

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 be to take part in a one-off interview.**

Why have you been invited?

You have been invited because, as an active member of a MS support group, you have a wide experience of living with Multiple Sclerosis. This experience will be essential in help us to understand the background for the project and plan our subsequent workshops with MS citizens. Up to 2 people from the support group will be interviewed.

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 interview will take place at GSA office in Forres, will be organised at a time convenient for you and will last approximately 2-3 hours. The interview will take the form of a discussion between you and a member of the research team and will focus on issues such as to the nature of MS, the life and experience of MS citizens, the role of MS carers and support groups, etc.

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 be 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 interview and fact-finding activities based on your professional experience of long-term conditions such as MS, it is unlikely that much distress will be generated.

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?

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