



Experience Lab
Backpack

Contents

| | |
|------------------------|---------|
| Lab Overview | Page 02 |
| Executive Summary | Page 04 |
| Experience Lab and DHI | Page 06 |
| Experience Lab Team | Page 07 |
| Project Background | Page 08 |
| Project Aims | Page 09 |
| Methodology | Page 10 |
| Mini-Lab | Page 11 |
| Experience Lab 1 | Page 12 |
| Paper Prototype | Page 14 |
| Digital Prototype | Page 15 |
| Experience Lab 2 | Page 16 |
| Overall Findings | Page 18 |
| Design Concepts | Page 20 |
| Scenarios of Use | Page 30 |
| Roadmap for Discussion | Page 32 |
| Conclusions | Page 34 |

GRIMORIE
RESPECT
THIS
MAGICAL
'JOCK'S JOURNAL'



LOOK BUT
DON'T TOUCH.

FINA

W
E
M

BACKPACK

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:



Participants: 9

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

Two Exp. Labs
+ 1 Mini-Lab

Lab Team:

» → Gemma Teal
» → Dr. Tara French
» → Dr. Jay Bradley

Person-owned
information

Navigating
Services

Multiple Sclerosis

Lab Location:

- Elgin



2016



10 Hours Experience
Lab time

+3 Hours Mini-Lab
time

Academic Output:

x1 x1 - Report
- Video

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



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 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 be 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 Lab was developed by the Institute of Design Innovation at The Glasgow School of Art.

The Experience Lab offers 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 Lab 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 |
| Louise Mathers | Photographer and Videographer, No Middle Name |

Project Partners: Backpack

| | |
|----------------------------|---|
| Alex Stobart | Mydex Data Services |
| 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 medical/personal records were held in one place?



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 whomever you want. It works like 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, 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 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:**

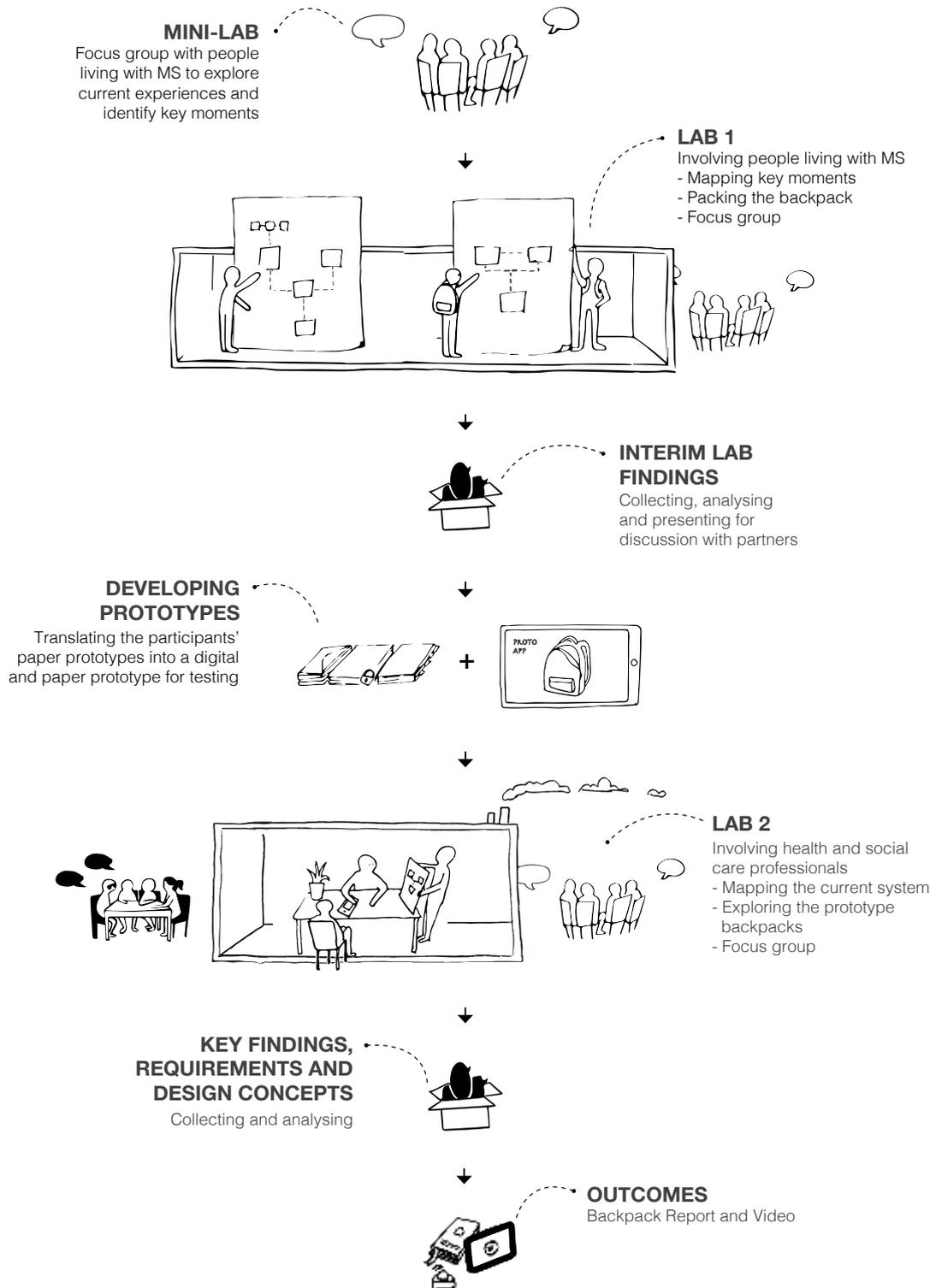
- Would the PDS be useful and of interest to people living with complex long-

