example, deterioration in sleep ahead of an asthma attack, or reduced activity outside of the home as someone becomes more frail. If constructed on the citizen’s terms, this could offer reassurance to them and their families that they would be offered help when it is needed, and in many ways, allow them to retain their independence safe in this knowledge.

9) Secure political will – most of the value described above comes through properly interoperable systems. However, interoperability is not only a technical concern. It has political, legal, organisational and semantic components. In short – this sort of eGovernment will not manifest without high level leadership and willpower to align capability and resources to the opportunity. The resource implications of a shift in service delivery of this kind are significant. However, it must be noted that capability need not only come from public coffers - industry partners are willing to contribute resources to the co-development of these solutions – and do not need exclusive or privileged access or rights to do so. They are looking to enhance their own understanding of this new marketplace and only require confidence that
when they commit resources, there is a reasonable chance of implementation at scale should the solutions prove effective.

10) Start a national dialogue – linked to the political will and citizen-centred design points is the need to have a national dialogue around eGovernment. Distrust in government around data sharing comes when it is perceived that the citizen has no control, and when public services are seen to negotiate data access for their purposes, rather than for a citizen’s direct benefit and articulated need. Instead a programme of research and design activity is required to understand acceptability of data sharing in the context of an empowered citizen jointly managing their own care. This can then inform a national dialogue that helps the country consider the options and understand how citizen ownership of their identity and data can drive a more seamless and effective public service offering to meet their needs.

4.3. Broader eGovernment Development for Future Care Integration

This section heavily paraphrases the European Science Foundation (Rigby, Keeling, & Hill, 2013).

Most European countries are now trying to integrate health and social care to provide more holistic, citizen-centred, community-based and integrated care. This adds a new dimension to debates about identity, data sharing, privacy and empowerment.

Reflecting on some of the trends highlighted above, they conclude that:

“the vision must move from electronic records for individuals to authorised access to inter-communicating record systems, which together give all the necessary information needed by a specified user for a specified purpose and context at a specified time regarding the individual. The research needed to progress this is not into technology (though developments in systems such as intelligent brokers is important), but into the issues of standardisation, terminologies, person and practitioner identification, indexing and governance, coupled with related studies of usability, intuitiveness, and education and training of users and of data subjects – the people-based issues.”

They call for social - technical research and policy development, with the following key needs:

1) **Citizen Identity** - needs to be consistently established in a trusted way in order for integration of citizen-centred care to be achieved.

2) **Professional Provider Identity** – needs to be consistently established in order to build trust between service providers in the circle of care around the citizen.

3) **Informal Carer Identity and Linkage** – this circle of care is incomplete and usually invalid without the inclusion of informal carers. Citizen-centred care depends on this full circle being created, and in many cases with linked or delegated authority for an informal carer. This is very difficult to achieve without some sort of citizen identification for both care receiver and informal carer.
4) **Privacy and Data Ownership** – systems need to be developed that protect the professional’s capability to offer effective care, while allowing a citizen the ability to limit the information being shared if desired. Informal carers must be accounted for in these systems.

5) **Autonomy, Access and Ethics** – in the event of a hospital attendance or emergency, citizens are reassured by comprehensive, integrated care records that link up all the people and processes required to ensure they have seamless and effective care. However, as care extends into their home and personal lives, some may be reassured by this integration, while others may find it intrusive. Research and design activity must explore:
   - how to make this integration acceptable and useful for integrating care in the community.
   - development of intuitive, citizen-centred interface, control and choice mechanisms. For example, to govern “agreement of who is in their informal care team, structured levels of information sharing, and client-determined differential access control algorithms, which, in turn, need to be backed up by the development of governance systems and related audit and sanctions.”
   - There must also be mechanisms for dealing with loss of full mental competence, and with conflicts between different involved parties.

