



Backpack

Summary of Findings

Backpack: Personal Data Store

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

It was suggested that this personal data store, which we have called a 'Backpack', could make it easier to access health and care services, and support services to be centred around the wishes and needs of the person.

Design researchers from The Glasgow School of Art worked together with a technology company (Mydex CIC) and a

health professional (Dr. Jamie Hogg, NHS Grampian) to explore and develop the Backpack idea with people living with Multiple Sclerosis (MS) and with health and social care staff. People living with MS were identified as highly knowledgeable co-design participants, due to the complex and progressive nature of the condition, requiring many different interactions with public services.

The aims of the 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. This summary describes the Experience Labs' activities on the project, and shares our findings and the ideas we collaboratively developed for the Backpack.

What did we do?

We held a focus group with people living with MS to gain insight into current experiences of living with MS, in particular the challenges of and strategies for managing personal information and accessing support.

The first Experience Lab brought together people living with MS to map some key moments of data sharing, before each

participant created a paper version of their Backpack using a specially designed tool. Working collaboratively with a designer, they explored what types of information they would want to store, and how they would want to organise, share and secure the information.

In the second Experience Lab, health and social care professionals mapped the many possible interactions a person living with MS may have with health and care services, and tested paper and online versions of the Backpacks made in Lab one. Finally we discussed how access to person-owned data stores would change the way they currently work.

Experience Labs

Experience Labs were developed by The Glasgow School of Art's Innovation School. They offer a safe and creative environment where researchers, businesses, civic partners and service users can collaborate to find innovative solutions to the health and care challenges facing our society. They are the core element in the Digital Health & Care Institute (DHI), one of the Innovation Centres funded by the Scottish Funding Council.

Experience Labs use a co-design approach and emerging design research methods to engage with 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 to gather feedback from end users.



What did we discover?

Both people living with MS and health and care professionals were very positive about the concept of the Backpack, and saw how it could be used to improve communication and make services more person-centred.

Supportive people and services

We learned some general qualities people living with MS value from the people and services that support them. Services should be orientated around their personal goals and needs, and should seek to offer convenience to make everyday life easier. People 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.

Access to health information

Participants would value the ability to access their own health information, with equitable access to the information their health professional holds about them. They also told us that health professionals working

in different services or health boards do not always share health information, and suggested that the Backpack would allow them to ensure their health professionals had access to all the relevant information. While they might not want to see lots of medical jargon, they would want to see their high level test results and have the ability to access the detail if required, e.g. to share with a health professional in a different region.

"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

"The thing about health information for me is availability trumps confidentiality"

Mini-Lab Participant

Security

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 to overcome concerns about security.

Person-centred

A key value of the Backpack is the ability to reflect the personality and interests of the owner. This concept was embodied in the paper backpacks made in Lab 1, 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.

In addition the Backpack should be adaptive and anticipate the needs of person as their health and care requirements change.