term conditions to help them navigate the system and access services?

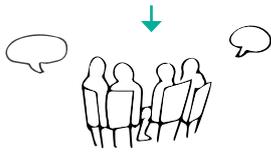
- How would people and their care network want to interact with such a personal data store?
- Who would they want to share their personal information with and how would they want to achieve this?
- How would this change the working practices of their health and care professionals?



Methodology



MINI-LAB



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 medical information
- Online data management and security
- Paper-based data management and security
- Experiences of accessing statutory services

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

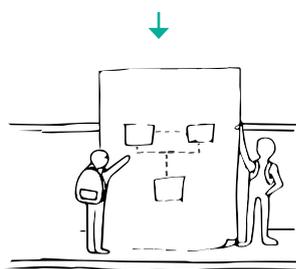


Key moments

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.

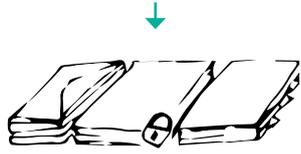
This was explored using the 'backpack' metaphor, with participants building up a paper file with cards representing the kinds of information currently held by health and care professionals, and held online (e.g. social media profiles) using connectors to allow the participant to indicate who they would 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.

The Labs were audio 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.

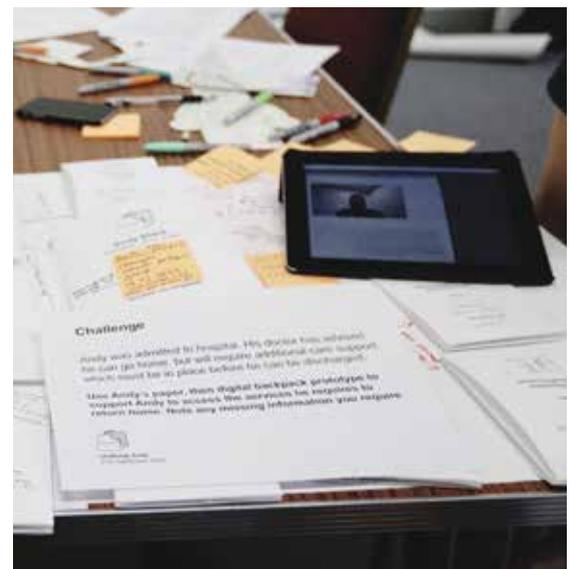
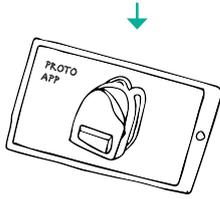




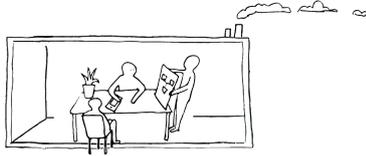
PAPER prototype



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 one 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 be 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 **orientated 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."

