

Cheshire & Merseyside DISCOVERY REPORT

Developing a regional,
citizen-focused health portal



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Executive summary

Mindwave has started conducting desktop and user research to fully assess the current experience of patients, service users and clinicians of the NHS Trusts in Cheshire & Merseyside, and how they would benefit from a digital platform, or PHR (Personal Health Record).

After careful analysis of data from research conducted, we identified significant factors that contribute to the current challenges the NHS Trusts are facing. Some of these factors were inherited from the system; eg lack of access to communication channels and data sharing between departments, lack of insight of patients' medical background, and an antiquated record-keeping system. Others were of a geographical/cultural nature: Cheshire & Merseyside has a disproportionately high number of high-risk groups in the region, plus poverty and social deprivation has an impact.

With a citizen-focused approach, we gained a good understanding of key audiences in the area by identifying 6 personas. To ensure that our solutions address all members of the public and that individual needs are met, we constantly examine and validate our approach with these personas in mind.

Based on our findings, we recommend that an ecosystem be developed based on a Personal Health Record platform (with versions currently in use at Mersey Care, South London & Maudsley and Oxleas) to provide seamless support across acute, physical, mental, community and social care, within robust interoperability standards. All citizens' health data is located in one place, and will allow the citizen and their entire care team to access it. Its transparency would empower citizens to have more control over their health and care. The data should be shareable between all applications within the ecosystem and outside through the use of FHIR (Fast Health Interoperability Resources) and open data structures - eg open EHR. It would also reduce the strain placed on the NHS Trusts, reduce administrative costs, and allow for better informed decision-making around physical and mental health, both by citizens and by clinicians.

Introduction

AND PROJECT GOALS

■ Background

The Citizen Portal project is central to the Cheshire and Merseyside region, achieving both their transformation objectives, their digital strategy and roadmap 'Digit@ll'. Cheshire and Merseyside STP have identified three strategic transformation objectives:

1. Improve the health of the C&M population
2. Improve the quality of care in hospital settings
3. Reduce the cost of administration

