

# **Helm for Leeds (Personal held record) Citizen Engagement Report 2019**

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# Executive summary

Helm is a Person Held Record (PHR) created by Leeds City Council in partnership with the NHS healthcare organisations in Leeds. Helm aims to help people in Leeds better manage their own care and wellbeing. To understand the problems citizens are trying to solve and how Helm may help in the future, mHabitat ran a series of citizen engagement activities. This included face to face conversations with 105 people across 10 locations in Leeds. Citizens were not linked to health and care involvement groups and were recruited via mHabitat local knowledge of communities across the city

One of Helm's proposed features is 'three things about me I want to share'. The majority of responses were linked to current and past health issues. Other topic areas included their lifestyle, support network and occupation. The value of these fields is unclear as many people either used this to communicate current symptoms/conditions or mentioned the same or similar information they would add to the permanent record.

The majority of people said they would use Helm at various (rather than specific) times and were happy to simply type the information into Helm. If the data was already being recorded elsewhere, such as app or medical record, people would prefer automatic extraction. Quite a lot of information people asked for could be pulled from existing records, such as the Leeds Care Record.

The most common use case for Helm was to share information relating to past or current medical issues with a relevant healthcare professional. People said they don't want to keep repeating themselves or are not always taken seriously. This highlights the need for buy in from healthcare professionals. The second most common use case is to track progress on one or more physical, mental or emotional goals, often as a self-initiated self-management.

A minority of people said they could or would not use Helm. Most of these either felt no need to track anything or were already using another method. Some people did not have the necessary resources or digital literacy, or didn't feel Helm was appropriate due to privacy or health anxiety concerns.

Other than people with current and/or chronic medical conditions, other user groups were identified who may benefit from Helm the most, including carers, frequent travellers, and those already using digital tracking. Focussing on specific user types can help set priorities for the technical development of Helm and create champions and case studies to aid with wider adoption.



# Introduction

Helm is a Person Held Record (PHR) for people in Leeds which supports the integration of health and social care. The project is led by Leeds City Council in partnership with the NHS healthcare organisations in Leeds. Helm aims to empower citizens, helping people to manage their own care and wellbeing better and prevent further health issues. It is a pioneer of the NHS login and therefore security was out of scope for the project.

The central Helm project team also utilise a core citizen steering group and the Joined Up Leeds project report was used as a springboard from which to define the mHabitat work. Joined up Leeds included a two-week period of conversations taking place across the city in which citizens discussed how their health and wellbeing data could and should be shared, the benefits of sharing, the concerns they have, and how information could be used for the benefit of people in Leeds.

## What did we aim to achieve?

In this project, mHabitat sought to engage a wide range of citizens to understand the problems they are trying to solve and how Helm may help. The insights will be used to inform the next stage of the Helm development roadmap. This roadshow of events focussed on face to face citizen engagement, accessing the public in a range of settings where there is a significant footfall/captive audience. It did not include groups who are linked to existing health and care organisations or networks. The ambition was to understand the needs and priorities in relation to using a digital patient held record, as well as any barriers.

## Citizen engagement

The mHabitat team used a set of designed tools (see appendix) to engage the public, based on existing insights and designed to elicit the public's views, ideas, problems and requirements. This work was underpinned by best practice in digital service design, a core element of mHabitats work. The activities aim to be quick, fun and easy to use. Accessibility factors were taken into account and team members supported each citizen to optimally engage during the events. Participants were also asked to complete an electronic survey on a tablet in order to collect demographic data for the Helm team. This data which was sent directly to Helm project leads cannot be linked to individual responses to preserve privacy.

From May till July 2019, the mHabitat team engaged 105 people across 10 locations, including:

- 01.05.19 - LDF19 Refugees and Asylum Seekers Event, Co Space North – 13 people



- 30.05.19 - Leeds Kirkgate Market Kitchen – 8 people
- 20.06.19 - Wetherby Town Hall – 10 people
- 28.06.19 - Garforth Library and OSC – 12 people
- 05.07.19 - Seacroft Tesco Extra – 13 people
- 06.07.19 - Kirkstall Leisure Centre – 13 people
- 10.07.19 - Lingwell Croft Surgery Carer's Group – 6 people
- 17.07.19 - Morley Community Hub - 12 people
- 23.07.19 - Rotary Club meeting at Horsforth Golf Club – 8 people
- 27.07.19 - Farsley Farmers' Market - 10 people

People were allowed to contribute to more than one use case (for example, they may track their blood pressure and sleep, or would use Helm in the morning and evening), and some people did not (want to) do part of the activity. Therefore, we will mainly report number of responses rather than the number of people.