Mini-Lab Participant

"...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."

Mini-Lab Participant

→ 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."

Mini-Lab Participant

"...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..."

Mini-Lab Participant

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..."

Mini-Lab Participant

"I would be empowered to answer the Doctor's questions."

Lab 1 Participant

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

→ Person-centred and Anticipatory

A key value of the Backpack is the ability to reflect the personality and interests of the owner. This concept was embodied in the Lab 1 prototypes, where "fun stuff" or personal interests were a feature of all, and for one particular participant this became the centre of their Backpack. This supports the need to

ensure the Backpack can accommodate this information to facilitate 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. While it is acknowledged that anticipatory care plans (ACP) exist to communicate the preferences of the person in terms of their clinical care, this highlights an important opportunity to enrich the ACP with personal and lifestyle information to enable person-centred care.

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.”

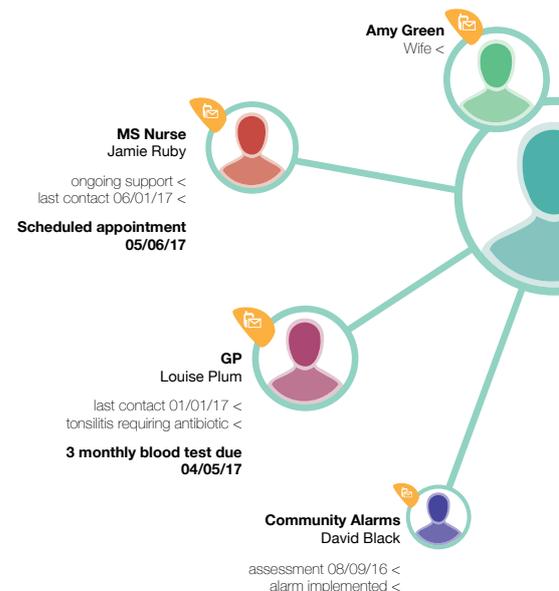
Mini-Lab Participant

“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.”