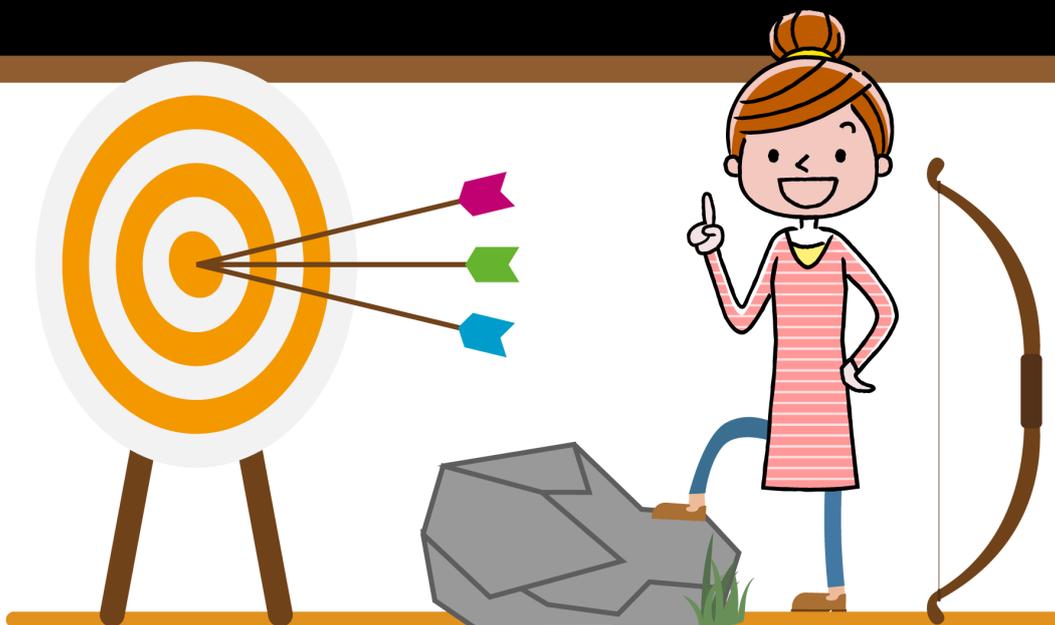
'DIGIT@LL' VISION: ¹

- *Empower individuals to care for themselves and take control of their own health and wellbeing*
- *Empower staff to have access to high quality information, equipped with the digital resources they need to deliver safe, high quality and efficient care*
- *Achieve a joined-up, efficient and informed patient journey, based on secure, real-time patient data*
- *Make Cheshire and Merseyside the area innovators want to come to learn about digital excellence.*

1 <https://www.cheshireandmerseysidepartnership.co.uk/news-and-publications/publications/24-digit-ll-strategy-compressed/file>

Objectives

- ✓ **Patients/Citizens:** Actively engage and co-produce with those we are here to serve.
- ✓ **Empower:** Deliver a set of digital health tools for citizens and staff.
- ✓ **Enhance:** Support all Places to have integrated digital systems meeting a minimum agreed level of digital maturity with brilliant basics everywhere.
- ✓ **Connect:** Deliver a connected information exchange with a single Information Governance framework.
- ✓ **Innovate:** Maximise the digital assets available across C&M, fully exploit the data and intelligence available to maximise the effectiveness of our services.
- ✓ **Secure:** Support all organisations to deliver robustly managed Cyber Security services.



■ Project brief

The Citizen Portal project will address aims across these areas including:

- Promoting physical, mental health and wellbeing by empowering patients to develop their own health and wellbeing record, and supporting self-care and self-management.
- Reducing the administrative cost of letters and appointments by giving citizens access to information digitally via a portal.
- Developing and using open standards.
- Running alongside the e-xchange interoperability work.
- Reflecting the user-led approach taken by Mersey Care in developing “MyPHR”.
- Learning from programmes including e-xchange, MyPHR and citizen portals in other regions and benefit from lessons learnt.

Specific aims for the project include:

- Citizens should have access to appropriate parts of their NHS records.
- Citizens should be able to contribute to their own health and wellbeing by tracking and monitoring their health.
- Citizens should be able to share their health and wellbeing information with others involved in their care journey, for example a carer, family, friends or clinical staff.