**An Enhanced Set of Personal Data Services**

Integrated care will require joint objectives for the virtual care team, determined using plain, common language, and in cooperation with the citizen who will take a central role alongside informal carers as appropriate. There needs to be a clear way of recording these objectives, as well as choices and preferences regarding the methods of achieving them. The roles and responsibilities for the various activities should be captured, and then any unmet skill requirements highlighted. This should then be shareable as appropriate. Key features of these sorts of services include:

- **Citizen-Based Differential Access Control** – “Whatever models are developed, final authorisation for setting access levels must lie with the citizen, who should be able to give protection to specific parts of their record, and to be able to give identified individuals, or functional groups, specific levels of access. For simplicity, this may well be based on a default model, but the options should be easy to apply. Further, means of citizens nominating a named trusted agent to exercise certain functions should be included.” (Rigby, Keeling, & Hill, 2013)

- **Data Contributions** – “Not least for reasons of veracity and trust in accuracy, only professionals and employed carers traditionally have been able to make record entries – though some exceptions such as patient diaries and patient completion of assessment questions, have value in specific settings. With increasing empowerment, and health co-ownership, this is increasingly seen as unnecessarily paternalistic as well as inefficient. There can be value in clients and their informal carers recording feelings, and functional changes, as well as vital sign self-monitoring, so as to inform the overall care process. Development of types of record adjunct, and criteria as to when the data should be included in the formal record, or the professional carer alerted to changes, need special study.” (Rigby, Keeling, & Hill, 2013)
• **Data Definitions** – “Vocabularies refer to the sets of terms used, and definitions can be attached. Taxonomies set terms into a structured, often hierarchical context of meaning. Ontologies are means of cross-linking different sets of terms. With the development of information science, vocabularies and terminologies are much more studied, but still remain specific to a professional area. Computing power gives opportunity to automate ontologies to cross-link terms, but the context-specific definitions and ground rules must be determined first. If workers from different health and care domains are to communicate safely, and if clients and informal carers are to interact with this, then much work needs to be done in developing these concepts.” (Rigby, Keeling, & Hill, 2013)

An OECD National Science Foundation international workshop (Rigby, 2011) aligns with this, identifying the need for a “Charter of Subject Rights for Electronic Record and Care Delivery Systems Containing Social Care Data”, recognising the rights of the citizen:

- to access not just recorded historic data but also dynamic data such as forward schedules;
- to express and record their own views and preferences;
- to record observations on their own health, functioning, and needs;
- to decide personal directions on individualised rules for information sharing to formal and informal third parties involved in care or family support;
- and to explicitly qualify rights of defined appointed representatives and agents.

## 5. Implications for Scotland

### 5.1. Current Principles and Strategy

This section analyses some of the publicly available strategy and policy from the Scottish Government in the context of the broader European lessons highlighted in this paper.

### 5.1.1. Identity & Data Sharing

The High Level Operating Framework for Scotland’s Digital Future (Scottish Government, 2015) highlights the following principles. The table below offers a version of these principles that reflects the difference in tone and intent when Scotland is compared with the countries leading on accessibility and usability of digital services.

<table>
<thead>
<tr>
<th>Scottish Principles</th>
<th>Finnish or Estonian Derived Alternative</th>
</tr>
</thead>
</table>

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Having a common approach based on Enterprise Architecture concepts and principles in all sectors will create a common framework and language which will assist organisations to communicate more easily when opportunities for re-use, convergence or cross-sector service delivery is required.