## Demographics survey

Most people (100 out of 105) consented to filling in the electronic survey. 82 respondents had an LS postcode while 17 were from other areas. 75% of respondents were between 25-64 years of age (see table below). No respondents were under 25. 85 respondents identified as British and a further 3 as 'white - other', 5 as Asian, 4 as black, and 3 did not want to disclose their ethnicity. 57 respondents identified as female, 41 as male, and 2 preferred not to say. 17 people considered themselves disabled while 82 did not. 27 people said they were a carer and 73 said they were not.

25-34	35-54	55-64	65-74	75+	Not disclosed
12	47	16	16	8	1

## Three things about me

One of Helm's proposed features is 'three things about me I want to share'. The most popular topic was current health issues people were experiencing, including symptoms, and current and chronic health conditions. Most of this information, other than new issues



that have developed since the user last saw a healthcare professional, would be part of the medical record (Leeds Care Record). The next most popular topic included complaints and needs, for example, 'I'm worried about privacy', 'I have to repeat myself every time I visit' 'I need more advice about X'. The third most popular topic was past and family medical history (for example, saying they had had cancer in the past).

About me	Number of mentions
Current health issues (symptoms, current and long-term conditions)	71
Past medical history	19
Medication (details, prescriptions, reminders)	17
Allergies	10
Blood/organ donor	5
Medical requirements/wishes	3
Pregnant	1
Dealing with appointments (such as book a new one)	10
NHS number	2
Doctor/emergency contact details	1
Insurance	1
Lifestyle (unhealthy habits, wants)	14
Exercise	17
Diet	10
BP	4
Blood type, height, weight	1
Weight	1
pH	1
Support network (family and friends, emergency contacts)	17
Being a carer	9
Being proxy	3
Occupation	13
Complaint/want	25

Medical information was the most popular theme overall (126 mentions). Other medical information including medications, allergies, pregnancy and medical wishes regarding treatment and donation were identified. Lifestyle topics came next (48 mentions), with exercise being the most mentioned single topic. There were 29 mentions about people's support network (available family and friends, carer and proxy duties) and 13 about their



occupation (for example working shifts or just started a new job). Finally, 14 mentions were about interacting with health and care services including dealing with appointments, NHS number, doctor's contact details and insurance.

## What would you use Helm for?

The most common use case was to share information with a relevant healthcare professional, often the GP. People felt they had to keep providing healthcare professionals with the same information and did not always feel taken seriously or capable to do so. Not having to provide the information themselves would reduce the burden on the patient and possibly save time and avoid misinterpretations. However, people were worried that the healthcare professional will not look at the data they have collected, either because they don't have the time (GP appointments are short and should be about 1 complaint only) or because they don't see the value (for example, not seeing the relevance of checking wellbeing parameters or not trusting the patient to record blood pressure accurately).

The second most common use case was to track progress on one or more physical goals in order to improve self-management, with exercise and diet/weight being most popular. Eight people also wanted to track their mood and/or feelings. In the majority of these cases, the goal and tracking was on the user's initiative and was not part of an explicitly prescribed lifestyle change.

Especially those who are interested in tracking their health or wellbeing often had already tried or were currently using apps and devices. In order for these users to consider switching, Helm may have to offer a substantially better user experience and/or automatically pull information from other apps/devices. Several people said they don't want to manually input information already available elsewhere.

Other suggested applications included storing medical information, including details about existing conditions (e.g. high cholesterol) and medication, as well as reminders to renew a prescription, take their medication and attend appointments. People said this would help them self-manage better. This may indicate a need to clearly articulate interfaces with the NHS app. Currently, users of this app may receive duplicate messaging reminders from the app and their GP IT provider. An additional one may not be required.

Having all this up to date information may allow people see trends and patterns (possibly impacting their self-management), and help them feel more informed. People also liked having the ability to be the one who is in control and choose with whom they wish to share specific information.