■ Personal Health Records

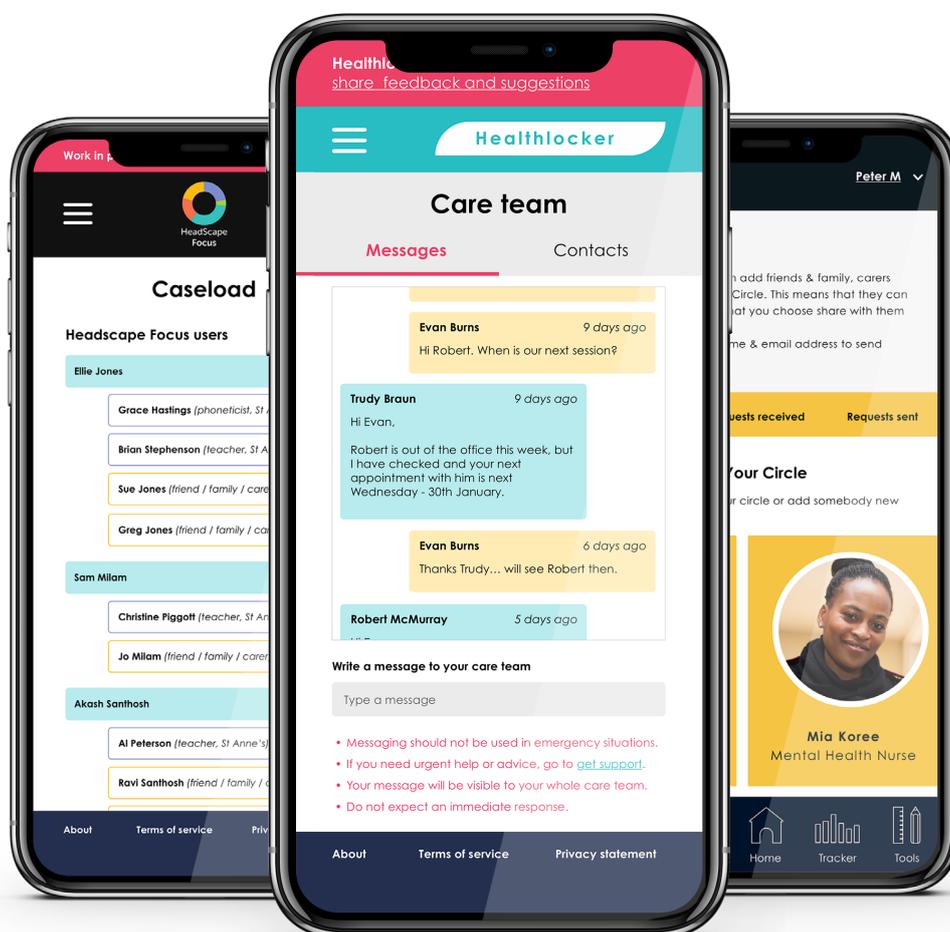
Mindwave has been working with a number of NHS Trusts for the last four years, (namely South London and Maudsley NHS Foundation Trust, Oxleas NHS Foundation Trust, Mersey Care NHS Foundation Trust, Birmingham and Solihull Mental Health NHS Foundation Trust, Worcestershire Acute Hospitals NHS Trust and Worcestershire Health and Care NHS Trust) to find out what their patients, service users and clinicians might want from a digital platform. The platforms are widely referred to as Personal Health Records (PHR), although the individual platform name differs for each Trust.

Our research continues to teach us new things with each trust that we work with, however there are some fundamental findings that are continuously validated as we progress our work:

- Patients, service users, carers and clinicians want to be able to see all of a person's health data, be it from health systems or user generated, in one place so that a more informed and more holistic approach can be taken with their health and care.
- All users would find it useful if a patient/service user is able to consent to share this data with their care team.
- DNA rates will reduce if patients and services users are able to access all of their appointments in one place, manage those appointments, and share them with their carers. Providing information on where the appointments are will also address this issue.
- Currently care plans, goals, crisis plans, treatment plans etc, are shared with patients or service users on paper. This leads to documents being lost and/or damaged - or put away and never looked at again. Providing digital access to these documents allows instant updates and will encourage engagement.
- All users would like tracking information to be stored and visible to the care team, so that more informed decision

making can be made - particularly around sleep, medication side effects, mood swings and individual problems that a person is experiencing. Accessible diaries that can be revisited to remind a user of what has happened between appointments, are also deemed useful.

- Being able to provide clinic letters and other documentation digitally, will reduce frustrations with receiving post late and/or post being lost. If provided digitally, these documents will then always be available and accessible.
- Better access to communication with a care team would reduce frustrations, particularly for carers when they can see that the person they care for is moving towards a crisis.
- **Connecting into clinical systems is the biggest blocker with regard to Personal Health Record platform development.**





THE CHESTER GROSVENOR
ESTABLISHED 1865

ROLEX

PEDESTRIAN ZONE
Mon - Sat
8 am - 6 pm
Except for loading
8:10 - 9:30 am
4:30 - 6 pm
At any time

Cathedral
Town Hall
Tourist Information
Starhouse

RETAIL SPACE
TO LET
CONTACT BY

CRIPPS
ROUSE
OLEF
PICKLES
1-800-947-7979

The Rows
Chester

NEW

■ Developments for Cheshire and Merseyside

Moving beyond trust-centred platforms, the Cheshire & Merseyside project aims to scale the PHR movement to a regional level:

The initial project will run for 18 months and will include pilot studies at three hospitals: St Helens & Knowsley, Warrington, and The Clatterbridge Cancer Centre NHS Foundation Trust.