<table>
<thead>
<tr>
<th>All public services will comply with a single, overarching approach to enterprise architecture that supports the e-Society programme. ICT investment project proposals of any scale will be decided upon by one national group.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having a common approach based on Enterprise Architecture concepts and principles in all sectors will create a common framework and language which will assist organisations to communicate more easily when opportunities for re-use, convergence or cross-sector service delivery is required.</td>
</tr>
<tr>
<td>A cohesive overview of data is required to ensure a consistent approach is taken and common standards for data will need to be considered. All work in this area must comply with the legal framework for data sharing, respect for individuals' rights to privacy and confidentiality and consider public confidence about when and how personal information is shared.</td>
</tr>
<tr>
<td>A single exchange / integration layer will be developed that requires the use of common standards. Every public service is legally required to open its databases and registers to this layer. The layer will operate to the principle that citizens only need to enter data once and that it will be reused until they update it. Citizens must be given oversight of how data is shared and used on this layer, and must be able to withdraw consent at any time.</td>
</tr>
<tr>
<td>Public services will be integrated into a shared approach to identity and authentication management.</td>
</tr>
<tr>
<td>There is a national identity managed by a separate trust centre. National ID use is mandatory for citizens, though there is no legal penalty for not adhering. The scheme allows seamless and effortless access and authentication for public services. This identity allows the exchange layer to draw together relevant data from all public databases and allows the citizen to gain oversight and control of their data. The citizen can then use their own data to power any service they need.</td>
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</table>

Scotland and Finland / Estonia have taken different approaches to the combination of enterprise architecture, data sharing and identity management.

The Scottish approach to the concept of identity is understandable given the negative media and political pressures exerted the last time this was openly discussed. However, the world has moved on, and in an era of porous and interlinked global databases a citizen’s data is already traded in a variety of ways, by both public and private sectors.

In this context, countries such as Finland and Estonia have developed and mandated a national identity scheme paired with a compulsory public service integration layer. This is an enabler of accountability and transparency in the way the public sector uses data, and has stimulated a culture in which citizens feel a much greater degree of ownership of their own data, can hold government to account on its use, and therefore trust their governments more.

Currently the Scottish citizen is identified and / or authenticated through a range of means including the NHS CHI number, benefits account numbers, council tax reference numbers, the National Entitlement Card, Drivers licences, YoungScot, Mygov.scot MyAccount, etc. Currently citizens have little to no control over or transparency with respect to most of the data associated with these
accounts and cards - many of which are not voluntary. In many cases these organisations have data sharing agreements to link databases to enhance the services provided to the citizen, but this is not seen by the citizen. This all persists because of the lack of will to unify these methods into one identity scheme with citizen ownership of this identification.

As of now, Scottish citizens have little control over their own data, and also do not enjoy the seamless service benefits enjoyed in countries that have national identity schemes. MyAccount is well positioned to become a national identity scheme, but because Scotland has not had a robust national dialogue, there is little ‘ownership’ of the MyAccount identity on the part of citizens. This is a ‘worst of both worlds’ option.

In parallel, Estonian and Finnish citizens enjoy the ‘best of both worlds’ - they can use one method to identify themselves for all services, and have the ability to consent to efforts to join this data up to improve the service they receive (e.g. auto-populating benefits forms, parking permit applications, etc.) They also have access to how services are using their data because any such use has to be associated with their identity and they can withdraw consent at any time, holding public services to account and protecting their privacy to a far greater extent than is possible in the disjointed model running in Scotland.

On the 1st of April 2018, Norway will adopt a National ID scheme. This means that now all of the European Economic Area countries except Iceland and the UK will have a single national scheme.

### 5.1.2. The Personal Health Record

An eHealth position paper discussed in the Scottish Parliament noted:

“The Government has set an objective that by 2020 citizens will be able to use a citizen “portal” to access a personalised view of their health and care information, enhanced and presented as required to make it accessible, informative and useful to them and their carers, and where appropriate make their own contributions to the information, thus sharing it with the relevant health and care professional. They will also be able to access authoritative information about managing their health, prevention and self-management of conditions. In addition, they will use secure two way electronic communication with their health and social care providers to book and manage appointments, order repeat prescriptions and, where appropriate, use eConsultation facilities, resulting in convenience for individuals and reduced transaction and administration costs for health and cares services. A “portal” should not be interpreted as being a website or an App. Instead, it is the mechanism through which information is exchanged using a “platform” that draws information from the appropriate sources and sends it to the appropriate destinations (information stores, computers, tablets, smartphones, clinical instruments, sensors, etc), while applying the necessary privacy and consent controls.” (Scottish Government, 17).

