

# Helm

## Good Practice: Engagement and Service Design

Helm is a citizen-led person held record (PHR) developed in Leeds. The Helm concept was created in response to research which indicated that local people would welcome a PHR which allowed them to manage and share information about their health, care and wellbeing. There was enthusiasm about how a personal health record could transform the way in which health and social care is delivered and this feedback provided the driver for Helm's initial scope and further development.

Engagement and co-design have been the cornerstone of Helm's development and direction of travel. In keeping with the Design Principles in the NHS Digital Service Manual, the Helm Team have worked consistently to uphold the principle of "Putting people at the heart of everything you do". Helm has consistently looked to patients, family, carers and health and care professionals to understand their needs and co-design a product that supports and respects them.

We also work within the guidelines set out in the Local Digital Declaration and the Government Data Service code of conduct design principles for data driven health and care.

### Our Approach

From the initial concept, to the design and implementation phase, we have engaged with people, carers and professionals. Key stakeholders were identified at an early stage and effective engagement and communications with people, patients, carers and professionals has underpinned Helm's approach.

The NHS Digital Person Held Records Adoption Toolkit sets out the importance of involving people every step of the way to ensure both citizen uptake and clinical buy in. The toolkit states that involving users and learning from them throughout your PHR development cycle will help you to achieve the following:

- understand who all your users are: this could be patients, the wider public, health and care staff, managers
- understand through testing and research if different user groups have conflicting needs
- understand [accessibility requirements](#) and the needs of specific groups, like those with low digital literacy and lacking support
- discover what health and care-related tasks your users need to do
- discover how they do those tasks now
- find out if, and how, a PHR will help them to do those tasks better
- involve users in decisions about procurement or commissioning PHR tools: they are the people the PHR must work well for
- test prototypes of the PHR, with all of your user groups
- understand how the PHR is actually used and what might be improved

- meet the [Five Year Forward View](#) vision of “a new relationship with people and communities”

### **Engagement activities**

Leeds Informatics Board commissioned a piece of research called [Joined up Leeds](#), to explore citizens and care professionals’ views on data sharing and a Person Held Record (PHR). The outcomes formed the basis of the first conversations around Helm and how people would use a PHR to support their health and wellbeing.

Following this research, Yorkshire and Humber Local Care and Health Record Exemplar (LCHRE) commissioned a further research project, [Joined up Yorkshire and Humber](#), to explore the beliefs that people have about how their health and care records could and should be used, their boundaries for what they are willing for their data to be used for, their concerns around how their data could be used, and the reassurances they want about how their data is safe.

The Helm team commissioned mHabitat, a local agency specialising in co-design and innovation, to understand how Helm could be used by the people of Leeds and best address their needs. mHabitat spoke to over 100 people in ten different locations across the City, with a view to understanding the key areas of functionality potential users are interested in and the problems they are facing that could be addressed by a person held record such as Helm. The findings from this engagement campaign were [published](#) alongside a list of over a hundred suggestions for potential features in Helm. These suggestions have been used to determine future priorities and provide the evidence for the Helm development roadmap.

We are working with Leeds City Council’s Co-production Group, to develop and test key elements of Helm’s design and functionality by sharing iterations of the product and listening to their views and feedback. In keeping with NHS England and the Coalition for Collaborative Care Guidelines, “Co-production is a way of working that involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation.” This principle has helped us to remain focussed on developing a product that will make a positive difference to people’s lives.

We have worked with groups of people in Leeds, with experience of, or a particular interest in certain clinical areas, to inform the development of key features of Helm. One area in which this approach worked well was in the development of Helm’s care plan functionality.

#### Care Plan Engagement Step by Step Process:

- Held patient engagement workshop sessions to explore the current CCSP (Collaborative Care and Support Plan) process, identify issues and determine how Helm can support, streamline and improve the process.
- Identified local GP practices with a particular interest in digital health and approached Practice Managers and Practice Nurses inviting them to get involved.
- Held engagement events with practices in Leeds to test the process from the practice perspective and identify how Helm can support healthcare professionals.
- Used this feedback to develop recommendations for Helm CCSP functionality developments and to inform the prototype.
- Work with patients and staff to continue the development cycle and further test CCSP iterations.

## **Key recommendations**

1. Position engagement at the heart of the project so all Helm team members are committed to its importance and the impact effective engagement can have on achieving successful outcomes.
2. Ensure key stakeholders are identified and given the opportunity to contribute from the initial onset of the project to maximise their interest in and commitment to the project.
3. Identify and work with existing groups of service users to increase opportunities for meaningful engagement.
4. Ensure feedback is factored in to all product development to ensure the voice of the people is heard in all strategic decision making.