OUTCOMES:

- Put citizens at the heart of their own health and care.
- Empower citizens to self-manage and lead their health and care journey.
- Create an “ecosystem” of trusted, interoperable apps and resources, and not be product or vendor dependent.
- Define the standards to which health and care data should adhere:
 - Safe and secure
 - Accessible by those who need it
 - Shareable by those who own it

“Empower citizens to self-manage...”

"The aim for Cheshire
& Merseyside and the
NHS overall is to reduce
unnecessary hospital
care and shift the balance
towards a pro-active
wellness system..."

Research

AND METHODOLOGIES

■ Desktop research:

We have drawn upon a wide range of comprehensive reports, including The NHS Five Year Forward View (5YFV), The Cheshire & Merseyside Sustainability and Transformation Plan (STP), 'Digit@LL' Cheshire and Merseyside Digital Strategy and The NHS Long Term Plan. In doing so, we have created a strong foundation on which to start building insight, and a basis on which to frame conversations with users.

PHE established high risk groups in the region; over 65s, regular drinkers and those with lower incomes. Cheshire and Merseyside has a high number of over 65s residents compared to the national average. It also has some of the poorest regions in the UK such as Liverpool, which has a 6% unemployment rate; 2% above the national average. In addition, the area has some of the highest rates of both liver disease and alcohol-related liver disease in England and is only second to the North East in having the highest rates of hospital admissions for alcohol related harm. ²

“The North West has some of the highest directly standardised hospital admissions rates that are attributable to alcohol in England. Liverpool has the highest rate in England and Halton and Knowsley are in the top ten (LAPE profiles, Data 2009/10)”

“In Cheshire and Merseyside all the local authority areas have significantly higher rates of hospital admissions that are attributable to alcohol than the England average, other than Cheshire East. Cheshire East has significantly higher rates of hospital admissions for women.”

Additionally, Cheshire and Merseyside has one of the highest rates of MRSA bacteraemia in England (1.8 per 100,000 population).

Consequently the top three population based prevention priorities for the area are: high blood pressure, alcohol harm and antimicrobial resistance (AMR). A reduction in the first two have identified benefits including reduced hospital admissions & “whole system impact” where appropriate (eg prevention of alcohol related violence). AMR prevention will have a longer-term impact.

The aim for Cheshire & Merseyside and the NHS overall is to reduce unnecessary hospital care and shift the balance towards a pro-active wellness system rather than a system that treats illness reactively. This will encourage better care outside of the hospital and enable individuals to feel empowered and hospital services to be improved.

We also looked at GP practice and A&E visits, admissions to hospital, NHS 111 and 999 calls, to try and give us a better understanding of the available health and care provision. Some of the information we found is regional and some is national.

GP VISITS:

Cheshire and Merseyside as sub-region or STP had 1,253,348 GP visits in 2018, with 2,546,060 patients registered with a GP, and only 49% of patients visiting a GP, it is in the bottom 4 sub-regions of that year. ³

	No. of appointments	No of registered patients	% of pop. that had appt.
NHS England South West (South West South)	1,565,761	2,632,430	59.47968227
NHS England South West (South West North)	1,367,578	2,461,889	55.54994559
NHS England North (Cumbria and North East)	1,674,890	3,034,384	55.19703505
NHS England North (Yorkshire and Humber)	3,139,509	5,843,817	53.72360223
NHS England Midlands and East (North Midlands)	1,908,443	3,696,356	51.6303895
NHS England Midlands and East (East)	2,320,496	4,512,539	51.42328964
NHS England Midlands and East (West Midlands)	2,172,789	4,236,918	51.28230001
NHS England South East (Kent, Surrey and Sussex)	1,982,483	3,958,570	50.08078675
NHS England North (Lancashire and South Cumbria)	789,389	1,591,178	49.61035158
NHS England Midlands and East (Central Midlands)	2,354,207	4,748,507	49.57783573
NHS England North (Cheshire and Merseyside)	1,253,348	2,546,060	49.22696244
NHS England South East (Hampshire, Isle of Wight and	1,952,696	4,026,315	48.49834154
NHS England North (Greater Manchester)	1,127,290	2,349,971	47.97037921
NHS England London	3,475,148	8,585,110	40.47878245