This set of requirements was codified into the ‘National Patient / Citizen Portal’ project. Since this point, various features have been considered and then plans put in place for a phased development.

However, this description above is an amalgamation of many capabilities, and the nuances between these different functions may be lost when this is considered as a ‘portal’ – which, as discussed earlier
in this paper, has its own limitations. This next section breaks down the Scottish Government’s statement above into a list of requirements and sets them in the context of the European experience and emerging understanding of the enhanced access and usability of digital services.

<table>
<thead>
<tr>
<th>Scottish Government Requirement</th>
<th>Capability</th>
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<tbody>
<tr>
<td>A view of their record</td>
<td>This is possible through a traditional Patient Portal with a unique ID reference number linked to several disparate databases.</td>
</tr>
<tr>
<td>Carer access to their record</td>
<td>The ability to identify both the citizen and their carer(s) and delegate authority to them. Achievable within a Patient Portal.</td>
</tr>
<tr>
<td>Personalisation options for their data</td>
<td>This becomes difficult within a centralised, state-controlled system. This function is likely to be superficial within a web based National Patient Portal. This would be easier if the citizen had options for the interface at a local level or through their own preferred app or service interface.</td>
</tr>
<tr>
<td>Make their own contributions to the record</td>
<td>Basic demographic changes – e.g. contact details, next of kin, etc. are easily handled within a Patient Portal. Deeper contributions – e.g. a citizen’s ‘story’, objectives, preferences and plans would be more appropriately stored in an untethered Personal Health Record, kept separate but adjoined via a consent model to the main record. This type of activity is deeply personal, requires a high degree of personalisation and should be held and formatted as local to the care setting as possible, entirely on the citizen’s terms but meeting basic standards to make it actionable by others.</td>
</tr>
<tr>
<td>Sharing their data with professionals</td>
<td>Any data input by a citizen or informal carer that may affect a treatment or care decision needs to be stratified for integrity and risk. Data provenance is crucial. A common domain ontology and set of standards for different data input types needs to be created to help build joint understanding and trust in citizen-generated data. This is beyond the functionality of a Patient Portal, or any centralised system. A distributed, standards based approach is required.</td>
</tr>
<tr>
<td>Access guidance about their health</td>
<td>Possible within a Patient Portal. The Finnish model is developing such guidance to be live and interactive, feeding from both the EHR and (Untethered) PHR to auto-populate self-management tools, personalising even the simple pursuit of guidance effortlessly. However, this requires an Exchange Layer, Identity provision and consent-driven access to both an EHR and PHR.</td>
</tr>
<tr>
<td>Secure, two-way communication with care providers</td>
<td>Possible within a Patient Portal. However, one of the first ‘rules’ of user-centred digital design is “do not create a new, bespoke communication channel”. If the service is personalised, it will be delivered via a medium they are already comfortable with. For many this is something as simple as text messaging. All that is required is a consistent means to assure identity for both participants in the communication.</td>
</tr>
<tr>
<td>Book appointments</td>
<td>Appropriate for a Patient Portal.</td>
</tr>
<tr>
<td>Order repeat prescriptions</td>
<td>Appropriate for a Patient Portal.</td>
</tr>
<tr>
<td>---------------------------</td>
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</tr>
<tr>
<td>Virtual or e-consultation</td>
<td>Appropriate for a Patient Portal. Some consideration should be given to these virtual consultations being made available within existing consumer offerings e.g. My Diabetes My Way, rather than at a centralised location only.</td>
</tr>
<tr>
<td>Mechanism to draw data from care service databases, citizen-held records and citizen apps and devices</td>
<td>This is traditionally seen to be part of the Patient Portal proposition – at least for the state-held electronic health record. However, due to the extremely diverse set of data sources and user needs associated with this transfer of data, it needs to be decoupled from the Patient Portal ‘single point of access’ interface. Instead the Patient Portal (as an interface) should use a separate, pan-public service ‘Exchange Layer’ to draw data from any relevant source, with rules around certification, consent, security and identity built into the layer. In this way a number of interfaces could offer this functionality, preserving citizen choice and personalisation across many services – health, care and broader public service.</td>
</tr>
<tr>
<td>A consent model to safeguard citizen ownership and privacy</td>
<td>This need to exist beyond the Patient Portal (and indeed the healthcare) use case. Any use of any citizen data should be governed by one, cohesive national consent model, and then deployed on an exchange layer common to all public and citizen held databases. This in turn can also allow the citizen to have a unified view of who is using their data and the ability to withdraw consent effortlessly when appropriate. This can then in turn only be realised with a unified, citizen-owned national identity.</td>
</tr>
</tbody>
</table>

