Backpack – Person Centred Health, Care and Wellbeing

Sponsor: Glasgow School of Art
Funding: Digital Health Institute
Principal Investigator: Dr Nicolas Van Labeke
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Protocol summary

Full Title	Backpack – Person Centred Health, Care and Wellbeing
Short Title	Backpack
Funding Body	Digital Health Institute
Sponsor	The Glasgow School of Art
Principal Investigator	Dr Nicolas Van Labeke
Sample Size	Mini-lab: 1 or 2 participants Experience Lab 1: 6-8 participants Experience Lab 2: 6-8 participants
Study Population	Mini-lab: group leader & volunteers from local support group (MS Moray) Experience Lab 1: MS citizens, recruited from local MS support group Experience Lab 2: public/third sector workers, with no experience of MS
Study Design	The study will involve participants in three distinct sessions during the project. The sessions will be used to inform the development of an eco-system for a Personal Data Store (PDS). Mini-lab: Semi-structured individual interviews with group leader and/or organiser from the local MS support group, to inform the shape and focus of the next two labs. Experience Lab 1 Workshop with MS citizens, to map out typical journeys through service points and supports of people receiving life-changing diagnosis. Experience Lab 2 Workshop with public/third sector workers, to "play out" the map and scenarios generated during Experience Lab 1.
Study Location	All labs to be held at the GSA Horizon Scotland (Forres), workshop in the Library space, breaks and lunch in the Social space.
Study Duration	Total study duration: 5 months WEEK 5: - Mini-lab (2 hours per interview) WEEK 10-12: - Experience Lab 1 (2 half-day sessions, 2-3 hours each, 1 week apart) WEEK 15: - Experience Lab 2 (2-3 hours)

1 Project brief

What if there was only one place where all your medical/personal records are. Every person just has this one space, 1 number, 1 folder, which we call here your personal **"backpack"**. Your **backpack** content can be whatever you want and can be shared with who you want. It works like protected folder from Drop Box: 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. This way it can make care more personal and imbedded in your daily life.

Together with MS 'experts' (patients, caregivers, family members) we want to create such a plan of action. This map will cover the first month after being diagnosed with MS, and will help you prioritise the things that you want to take care off. The further you go in time the more personalised the map will be. After months you find yourself in a highly personalised 'level' (like in a computer game) in your plan of action.

We have chosen a MS scenario to further investigate this concept of having a **backpack**, because this is a very complex illness, no patient is the same, and asks for a better interaction with health and care.

2 Background

The proposal seeks to understand the personal behaviours, journeys and access points of Multiple Sclerosis (MS) citizens, in order to build out an eco-system for a Personal Data Store (PDS) and elicit issues around personal control over personal data.

Research and recent reports highlight the urgent need for more integrated person-centred services as a means of delivering better patient outcomes, better clinical outcomes and better economic outcomes. Different implementation scenarios carry different configurations of cost, risks and benefits for different stakeholding groups, and the implementation of digital services has suffered in the past from lack of co-production or consultation with people and stakeholders on the ground before implementation.

The proposed project will enable a group of citizen participants (plus organisations and their representatives) to interact in person-centred scenarios. These individuals may have long term conditions or professional interests with such condition – we have identified Multiple Sclerosis (MS) as a potential starting point – and we will identify needs, barriers, benefits and co-produce implementation scenarios.

3 Aims of the project

The proposal seeks:

1) to understand the personal behaviours, journeys and access points of MS citizens
2) to inform participants of personal control over personal data, and
3) to scope out an eco-system for a Mydex-based PDS.

The work will be supported by the DHI Experience Lab team in Forres, and will take place physically in the area covered by NHS Grampian, where the project partners already have strong supports (e.g. Alliance and Carer's Trust) for connecting Mydex PDS and local services.

Some of the key questions the project is aiming at addressing are:

- How do people think about the future when they have a new diagnosis?
- What are the personal behaviours, journeys, stories and access points (administration, services) of someone receiving a life changing diagnosis?
- How should they be prioritised? How does a mapped out plan of action for the first month after receiving a life changing diagnosis?
- How can people and their care network interact with a personal data store (PDS) that helps them to store, access and share their data?

4 Study design

The overall theme of the Labs will be to design and trial run a MS-informed version of the **"Snakes & Ladders"** board game, mapping out points of passage (the **"grid"**), obstacles in current journey (the **"snakes"**) and opportunities offered by a Digital Personal Data Store (the **"ladders"** and **"backpack"**).