A&E:

“The number of people going to A&E has risen substantially over time. In 2016/17 there were 23.4 million attendances at A&E departments – the equivalent of 63,000 attendances on average each day. Between 2011/12 and 2016/17, A&E attendances grew on average by 1.7 per cent each year, and increased by 1.9 million in total (or 8.8 per cent). This is the equivalent of an extra 5,100 more A&E attendances each day. The growth in attendances has been higher in type 3 A&Es (such as walk-in centres and minor-injury units), compared to type 1 (major) or type 2 (specialist) A&Es.”⁴

ADMISSIONS TO HOSPITAL - NATIONALLY:

“9 November 2016: Hospital admissions in England rose to record levels last year, with 16.2 million admissions during 2015-16 - up from 12.7 million ten years ago. Over the same time period, the population has also

grown, although at a much lower rate than hospital admissions - around 8 per cent (50.6 million to 54.8 million) - compared with an overall growth of nearly 30 per cent for hospital admissions.”³



⁴ <https://www.kingsfund.org.uk/projects/urgent-emergency-care/urgent-and-emergency-care-mythbusters>

⁵ <https://digital.nhs.uk/news-and-events/news-archive/2016-news-archive/hospital-admissions-hit-record-high-as-population-ages>

NHS 111:

“Members of the public called the NHS 111 service 1.4 million times last month, an increase of 8% compared with the same time last year (Aug 2018).”⁶

“The data shows the service continues to grow as 73.8% of visitors ‘in hours’ (weekdays 8am to 6pm) and 70.4% of visitors ‘out of hours’ (evenings, weekends, bank holidays) are using NHS 111 online for the first time.”⁷

“Around 13% of all NHS 111 online journeys end with self-care advice, almost half (48%) of all triages direct users to contact primary care and about a quarter (24.7%) of journeys end with instructions to ring 999 or attend A&E. In total 6.8% are advised to seek dental treatment and 7.4% are given other treatment dispositions, including speaking to a pharmacist.”⁷

The BMJ says that,

“There was no evidence that NHS 111 changed use of most of the emergency and urgent care services it was possible to measure. There was a large reduction in use of NHS Direct as calls transferred to NHS 111 but an increase in numbers of emergency ambulances sent to patients and there is potential that overall demand for services across the emergency and urgent care system could increase.”

“...approximately 50% of the current callers to NHS 111 are directed to primary care where they consult a doctor or nurse.”

“A mid-point analysis showed that, in all, an average of 73% of referrals were deemed as clinically appropriate by GP respondents”⁸

⁶ <https://www.england.nhs.uk/2018/08/record-numbers-of-people-getting-urgent-nhs-help-over-the-phone/>

⁷ <https://digital.nhs.uk/news-and-events/latest-news/nhs-111-online-hits-one-million-triages-mark>

⁸ <https://bmjopen.bmj.com/content/3/11/e003451>

On the other hand, NHS England tells us that,

“More than one in four people said they would have gone to A&E and 16% said they would have called an ambulance had 111 not been available.”⁹

999 CALLS:

“Evidence shows that less than 10 per cent of 999 calls are for genuinely life threatening conditions, yet ambulance services currently categorise around 40 per cent of calls as such, partly because call handlers have only 60 seconds to gather the information they need before an ambulance vehicle must be sent.”⁹