The infrastructure that sits beyond a centralised health interface is recognised in Scotland’s broader strategic approach. Scotland’s Digital Future: Delivery of Public Services Action Plan 2015-2020 (Scottish Government, 2012) outlines a vision in which “citizens readily know how to and can access personal information held about them, allowing them to confirm accuracy and to choose if they wish to create their own personal data store” and “citizens feel confident that personal data is being shared responsibly to create better and more responsive services which meet their individual needs”.

The Health & Social Care Information Sharing Strategic Framework (Scottish Government, 2015) determines that “partnerships should review existing processes to ensure greater involvement of people in creating and contributing to the information that underpins their care and support.” Section Four of this framework outlines actions to deliver on this principle – namely – “Scottish Government to develop plans for a public debate on how people should be enabled to play a greater role in creating and sharing health and care information”. However, the action timescale was left as ‘TBC’ and it would seem this public debate never took place.

The lack of public debate means that more systemic change of the kind found in other European countries cannot happen. The more fundamental digital building blocks highlighted in this paper require a dialogue and proof of the acceptability of a unified identity and consent-driven sharing of personal data across public services. In lieu of this debate the Patient Portal concept is appealing – it would require change only to NHS-controlled resources such as the EHR, CHI registry and the creation of an NHS login. It would add much needed functionality from a service point of view in the form of appointment and repeat prescription booking in a centralised, cost-effective manner.
However, in pursuit of a national single interface that aspires to load all the previously listed digital health and care functionality behind it, we are in danger of defaulting to a format that centralises first and personalises second, and is based on how the health and care system would like citizens to behave, rather than being responsive to the reality of how they will behave. This is a format that has been repeated over the years and sees the UK 18th in Europe for usability and accessibility of digital public services.

Rigby et al (2015) summarise the issue well, stating that: “Most current evaluation studies have focussed on the immediate and somewhat mechanistic access to the current record, held electronically, within current philosophies of a professional-client service relationship. Something of a paradigm shift is needed to move to how the new, technology-supported, patient-centric coordinated care is organized with the citizen central and by no means subordinate. Here evaluation needs to be one of communication as an aid to co-production, requiring very different constructs and measures. Then there is the further complication and barrier, that even modern services are too frequently designed by educated professionals and policy makers for ‘People Like Us’, and thus still fail to serve the disadvantaged and societally disconnected, even though they are known to have greater health needs.”

Instead, the broader set of capabilities beyond the traditional portal approach needs to be considered, and must be built upon a dialogue with citizens focused on the desirability and acceptability of modern data sharing to support digital services on their terms.

5.1.3. Case Study – A Personal Data Store for people with Multiple Sclerosis (MS)

One example of this citizen-centric, co-produced approach comes from the DHI’s work with people with MS. The findings were as follows (DHI, 2017):

The concept of a person-owned data store (or ‘Backpack’ as the users called it) that would allow the person to securely manage and share their personal information was positively received by both people living with MS and health and care service providers.