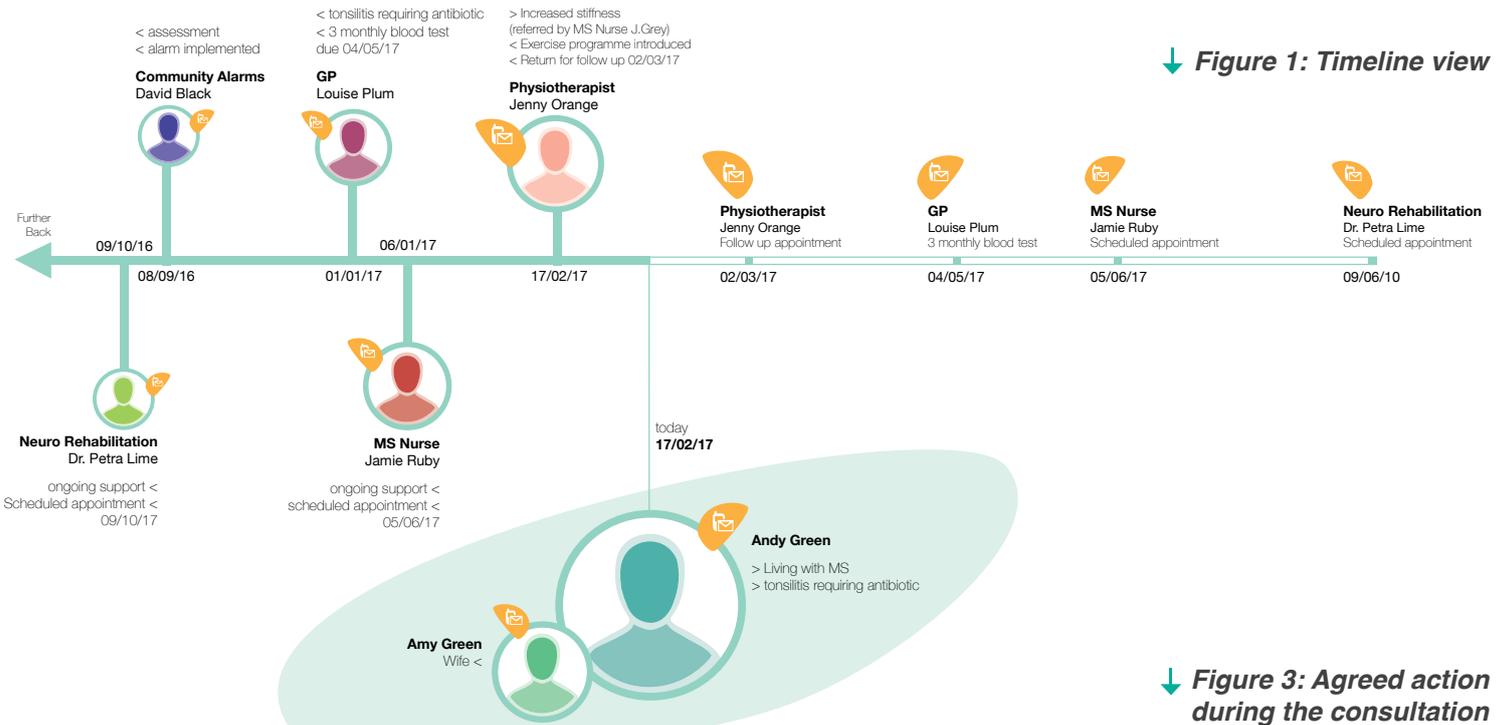
Mini-Lab participant



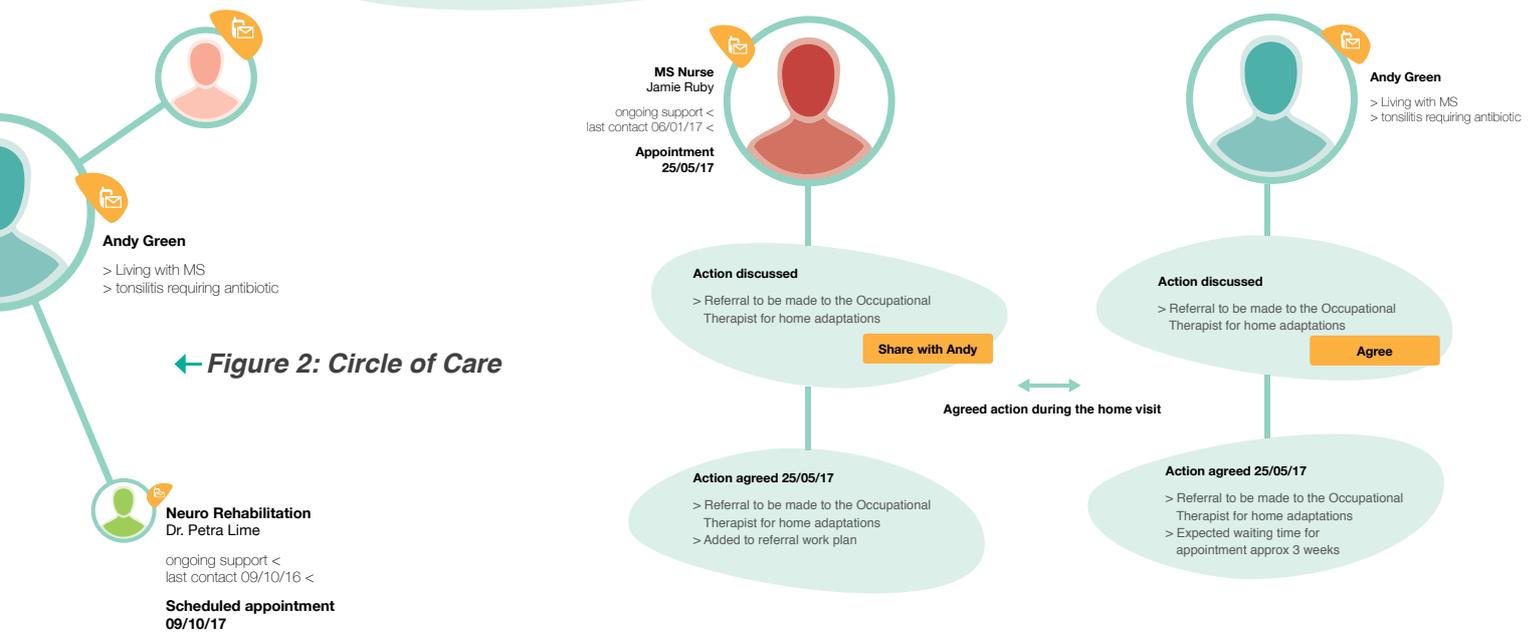
Key Ideas

→ 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



↓ Figure 1: Timeline view



← Figure 2: Circle of Care

↓ Figure 3: Agreed action during the consultation

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 care 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.

Health Story

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]

Health story in video form

Video of home environment

Medications

Antibiotics (20/10/16)
Vitamin D (since 2011)
Insulin dependent (since 1990)

Demographics

d.o.b: 12/09/65 (51 years old)
CHI: 12095511

Test Results [full results available on request]

- > EDSS: 6, 13/02/16
- > MRI: no new activity or active lesions on brain, patchy lesions on thoracic spinal cord, 13/11/10
- > Blood tests: raised white blood cells
- > LP: IgG oligoclonal bands
- > Timed-25-foot walk: Failed
- > HbA1c: 36.0 mmol/mol (5.4%) on 02/04/16
- > Blood pressure: 199/99 mmHg on 02/04/2016
- > Blood Glucose: 7.00mmol/L on 02/04/2016

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. Eligible 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

“...he (social worker) just confused me about what I was eligible for and what was possible and what I discovered subsequently was that I wasn’t eligible for anything and nothing was possible...”

Mini-Lab Participant

Many applications to gain access to support require people to prove your 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

Verified
Information

Download
Certificate

- 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').

