

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 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, raise awareness among selected groups of public and private sector workers, inform participants 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 one half-day workshop.**

Why have you been invited?

You have been invited because we have identified your professional background as where raising awareness about MS and personal data stores would be the more beneficial to the aims and objectives of the project. Up to 8 people from a similar background will participate in the workshop.

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 workshop will take place at the Alexander Graham Bell Centre for Digital Health in Elgin and will last for approximately 3-4 hours. The workshop will involve a range of activities such as role-play and focus group discussion based on scenarios created in a previous workshop, and sharing your experience of going through journeys that are typical to long-term conditions.

The overall theme of the workshop will be to design a MS-informed version of the “Snakes & Ladders” board game. You will be presented with a board game designed by a group of MS citizens in a previous

workshop. The board was built on the basis of scenarios involving people being recently diagnosed with MS. After a general introduction to MS and MS citizen, you will be given similar scenarios to play out on the board game with the other participants. You will have the opportunity to translate your own experience into game, by changing the points of passage (the “grid” of the board game), the obstacles in journey (the “snakes”) and the opportunities offered by the personal data store (the “ladders” and “backpack”). Throughout the workshop, 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 workshop, 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 and declining to take part will have no effect on your present or future care. 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 access to any health care or support group related activities.

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 activities based on the journeys of citizen living with long-term conditions such as MS. Since the objective is to discuss your professional experience of interacting with such situations and relevant public services rather than individual health status, it is unlikely that much distress will be generated. Such risk is also minimised by running the workshop 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

Nicolas Van Labeke
Research Fellow & Creative Technologist

The Institute of Design Innovation
The Glasgow School of Art
Horizon Scotland
Forres
IV36 2AB
Tel. 01309 678 146

Email: Nicolas.van-labeke@dhi-scotland.ac.uk

Tara French
Research Fellow

The Institute of Design Innovation
The Glasgow School of Art
Horizon Scotland
Forres
IV36 2AB
Tel. 01309 678 146

Email: tara.french@dhi-scotland.com

Design Director

Mr Don McIntyre

The Institute of Design Innovation
The Glasgow School of Art
167 Renfrew Street
Glasgow G3 6RQ
IV36 2AB
Tel. 0141 353 4500

Email: d.mcintyre@gsa.ac.uk