

# Participant Information Sheet

---

## Research Project

### Backpack – Person Centred Health, Care and Wellbeing

You are being invited to take part in a research project that is being led by The Glasgow School of Art. Before you decide whether to take part it is important that you understand why the research is being undertaken and what it will involve. Please read the following information and contact us if anything is unclear or if you require further information.

### What is the purpose of the research project?

What if there was only one place where all your medical/personal records were stored. Every person just has this one space, one folder, one personal data store, which we call here your personal “backpack”. Your backpack content can be whatever you want and can be shared with who you want, under your control, specially designed for your personal situation. This way it can make care more personal and embedded in your daily life.

We have chosen a Multiple Sclerosis (MS) scenario to further investigate this concept of a digital backpack, because this is a very complex illness, no patient is the same, and it requires a better interaction with health and care services. The research seeks to understand the personal journeys MS citizens are going through following diagnosis, inform participants and MS citizens of personal control over personal data, and explore how such a digital backpack would be deployed and adopted. The expected duration of the overall project is 5 months; **your participation will involve taking part in two half-day workshops.**

### Why have you been invited?

**You have been invited because you have a personal or professional experience with Multiple Sclerosis, which will help us to explore and role-play scenarios. Up to 8 people will participate in the two workshops.**

### What will the research involve?

If you agree to take part, you will be invited to sign a consent form to confirm that you understand what is going to happen in the research project and are happy to participate.

The two workshops will take place at the Alexander Graham Bell Centre for Digital Health in Elgin. Each workshop will be organised on two different days, at a time convenient for all last for participants, and will approximately 3-4 hours. They will involve a range of activities such as role-playing, focus group discussion and brainstorming ideas to define different journeys and share your experiences.

The overall activity of the two workshops will be to design a MS-informed version of the “Snakes & Ladders” board game. You will be presented with scenarios involving citizens being recently diagnosed with MS and, by exploring the scenarios with other participants, you will be collectively building out points of

passage (the “grid” of the board game), obstacles in journey (the “snakes”) and opportunities offered by the personal data store (the “ladders” and “backpack”). During the first workshop, you will be translating your own experience into the scenarios, gradually building a first basic board. During the second workshop, the group will start from the same board and, by introducing the personal data store, you will be exploring how the “backpack” could change the scenarios and the experience of MS citizens. Throughout the two workshops, you will be actively supported in your activities by expert facilitators from the Glasgow School of Art, what we call “co-design” sessions. At the end of the workshops, you will be given the opportunity to reflect on the whole process and tell us about your experience so far.

Photographs, video and audio recordings will form an integral part of the research data gathered. Videos and photographs might be used in presentations and public displays and you could potentially be identified from them. Please indicate via the consent form or speak with one of the research team on the day if you are uncomfortable with being recorded.

Please note that all travel costs will be reimbursed and refreshments and lunch provided.

### **What will happen to the results of the research project?**

The insights from the project will inspire and offer direction to the development and adoption of personal data stores. The information you provide will be included in an internal research report to be held by the Digital Health Institute and will also inform a report to be delivered to the project partners. You will have the opportunity to meet representatives from all project partners during the day.

The information may also be included in an academic publication and may be presented at a conference. Your information would be used solely for the purpose of the project and no other reason and will held in accordance with the Glasgow School of Art Data Protection Policy.

### **Who is organising and funding the research?**

The project is being organised and funded by The Digital Health Institute (DHI) which is a Scottish Funding Council funded initiative between The Glasgow School of Art, The University of Edinburgh and NHS 24, to bring together health, care and third sector professionals, academics and industry partners to work together innovating for societal benefit with economic advantage. The partners of the project include MyDex CIC (a Community Interest Company which provides personal data stores and identity services controlled by the user), the University of the Highlands and Islands, NHS Grampian and the Moray Council. The workshops that you have been invited to participate in are led by the Glasgow School of Art.

### **Do I have to take part?**

Taking part is entirely voluntary. It is up to you to decide. We will describe the study and go through the information sheet. We will then ask you to sign a consent form to show you agreed to take part. You are free to withdraw at any time, without giving a reason. Withdrawing from the research will not affect your professional or work-place standing.

### What are the benefits and risks if I take part in the research?

This research project gives you and other participants the opportunity to shape, not only the future deployment of Personal Data Store, but also a research and societal agenda for many other users, as the aims and implications of the project are not confined to MS citizens.

The research involves focus groups and co-design workshops with other participants living with long-term conditions. Since the objective is to discuss your experience of planning life-changing journeys and interaction with services rather than your individual health status, it is unlikely that much distress will be generated. Such risk is also minimised by running the workshops on the basis of stereotypical scenarios rather than your own.

### What should I do if I want to complain?

Verbal complaints during the Experience Labs should be made to the lead researchers present on the day who will make themselves known to you. Contact details are included on this Participant Information Sheet for both the lead researchers and a Design Director should you wish to make a complaint by phone, email, in writing, before, during or after the Experience Labs. The lead researchers or Design Director will ensure to respond to the complaint within 48 hours of receipt and resolve it before the end of the project as a maximum. In case of harm arising from participation to the research project, arrangements have been made by the sponsor, The Glasgow School of Art, to meet the potential legal liability of the research team.

### Who should I contact for further information?

#### Lead Researchers

<p>Nicolas Van Labeke Research Fellow &amp; Creative Technologist</p> <p>The Institute of Design Innovation The Glasgow School of Art Horizon Scotland Forres IV36 2AB Tel. 01309 678 146</p> <p>Email: <a href="mailto:Nicolas.van-labeke@dhi-scotland.ac.uk">Nicolas.van-labeke@dhi-scotland.ac.uk</a></p>	<p>Tara French Research Fellow</p> <p>The Institute of Design Innovation The Glasgow School of Art Horizon Scotland Forres IV36 2AB Tel. 01309 678 146</p> <p>Email: <a href="mailto:tara.french@dhi-scotland.com">tara.french@dhi-scotland.com</a></p>
--	---

#### Design Director

<p>Mr Don McIntyre</p> <p>The Institute of Design Innovation The Glasgow School of Art 167 Renfrew Street</p>
---

Glasgow G3 6RQ  
IV36 2AB  
Tel. 0141 353 4500

Email: [d.mcintyre@gsa.ac.uk](mailto:d.mcintyre@gsa.ac.uk)