| Patient Name | Change (priority order) | Expand |
|---|---|---|
|  Andy Green | => admitted to hospital May 29th 2017 (Dr Green, Nurse J. Holmes) |  |
|  Emma White | => referred to Physio (Dr Dr. Black) => appointment scheduled for May 30th 2017 |  |
|  Roofie Smith <small>01 234 56789 rsmith@gmail.com</small> | => referred to Occupational Therapist (Dr Dr. Smith) => home visit scheduled for June 10th 2017 Roofie needs to be assessed due to new symptoms of numbness and problems with balance. Home environment may need modifications to reduce risk of falls. |  |
|  Jan Pink | => Husband has been admitted to hospital (Jan Pink, May 24th 2017) => Home care support requested social work assessment pending |  |
|  John Brown | => Traction (Dr Dr Brown) => Antibiotic prescribed (Dr Dr Brown, May 24th 2017) |  |
|  Ben Forest | => Community Alarm requested (Joanna Forest, May 29th 2017) => Home assessment scheduled June 1st 2017 (Alarm team, Kay Jones) |  |
|  Betty Blue | => Community Alarm requested (Betty Blue, May 29th 2017) => Home assessment scheduled June 1st 2017 (Alarm team, Kay Jones) |  |



EMAIL ALL Patients
clear now

Scenarios of Use



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.

CONCEPT 2

Health Story

CONCEPT 3

Smart Form Filling

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.

CONCEPT 1
Mapping Interactions

CONCEPT 2
Health Story

CONCEPT 3
Smart Form Filling

CONCEPT 4
Tools for the Specialist MS Nurse

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.

CONCEPT 1
Mapping Interactions

CONCEPT 2
Health Story

CONCEPT 3
Smart Form Filling

CONCEPT 4
Tools for the Specialist MS Nurse

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.