I want	So that	Number of mentions
To be able to share info with my GP/HCP <i>and know they will look at it</i>	I don't have to keep telling the same story and get treatment when I need it	51
To be able to set goals and track my progress against them	I can monitor and manage myself better	37
- <i>diet</i>		13
- <i>exercise/activity</i>		26
- <i>sleep</i>		9
- <i>weight</i>		9
- <i>pain</i>		4
The app to integrate with any other apps and devices I currently use	I don't have to manually input stuff	35
To be able to store my prescriptions and details about medication	I am better informed and can be reminded	31
Receive reminders about medication/prescriptions/appointments	I don't miss anything	28
To be able to store data related to me existing medical condition BP, cholesterol, allergies etc	I can monitor and better self-manage	22
To be able to see trends in the different data channels I input into	I can see the bigger picture and see what impacts on me	21
To be able to view a live version of my full medical history	I am better informed and can shared it with the relevant people	21
To be able to choose who I share my info with	I have control over who sees it	21
To track how I'm feeling	I can monitor my mood and better self-manage	8



## How would you prefer to enter data?

The majority of people (79 mentions) said they would simply type the information into the app. The next most popular option (48 mentions) was to automatically pull information from devices or apps they already use (31 mentions) or existing NHS services (such as medical record and appointment booking (17 mentions). The third preferred option (38 mentions) was using the device's camera to take a photo, scan a code or make a video.

How would you enter data?	Number or mentions
Type	79
Automatically pull from elsewhere (device, app, medical record)	48
Take photo	27
Selection (drop down list, tick boxes)	15
Voice to text	13
Scan	10
Doctor or nurse enters it for me	5
Scales	4
Video	1

Nine people (13 mentions) said they would use voice to text but most of these (six people) were also happy to type. Eight people (15 mentions) suggested some prepopulated choices, such as drop down lists and tick boxes for quicker recording. Similarly, two people (four mentions) would like to have scales (one mentioned a scale from 1-10, the other a scale of happy to sad faces). Two people (five mentions) said they wanted their healthcare professional to enter data from their current visit.



## When would you use it?

The majority of people said they would use Helm at various times. The next most popular responses were 'all the time', 'morning', 'evening' and 'never'. Only three people indicated a preference for the afternoon. One person added a new category, saying they would only use it monthly.

<b>Various times</b>	39
<b>All the time</b>	18
<b>Morning</b>	14
<b>Evening</b>	14
<b>Never</b>	14
<b>Afternoon</b>	3
<b>Monthly</b>	1

## User stories

The majority of people found it quite hard to suggest information they would store and why. Most were able to think of some information after being given some examples and thought they would probably use the app. Quite often, these people did not have any serious medical conditions or were not actively tracking any aspects of their lifestyle (although some were using steppers built into their smartphones).

Other people were very interested and came up with lots of information they would like to store. These people are often already quite 'activated' and tracking or wanting to record health and/or wellbeing about themselves and possibly careers, where they were an informal carer.

Those who identified themselves as healthy people mainly wanted one place to track their goals, get reminders and the option to share with others. People accessing services also wanted all their information in one place in order to use it for self-management (such as monitoring, prescriptions) and to share with healthcare professionals. Several people assumed their medical information was already automatically shared between various healthcare professionals, such as their GP, hospital and community nurse. Another common topic was that people had to keep repeating themselves every time they see



(new) healthcare professionals and that they are not always confident they are providing the correct information. This prompted some people to suggest they might request the professional to enter data in Helm for them.

Carers spoke about needing more support (for example respite care), and making sure their own health and wellbeing remains a priority as well. They also wanted more recognition; for example, being disregarded and not listened to by the doctor. Many carers voiced a lot of frustrations about the current health and care system and this may have contributed to their overall scepticism about Helm. On the other hand, some carers said they could see a use for Helm if it would be about tracking and sharing information about the person they care for instead of, or in addition to, themselves and in particular while on the move (many were working).

A group of around 15 people were clear that they could or would not use Helm. Most of these either felt no need to track anything (for example, 'I can remember' or 'I'm healthy') or were already using an app they were used to and happy with. Some people did not have a smart device or internet access at home or did not feel confident using them or about how much data it would use if they had a basic smartphone. This they seemed to assume was linked to age; as suggested by one person: 'only the younger generation can use apps/internet - older people prefer keeping a paper diary/record'. This is not backed up by data but is an important perception to address.

A few people commented that they had privacy concerns about using Helm (for example 'who will be able to see it' or 'what is the possible impact on my insurance'). Two people wondered if something like Helm could be dangerous for someone with health anxiety, as they might get more worried as it becomes easier to track and share (perceived) health issues. This would need to be considered in future clinical safety assessments.

Equality and diversity issues:

Some people were quite negative about the idea of an app and/or it being NHS/LCC branded. For example, one person said they wouldn't want to give any non-medical information to the NHS due to how a given NHS service had singled out their child with special needs compared to their other children (positive discrimination). Another person said they had felt seriously discriminated against, based on their ethnicity, while they were a patient in a given NHS hospital and now find it hard to trust anything to do with the NHS.