People living with MS highlighted several characteristics that support positive interactions with people and services, which can be translated into design principles for the structure, language, look and feel of the Backpack. Insights about security and data sharing suggest that participants were pragmatic about the risks of loss of privacy in exchange for the perceived benefits of convenience and equitable access to information, empowering them in their interactions with statutory services. Participants highlighted the importance of designing the Backpack to accommodate and reflect their personality and interests, facilitating everyday life and activities. Health and care professionals would also value this information, supporting them to understand what the person enjoys and tailor their care to their aspirations.

Health and care professionals could see how the Backpack would overcome many of their current challenges in: accessing information from other health and care professionals, better understanding the needs and wishes of their service users and managing increasingly large case-loads.
The four design concepts presented offer insight into how people living with MS and health and social care professionals would envisage person-owned data stores working for them in practice, offering a fresh perspective to existing conversations between technologists and Government strategists. These concepts include:

1) **Mapping Interactions** – making visible the complex interactions of multiple carers with the citizen.
2) **Health Story** – offering a way for a person to tell their own story their own way, to do this once only and then use this and their preferences to drive the way they want their care delivered.
3) **Smart Form Filling** – allowing benefits forms to be auto-filled from the Backpack, significantly reducing the emotional burden this process places upon the person.
4) **Tools for the MS Specialist Nurse** – this is a staff facing view of the backpack, that allows the specialist case worker a dashboard view updated whenever the person or another care professional changes or updates information in the Backpack that might mean more or different support is needed.

The benefits of involving citizens and health and care professionals in this conversation are highlighted by the innovative and practical nature of the proposed concepts. Their ongoing participation is vital to ensure that any developments in this area meet the needs and aspirations of the people who will use them.

### 5.2. Recommendations for Strategy Going Forward

In summary, to close the gap between Scotland’s high level of overall digital progress and relatively low levels of access to digital public services the following recommendations are made:

1) **Renew some basic principles** - better recognising that:

   - **There is a balance of benefits** – between consistent, centralised digital infrastructure and more local and diverse use cases and interface needs.
   - **Personalisation** - can be the customisation of a generic ‘whole system’ service, but it is more effective to design a range of interoperable services that are built from first principles to meet end user needs.
   - **Access to data is not ownership of data** – and that empowerment is limited when ownership is limited. The concept of an untethered Personal Data Store (so beyond just a health record) must be pursued as a means integrating new service models, driven by the citizen.
   - **Meaningful contribution to co-management of care** - means the joining of two equally important sources of information, preferences and plans (the care provider and the care receiver), not just the ability for citizens to customise or feedback on services as they are.

2) **Learn from international experience** - there are common features adopted by the European countries leading on both the development of digital public services. These could be pursued to support upcoming strategy work:
• **Think beyond health and care** – much of the value will come from non-health and care sources.

• **Distribute services** – centralise only standards and common, open, enabling infrastructures.

• **Partner with, don’t just procure from, industry** – who can flex and personalise a citizen’s digital interfaces and tools, while generating economic value for Scotland.

• **Centre design on the citizen** - drive the development process by understanding how citizens want to engage with digital public services – do not digitise current processes.

• **Develop a common approach to identity** - that enhances ownership and transparency around personal data and enable new personalised digital services driven by consent.

• **Develop a data exchange layer** – that supports the consent-driven reuse of data through an open, secure and standards-based intermediary layer that all public service databases can connect to.

• **Develop an ‘untethered’ personally held data approach** – that offers true ownership of personal data and the means to securely consent to the sharing of this data to power services that meet citizens’ needs in a flexible way.

• **Capitalise on the infrastructure** - for enhanced, joint decision making and preventative approaches to care.

• **Capitalise on the infrastructure** – for integrated care – enabling consent-driven data sharing between partners and allowing a citizen to drive care planning from their own personal record.

• **Secure political will** – this approach to digital services has political, legal, organisational and semantic components – not just technical ones. In short, this sort of eGovernment will not manifest without high level leadership and willpower to align people and resources to the opportunity. The resource and capability burden can be shared with industry to reduce the public sector costs while stimulating the local economy.