CONCEPT 1
Mapping Interactions

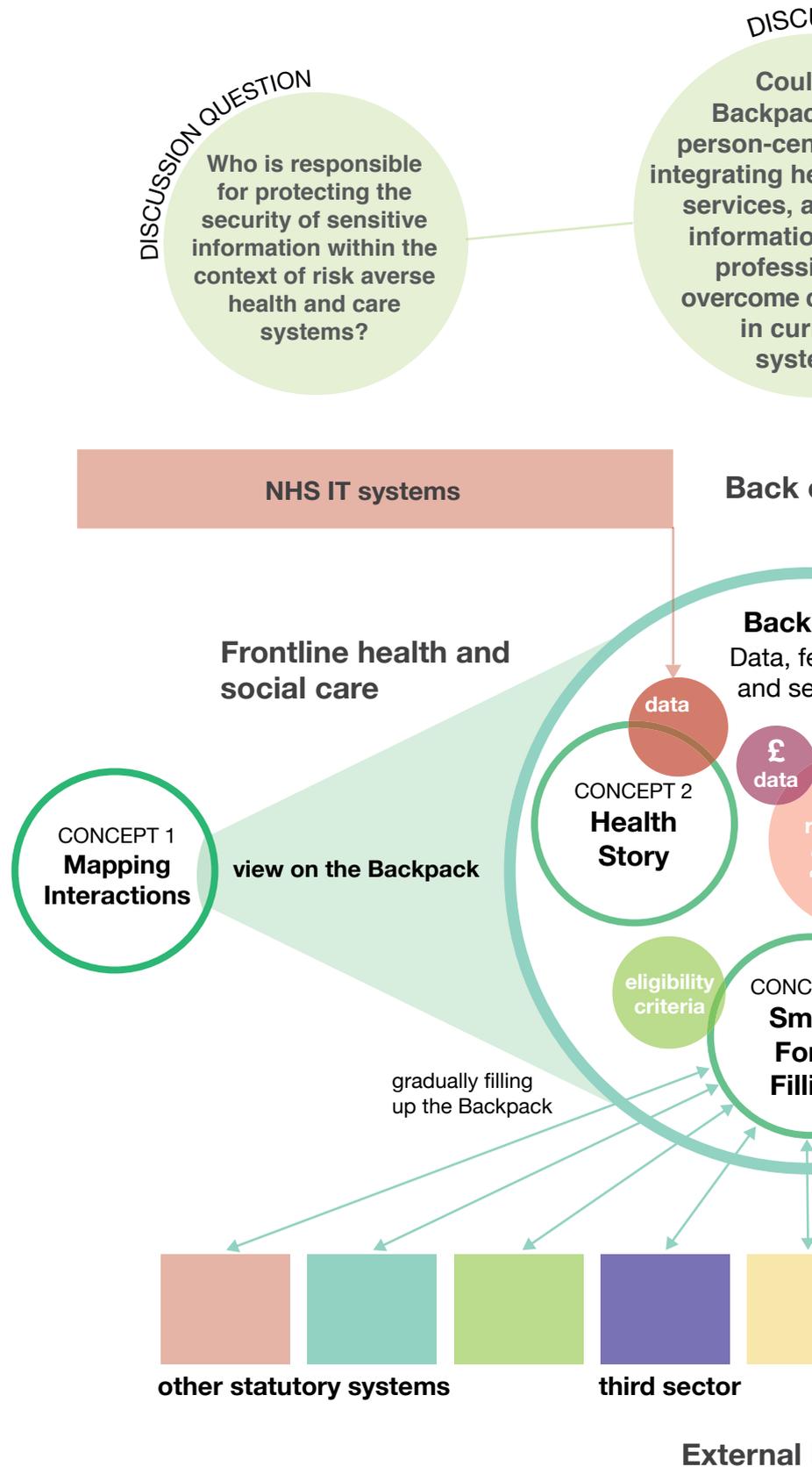
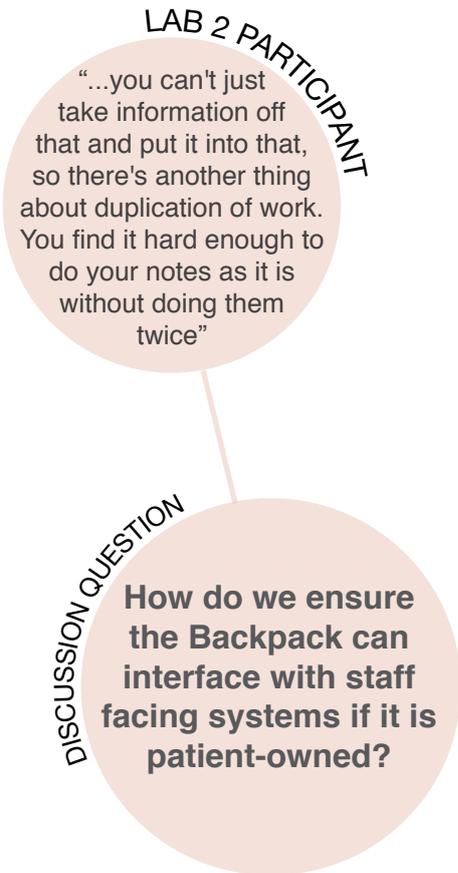
CONCEPT 2
Health Story