⁹ <https://www.england.nhs.uk/2019/05/nhs-111-prevents-unnecessary-ae-visits/>

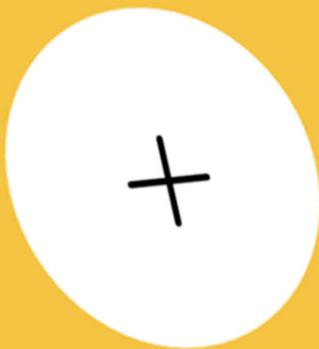
Your circle

Requests sent

Requests received

Your circle

View who is in your circle
and choose what you'd like
to share with them



Add somebody
new to your circle

Dr M



Care



Circle



Home



Tracker



Tools

■ User research

Government user research guidelines advise that “you’ll usually need between 4 and 8 participants for each round using methods like experience mapping, contextual research, in-depth interviews or usability testing”.¹⁰

For this initial discovery work, we sourced a group of thirteen Cheshire & Merseyside residents who had accessed acute hospital services in recent years, as both service users and/or carers for family members.

This research revealed individual stories and people’s frustrations about current experiences of acute healthcare in the region. These stories were analysed, validated and filtered to enable the most relevant insights to be uncovered, from which a first stage digital solution for the Cheshire & Merseyside region can be developed.

METHOD:

The primary methods of research consisted of a brief survey collecting demographic data, followed by in-depth qualitative 1:1 interviews & focus groups, each lasting between 60-120 minutes. These were audio recorded and transcribed by an independent collaborator for later analysis.

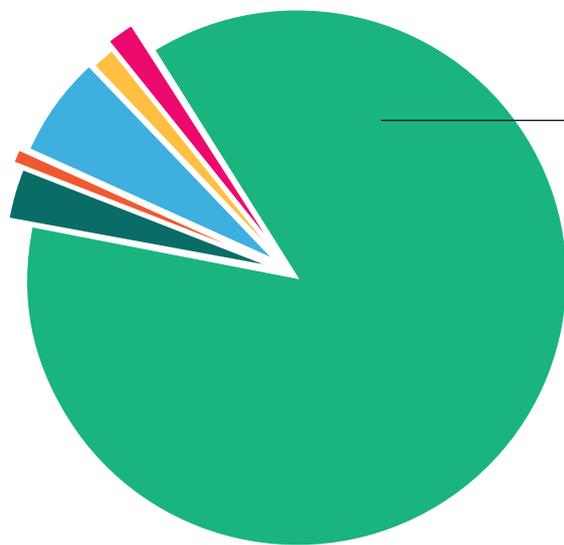
Questions were posed around prior experience of access to health services and data, followed by a discussion related to visions for what an ideal solution could consist of. This was clarified through a drawing exercise, which teased out the primary needs and helped users to think about what a personal, digital roadmap might look like.

Existing prototypes were then offered to participants for A/B testing and for comparison to their roadmap. This drew out further detail and subsequent evaluation of the appropriateness of the prototypes with regards to the participants’ desired experiences. The specific outcomes of this user testing will be discussed later in the report.

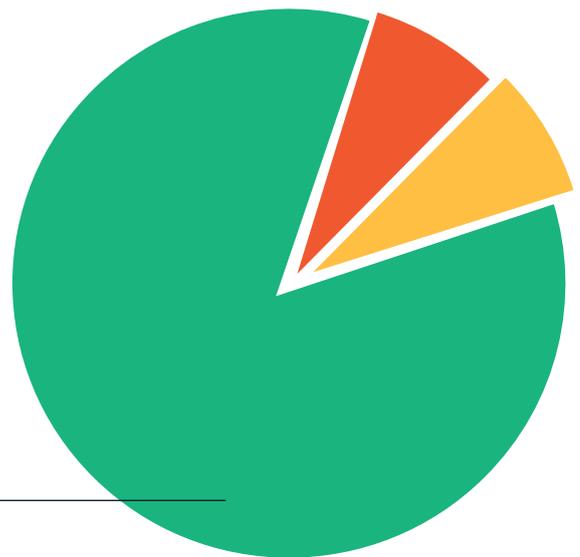
¹⁰ <https://www.england.nhs.uk/2019/05/nhs-111-prevents-unnecessary-ae-visits/>

■ Participants

The participants interviewed were patients, service users and carers aged between 34 and 63, from across the Cheshire & Merseyside region, as typical representatives of the regional demographic. These were predominantly white, British, cisgender individuals with a moderate income, in full-time work. These individuals were mostly confident with technology and used health apps to some extent already, primarily on smart phones and laptops, to access NHS services and track their well-being.