• **Start a national dialogue** – linked to the political will and citizen-centred design points is the need to have a national dialogue around eGovernment. Distrust in government around data sharing comes when it is perceived that the citizen has no control, and when public services are seen to negotiate data access for their purposes, rather than for a citizen’s direct benefit and articulated need. Instead a programme of research and design activity is required to understand acceptability of data sharing in the context of an empowered citizen jointly managing their own care. This can then inform a national dialogue that helps the country consider the options and understand how citizen ownership of their identity and data can drive a more seamless and effective public service offering to meet their needs.

**3) Re-profile the Patient Portal activities**

We should renew our understanding of the different components required to achieve the 2020 commitment. Breaking these down into two development tracks:

1) **The Patient Portal should proceed** based on reusing existing capability rather than creating something bespoke. It should focus on the transactional benefits commonly associated with Patient Portal technologies in the short term to yield benefits primarily for health and care service delivery. Activities would ensure that a citizen could:
   - Access their Electronic Health Record or let an informal carer do so,
• Edit basic demographic information – potentially linked to the CHI registry,
• Access static guidance about their health and care,
• Book appointments and repeat prescriptions,
• Securely communicate with professionals via messaging and virtual consultation.

2) Initiate and resource innovation activity to explore how the citizen wants to engage with digital public services and then develop appropriate, interoperable solutions to support this in a manner that is congruent with the Patient Portal development. This may yield several digital infrastructures that are more fundamental than the Patient Portal, and that might span more than just health and care needs. Activities would ensure that a citizen could:
• Personalise their own record and information,
• Make contributions around their life story, objectives, preferences, and care planning,
• Share data they generate with professionals,
• Take advantage of an exchange layer that joins up data to offer personalised services,
• Connect consumer devices into their records in the context of novel self-management services,
• Develop a high degree of control over their own data, with consent driving data sharing.

Update (25/03/18) - Note that since the previous publication of this paper, the Scottish Government has now decided to proceed on this twin track basis. The 'Portal' language has transitioned into the development of a single digital health and care platform – with a focus on interoperability across many possible interfaces. A review is currently being undertaken to scope out the target reference architecture for this new approach.

5.3. Conclusion

This paper has planted some flags for developments Scotland is primed to undertake. We have the capability and technology already, and while other countries have been first to demonstrate the potential, Scotland has a better starting position than many of our European peers due to our cohesive policy and strategic approach driving towards citizen-centred, integrated care.

Realistic Medicine, as espoused by the Chief Medical Officer, can be achieved by enhancing our ability to share data in a consent driven fashion, allowing more seamless and personalised services, with diversity for citizen but built on a consistent core infrastructure and standards base. Key to this are three interlinked concepts:

1) If the citizen is to be empowered, then they must own their own data, must see the data held by other about them and must be able to limit how data is shared effortlessly and directly
2) Care is distributed – so the digital infrastructure must not centralise power and access.
3) Personalisation is more than just customisation of generic services - permission-less innovation must flourish near the citizen, but within a governed set of standards and norms to protect quality of care.
A distributed care system supported by a distributed, but standards based digital infrastructure, is exactly what the Scottish digital health and care marketplace needs to flourish. The leading e-societies of Europe are now capitalising economically on their open, distributed, data rich systems. Businesses are able to add value significantly quicker with far fewer barriers, and can demonstrate benefits directly to citizens. This in turn then allows them to engage with global markets that are increasingly working to the same consumer focused, distributed delivery models.

One remaining barrier to progress in this area is the issue of privacy – especially as this links to the politically sensitive nature of a unified digital identity. However, there is no need for a mandatory identity scheme now – many of the benefits could be achieved within the health and care domain by the relatively simple development of an untethered personal data store that can be linked to the CHI number and / or MyAccount with the citizen’s active consent. Those groups that need integrated care and ownership of their own data could achieve this in the immediate future, and this in turn could help Scotland understand the benefits of this type of citizen empowerment.

6. References