Design Concepts

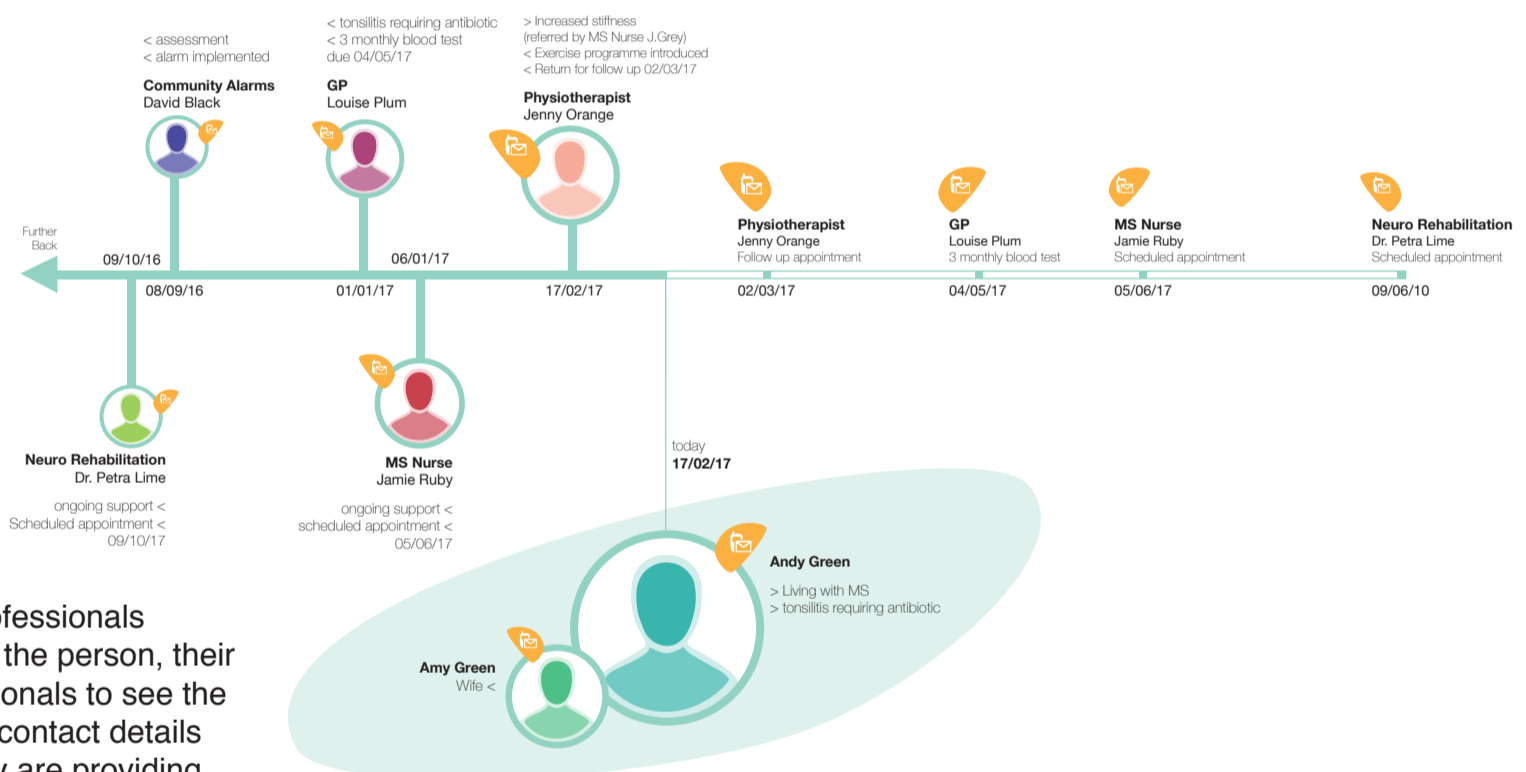
Four design concepts were created in response to key insights or challenges.

Insight 1

The health and care system is very complex and it is often challenging to find the person or service that can help.

Concept 1: Mapping Interactions

The Backpack should map the care interactions around the person, providing high-level information to make visible the complex network of professionals supporting the person. This would allow the person, their family and their health and care professionals to see the care that is currently in place, providing contact details and a short summary of the support they are providing. This could be shown as a circle of care or on a timeline.



Insight 2

People living with MS described having to recount their 'story' every time they connect with a professional or service, which is emotionally draining and time-consuming.

Insight 3

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.

Insight 4

The MS nurse manages a very large case load of patients and does not receive information when there has been a change in their situation (e.g. an admission to hospital) or the outcome of a referral to another service.

Concept 2: Health Story

A 'Health story' would provide a space within the Backpack for the person to share their story in their own words, using video or written narrative, supported by key dates and facts.

Concept 3: Smart Form Filling

The Backpack could gradually fill up with information as the person completes forms and could automatically draw in data from existing sources. 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 (e.g. this person is on the MS Scottish Register) to automatically prove eligibility for services (e.g. Blue Badge).

Concept 4: Tools for the Specialist MS Nurse

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 emails to all their patients via the Backpack.

Next steps

We hope to share the findings of the project with policy makers in health and care, to highlight the challenges identified and the need for new resources to support information sharing and communication between people and health professionals. We are continuing to work on the Backpack concepts to help to further develop, test and demonstrate the potential benefits of these approaches in supporting person-centred and convenient access to services.

For more information

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