CONCEPT 3
Smart Form Filling

Roadmap for Discussion



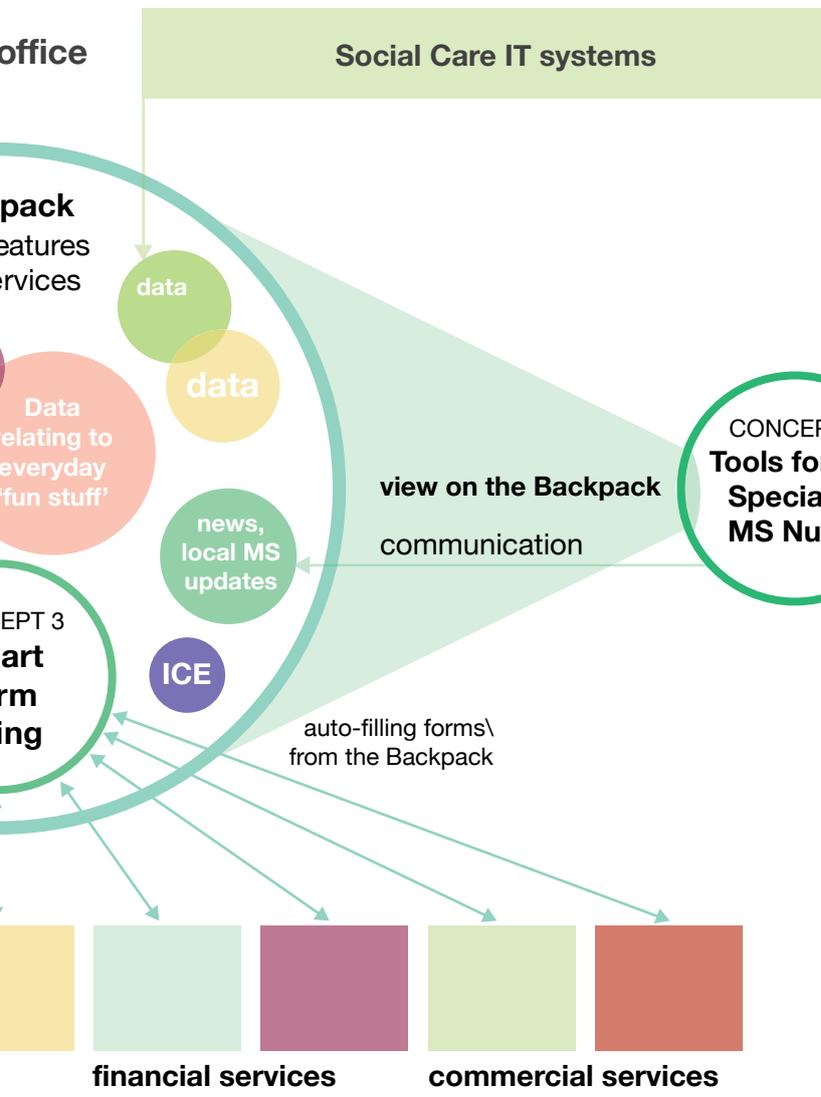
This visual is intended to explore how the concepts interrelate, and how the Backpack integrates with other statutory and commercial systems. In addition to generating awareness of the context and developing the concepts, the Experience Labs also raised a number of questions and comments for discussion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



DISCUSSION QUESTION
 Should the Backpack offer a streamlined way of health and care and sharing information between professionals to address deficiencies in current IT systems?