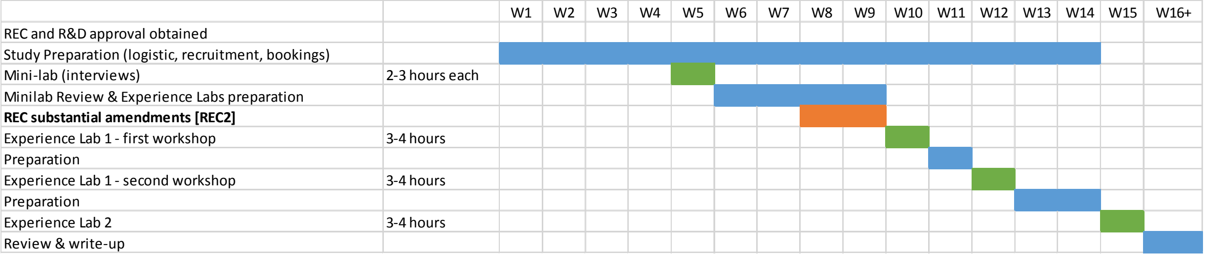
The primary objective of the project, through the co-design, implementation and trial run of a workable version of the board game, will be to identify key opportunities for the PDS, grounded on the journey mapped out on the board.

A secondary objective of the project, through the recording and exploitation of the trial run of the board game, will be the potential creation of educational and promotional materials aimed at raising awareness of MS and its implication for day-to-day life.

The proposal comprises three **"Experience Labs"** (scoping, co-design and optimisation), organised as semi-structured workshops, involving focus groups, interviews, observations, reflective activities (written and/or video) and co-design of paper prototype.

Labs will be video-recorded in order to gain rich, qualitative data on the user experience. The data gathered will be analysed using appropriate qualitative analysis suited to the methodology (e.g. thematic analysis in order to reveal emerging and recurrent themes).

4.1 Provisional Timeline



		W1	W2	W3	W4	W5	W6	W7	W8	W9	W10	W11	W12	W13	W14	W15	W16+
REC and R&D approval obtained																	
Study Preparation (logistic, recruitment, bookings)		🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦		
Mini-lab (interviews)	2-3 hours each					🟩											
Minilab Review & Experience Labs preparation							🟦	🟦	🟦	🟦							
REC substantial amendments [REC2]									🟧	🟧							
Experience Lab 1 - first workshop	3-4 hours										🟩						
Preparation												🟦					
Experience Lab 1 - second workshop	3-4 hours												🟩				
Preparation														🟦	🟦		
Experience Lab 2	3-4 hours															🟩	
Review & write-up																	🟦

4.2 GSA Experience Labs

The proposed activity is a series of **"Experience Labs"**. **Experience Labs** are a core aspect of the Digital Health Institute, a Scottish Funding Council Innovation Centre led by the University of Edinburgh and The Glasgow School of Art (www.dhi-scotland.com). Although **Experience Labs** are not a new concept, they are a new way of working collaboratively within the health and social care context in Scotland. **Experience Labs** provide the opportunity for extreme collaboration in a safe and flexible environment where academics, business and civic partners can co-create and co-design

sustainable solutions together with end-users. The inclusion of end-users is crucial to the success of the innovation in order to develop solutions that match their needs and preferences.
The research approach within the **Experience Labs** is person-centred and driven by design methodologies. The environment of the **Experience Lab** aims to replicate real life practice allowing for the trialling of ideas through rapid cycles of experience. The Labs involve participants engaging in a series of activities placing the user at the centre of the design process. These activities involve observation, brainstorming and prototyping of ideas. Prototyping enables the progression of thinking and ideas through physical making; a safe space for failure leading to faster learning; and encouragement and permission to explore new behaviours. The Labs involve paper prototyping and gradually lead to experimentation with a functional prototype. This involves an iterative process of several cycles where ideas are reviewed, adapted and refined.

Experience Labs open up the design process to encourage creativity, and allows users to experience digital technologies as well as gather deep insights on their experience, behaviours and attitudes. **Experience Labs** are an emergent process that cannot be predetermined, similar to Participatory Action Research. Lab evolves as those engaged deepen their understanding of needs. The Labs provide not only the opportunity for collaborative relationships to develop but open the opportunity for new communicative spaces and experiential learning.

4.3 Mini-lab (Scoping)

Purpose: gathering insights around MS in general, getting to know the people, their needs and supports.

Participants: 1 or 2 MS caregiver(s) from local support group (e.g. MS Society Scotland, MS Moray)

Methodology: Interviews

Location: GSA Studio (Forres)

Timing:

- 2-3 hour individual interview
- All interviews within the same period (week 5), at time convenient for interviewee

Outcomes: understanding of MS and MS citizens; boundary mapping (points of passage, see **Experience Lab 1**); identification of participants and stakeholders (see **Experience Lab 2**)

Description:

- Interviews to be video-recorded (and transcribed for analysis and storage)
- Topics of discussion will be defined at a later stage but will include, as a minimum:
    - Developing a basic understanding of MS
    - Identifying and recruiting potential participants (**Experience Labs 1 & 2**)
    - Eliciting initial set of points of passage (e.g. administrative tasks, actors, networks, etc.)