# Helm Use Case for cancer and diabetes

## Cancer

One use case was a man over 50 years of age who did not engage much with digital tools but would like to share his bowel cancer check-ups (after having had surgery) with his daughter. This man also mentioned his bowel cancer as one of the '3 things about me'. Four other people mentioned having (had) cancer as part of the '3 things about me'. One user story was about a person who has been treated for cancer and lives 40 miles from their oncologist. They would like to receive updates on their cancer/remission state remotely rather than face to face to avoid having to travel so far.

## Diabetes

One use case was given by a man aged between 25-35 who wanted to track his blood sugar in order to maintain a healthy level, which they would share with their GP and hospital. One user story involved a person who keeps fit and wants to share their exercise with the practise nurse to show they are managing their type 2 diabetes risk. In the '3 things about me', five people mentioned they have diabetes, one person said they are pre-diabetic and another one mentioned a family history of diabetes.

# Helm New Use Case for public engagement:

## Carers

Collated feedback from the public involvement activities seemed to indicate a user generated use-case which centres around carers.

Key elements:

- Carer access via a companion app or linked accounts to support those unable to manage the app alone
- Log related function that would enable a carer/the user to keep their own record of all contact with services - not just statutory but also related to wider care and wellbeing such as 3rd sector support or access to private physio using a health scheme such as Vitality. This would generate a more holistic log of activity which was impacting their lives and financial situation - for example carer unable to work due to the scale of time dedicated to caring activities (those over 50 hours for example)
- Function of linked parking was suggested where appointments were pinged through the app with a link to pre bookable, paid parking which might for example give a discount for online payments



- A wish for appointments made via the app/NHS app or GP systems to be kept digital and not result in paper (currently this is the case even for online bookings) enabling a complete log - one place for everything
- Access offline (no need for data/wifi) to carer related health history and meds for when people are on the road, abroad etc so that it is quickly available in an urgent care situation. Another example is having access to prescription details for glasses and contact lenses to be taken on holiday in case people broke their glasses or ran out of contact lenses.
- Companion app for carers which has an emergency button if the person is unable to give access in a critical situation - this could also be a named travel companion and use a system similar to the DVLA hire car code system where it is only valid between certain times while away and has extra security such as a thumbprint access (already in use via NHS app).
- Reminders coming to carers as well as the person where this is needed - set up in the person's account so they can disable at any time. They also requested a permanent link for couples with fluctuating needs so they can manage as a team/partnership. Example - one partner is physically disabled but digitally enabled while their partner has a degree of cognitive impairment and is prone to UTIs which can further impede their cognition, especially in unfamiliar environments such as on holiday

## Summary and recommendations

Most entries in the time-limited *3 things about me were medical or health service related*; despite clear instructions to the participants this did not have to be related to their health. Many people either used this to communicate current symptoms/conditions or duplicated (part of) the same or similar information they would add to the permanent record, for example a past illness or how much they exercise. More research is needed to see if this feature can add value and the question may need re-wording to reduce confusion.

A large cohort said they would use Helm to share information with their healthcare professional and avoid having to 'repeat themselves'. Some people were worried that, for example, their GP wouldn't have time or be interested in data they had collected themselves. Several people said that they would be more likely to use Helm if it was recommended by a trusted healthcare professional. This highlights the importance of seeking *buy in from healthcare professionals*.

The majority of people seem happy to simply *type* in their data, without the need for more complicated methods of data entry at this point in time. The main exception is people who are already recording data via devices or apps. In order to convince this cohort to switch, Helm may need to pull information from their other apps/devices automatically and provide an equally good or better user experience.

A focus on *specific groups/use cases* may be helpful for the next stage. People who are already tracking their health or wellbeing, or are interested in doing so, already possess the



intrinsic motivation and interest to use Helm. Carers and people who travel may be convinced by the large potential benefits Helm could offer them. Having a group of early adopters who can champion and participate in evaluation, such as case studies, can improve wider adoption.

These insights, and the themed raw data accompanying this report, can be used to guide technical development priorities for Helm, such as a simple interface, automatic extraction of information from an app, device or medical record, and the ability to share access with a carer or travel companion.



# Appendix - HELM activity sheet

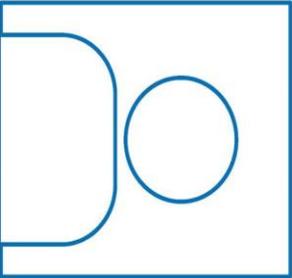
Information I would store:

I would use it to:

I would enter this by:

I would share it with:

The impact on me is:



My age:

- 16-24

- 25-35

- 35-50

- 50+

My gender: \_\_\_\_\_

**Top 3 things I want health professionals to know about me:**  
(e.g. I work shifts)

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_




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