DISCUSSION QUESTION
 Should it sit outwith 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?
What is the business model?

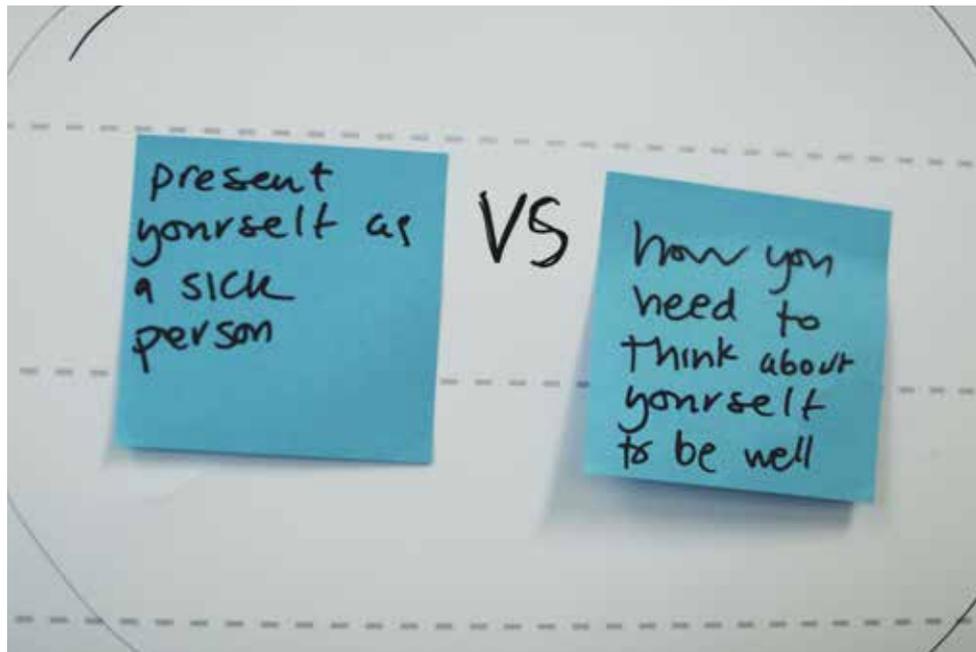


CONCEPT 4
Tools for the Specialist MS Nurse

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

DISCUSSION QUESTION
CONCEPT 4:
 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?

Providers





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.





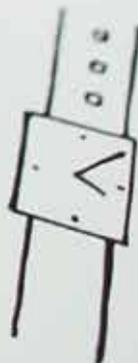
“

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’.”

TOP
SECRET

FRAGILE

Short term access



Open access



Open with key



Access restricted



Copyright

This publication is copyright. Apart from any use as permitted under the Collaboration Agreement no part may be reproduced in any form without written permission.

Disclaimer

This document has been prepared in good faith on the basis of information available at the date of publication without any independent verification. The Digital Health & Care Institute (DHI) does not guarantee or warrant the accuracy, reliability, completeness or currency of the information in this publication nor its usefulness in achieving any purpose. Readers are responsible for assessing the relevance and accuracy of the content of this publication. The DHI will not be liable for any loss, damage, cost or expense incurred or arising by reason of any person using or relying on information in this publication.

For more information please contact:

Gemma Teal, G.Teal@gsa.ac.uk

Dr Tara French, T.French@gsa.ac.uk

Dr Jay Bradley, J.Bradley@gsa.ac.uk

or visit: www.gsa.ac.uk/ExpLabs

