

Impact of involving people with lived experience of digital barriers in a co-design project on addressing belief and trust barriers to using digital health services:

A case study of the involvement of Forward Carers

October, 2025

Health & Wellbeing Alliance Outcomes:

- Improved knowledge of barriers and enablers to accessing services
- Increased sharing of lived experience with VCSE, system partners and providers

Context:

Forward Carers are a community interest company, supporting unpaid carers to live fulfilling lives. Through the initial desk research we had conducted for this project, and through engagement with other HWA partners, we had identified carers as a potential priority group, given additional challenges faced in managing access to health services for the people they care for. We approached Forward Carers to invite them to collaborate on the co-design phase of the project, as they are an active member of the National Digital Inclusion Network, providing digital access and skills support to their service users.

Forward Carers agreed to host two co-design workshops, inviting around 10 of their carers to participate in both sessions, and helping to set expectations about the process and what they would be participating in. On organising these workshops, Forward Carers asked whether they would be able to use part of the first session to ask a few questions of the carers about accessing and using their own digital services, to help shape the accessibility of these services, in particular the Carer's Assessment process.

Forward Carers also conducted a simple feedback questionnaire after each workshop, to understand participants' experiences of contributing to the co-design process. The insights from these questionnaires have illustrated the value to the participants of being part of the process.

Outcome 1: Improved knowledge of barriers and enablers to accessing services

From the insights gathered by Forward Carers at the end of each co-design workshop, we can see that many of the participants felt very positive about their experiences, and felt that their contributions had been acknowledged and useful for the process. For example:

“I felt valued and I felt like my opinion was needed/included.”

“We are listened to and we can tell that our opinion and feedback matters”

From comments made during the workshops and in the feedback questionnaires, we can see that sharing of lived experience helped some people to feel more connected with other carers and valued the opportunity to hear the experiences of people in similar positions to them:

“It has been really engaging to listen to others and reflect on how I feel about issues around digital health.”

“Felt connected to other carers in similar situations.”

We also heard of how the sharing of views and the participation in the workshop activities led to some people feeling more confident to engage with digital health services, having heard the experiences of others and shared ideas and experiences about specific tools and apps:

“Make me more able to participate in digital websites for healthcare in the future”.

“We have been able to share resources we find useful with one another, e.g. Livi app”

This highlights the value of conducting co-design work with people with lived experiences, not only for producing resources that are relevant and appropriate for supporting those communities, but also for building the knowledge and capability of those people to navigate and access (digital) health services, through peer learning and support.

Outcome 2: Increased sharing of lived experience with VCSE, system partners and providers

Prior to hosting the co-design workshops, Forward Carers asked if they could take some time at the end of the workshops to ask their own questions of the participants, in relation to developing an online approach to conducting Carer's Assessments. The Carer's Assessment is an in-depth conversation with carers about the individual help and support they may need across different aspects of their life, work and caring responsibilities. The

assessment has typically been conducted face-to-face or over the phone, but in the first workshop, staff from Forward Carers asked participants how they felt about the idea of completing a Carer's Assessment online. Building on the insights around belief and trust barriers from the workshop discussion, staff were able to elicit valuable feedback from participants about considerations for making an online assessment process accessible and user-friendly.

Following the first workshop, Forward Carers used the feedback to adapt their approach to designing the online assessment process. They then engaged participants from the workshop in two separate discussions on the topic, to develop and refine the online approach further. Workshop participants were also engaged in user testing of the beta site for the online assessment process, and feedback from this is being applied to make further improvements.

“The insights we gathered from Carers – through the initial co-design workshops, and later through engagement and user testing – have been truly invaluable. Their feedback confirmed the importance of offering new types of online support and directly shaped the development of our new online Carers Assessment, right down to the wording. More importantly, it gave us a deeper understanding of Carers’ priorities, aspirations, and concerns.

When launched, this new online Carers Assessment will offer a flexible, accessible option for those who prefer to engage digitally. It will enable Carers to reflect on their needs at their own pace, access support outside of traditional service hours, and complete the process in a way that works for them.

At Forward Carers, we believe co-production is not just the right thing to do – it leads to better outcomes. And ultimately, that’s what drives us.”

Anna Smith, Executive Manager, Forward Carers

This highlights the value of the co-design project and process for supporting VCSE organisations to engage and learn from people with lived experience, informing the design of their own services, to ensure they are accessible and inclusive. With the example of the Carer's Assessment process, ensuring this meets the needs of different carers may well lead to better engagement with and uptake of health and care services by carers and those they care for.