4.4 Experience Lab 1 (Co-Design)

Purpose: Map out a typical journey (“plan of action”) for the first month(s) after diagnosis

Participants: 6-8 volunteers recruited from the local MS support group (e.g. MS Society Scotland, MS Moray) and specific public/third sector stakeholders (e.g. Moray Council, Independent Living Centre)

Methodology: focus group, mapping activity, role play

Location: GSA Studio (Forres)

Timing: 2 half-day grouped sessions

Outcomes: shared experience; prototype of a MS-informed **"Snakes & Ladders"** board game

Description:

- Both session based on the role-play of an hypothetical scenario (see "MS Role-playing scenario" below)
- Group Session 1: Sharing experiences
    - Semi-structured focus group
    - Participants to translate their experience onto the hypothetical journey
    - Points of passage, actors, objects, etc. to be materialised on cards
- Group Session 2: Co-creating the board game
    - Organising cards in structured narrative/path
    - Obstacles to be identified
    - Opportunities for PDS to be identified
    - Review, refine and optimisation of overall journey
- Post-lab reflective session with each participants (brief video-recorded self-report on experience)

4.5 Experience Lab 2 (Optimisation)

Purpose: Trial run of the journey created during **Experience Lab 1** with front-line service providers, to validate the mapping and elicit further opportunities for the PDS.

Participants: 6-8 volunteers recruited from Moray Council front-line services and other relevant third sector organisations

Methodology: focus group, role play, game play, interviews

Location: GSA Studio (Forres)

Timing: 1 half-day session

Outcomes: shared experience; optimised prototype of the board game; "video diaries" of gameplay and reflective activities

Description:

- Session based on the role play of the scenario ("Alison MS diagnosis", see below)
- Capture of the experience/perspective of service providers on the MS journey devised by participants in **Experience Lab 1**
- Trial run and optimisation of the board game created during previous lab
- Post-lab reflective session with each participants (brief video-recorded self-report on experience)

4.6 MS Role-playing Scenario

"Alison is the young mother of a four year old son. Her husband works offshore – 3 weeks on, 3 weeks off and so she is often playing the part of a single parent. She works and her mother, who lives in the next town, is her childminder and Alison drops her son off there and picks him up as her mother cannot drive.

Alison has been attending the GP recently due to worrying signs of ill health which comes to a head one evening when she crashes her car, attends A&E and is given the devastating news that she has MS."

Potential Interactions	**Reasons**
NHS – GP, consultant, specialist nurse, pharmacy, physiotherapy, OT	Medical intervention
Local Authority - Social Work	Blue badge, home care, adaptations, Telecare, Home care,
Employer	Time off, Flexible working, Occupational Health
Husband's employer	Time off
Education Department	Son's schooling
DWP	Benefits Check
Insurance	Benefits
Family	Moral support/understanding implications
Moray MS Network (online and physical meetings)	Peer support
DVLA	Advice re driving
Online supermarket delivery	Ease
Living it Up (Shine); Volunteer Centre; RVS	Volunteer support – e.g. driving son to childminder
Transport agencies	Transport options
LA - Revenues	Council Tax reduction
LA - Registrars	Register death
HMRC	Tax code/Child Tax Credits
Insurance	Life insurance claim
Bank/Building Society	Notification
LA - Education Dept	Children's schooling
LA – Social work	Initiate child carer's assessment
Quarriers Carer Support services	Carers' assessment
NHS – GP, consultant, specialist nurse, pharmacy, physiotherapy, OT	Medical intervention
DWP/Pensions Service	Benefits Check
Solicitor	Legal advice – Enduring Power of Attorney
Third sector organisations such as AlzScot	Peer support, volunteer support
Family	Moral support, understanding implications

5 Recording

Experience Lab activities will be video-recorded and photographed, requiring participants' consent (template attached). Video and picture files will be used by the team only for reviewing discussions and interactions with the workshop materials. Video files will be transcribed and anonymised. All generated data will be stored securely. Photographs including participants will only be used in publications and presentations if consent is given.

6 Project partners and coordinators

- **Alex Stobart**, Mydex CIC

Mydex CIC (www.mydex.org) is a Community Interest Company which provides personal data stores, identity services and assurance and data flows controlled by the user/owner. Central Government, NHS, Local Authorities and other service providers can provide data, and / or be afforded access to this information by the person who owns the data, as a basis for service provision. The individual is at the centre, and has personal control over personal data. This is in contrast to the normal provision, where each service provider has a data base with some information about the user, and the user must access the service provider and their different data-stores for each service.

- **Jamie Hogg**, NHS Grampian (http://www.nhsgrampian.org/)
- **Grant Cumming**, University of the Highlands and Islands (http://www.uhi.ac.uk/)
- **Lorna Bernard**, Moray Council (http://www.moray.gov.uk/)
- **Alan Beevers**, MS Moray (http://www.msmoray.net/)

7 GSA researchers

- Dr Nicolas Van Labeke (Research Fellow, CI)
- Dr Tara French (Research Fellow, PI)
- Sanne Ree Barthels (Designer, PI)