

Backpack – Executive Summary

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The Personal Data Store (PDS), herein referred to as the Backpack, was proposed as an opportunity to improve the experience of accessing services and enabling integrated and person-centred care. The project explored the potential solution developed by the project partners: Mydex CIC, a community interest company who specialise in personal data management, together with NHS Grampian and Moray Social Health and Care Partnership.

The overall aims of the research 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.

To meet these aims, design researchers at The Glasgow School of Art led a participatory design process with people living with MS and health and social care professionals. People living with MS were identified as highly knowledgeable co-design participants, due to the complex and progressive nature of the condition, requiring wide-ranging interactions with statutory services.

Participants living with MS were involved in a Mini-Lab to explore current experiences of accessing services and managing information and an Experience Lab, which used design-led activities to map key moments of data sharing and developed paper-based prototypes of the Backpack.

A second Experience Lab involved health and social care professionals in testing prototypes of the Backpack, identifying user requirements from the perspective of service providers, and understanding how access to person-owned data stores would change current working practices.

Analysis of the conversations, maps and prototypes led to: i) a wealth of insight about the current experience and challenges of service users and providers; ii) the identification of a set of overall principles to shape the development of the person-owned data store; iii) synthesis of the main ideas for functionality as four overarching but complementary concepts that describe how the Backpack could manifest; and iv) a number of scenarios of use to describe how the principles and concepts could support person-centred and convenient access to services.