ETHNICITY BREAKDOWN OF UK



ETHNICITY OF RESEARCH PARTICIPANTS

- Asian
- Black
- Mixed
- White British
- Other
- White other

GENDER OF PARTICIPANTS

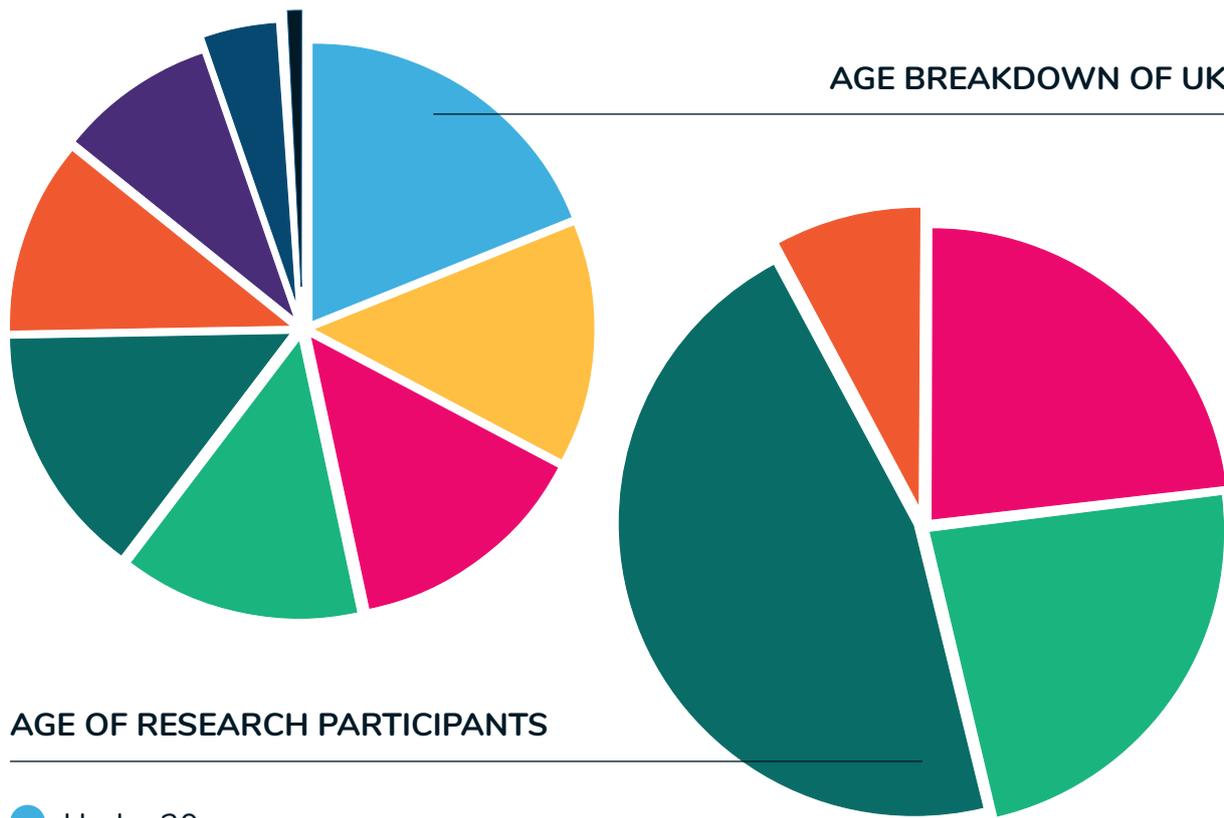


Male



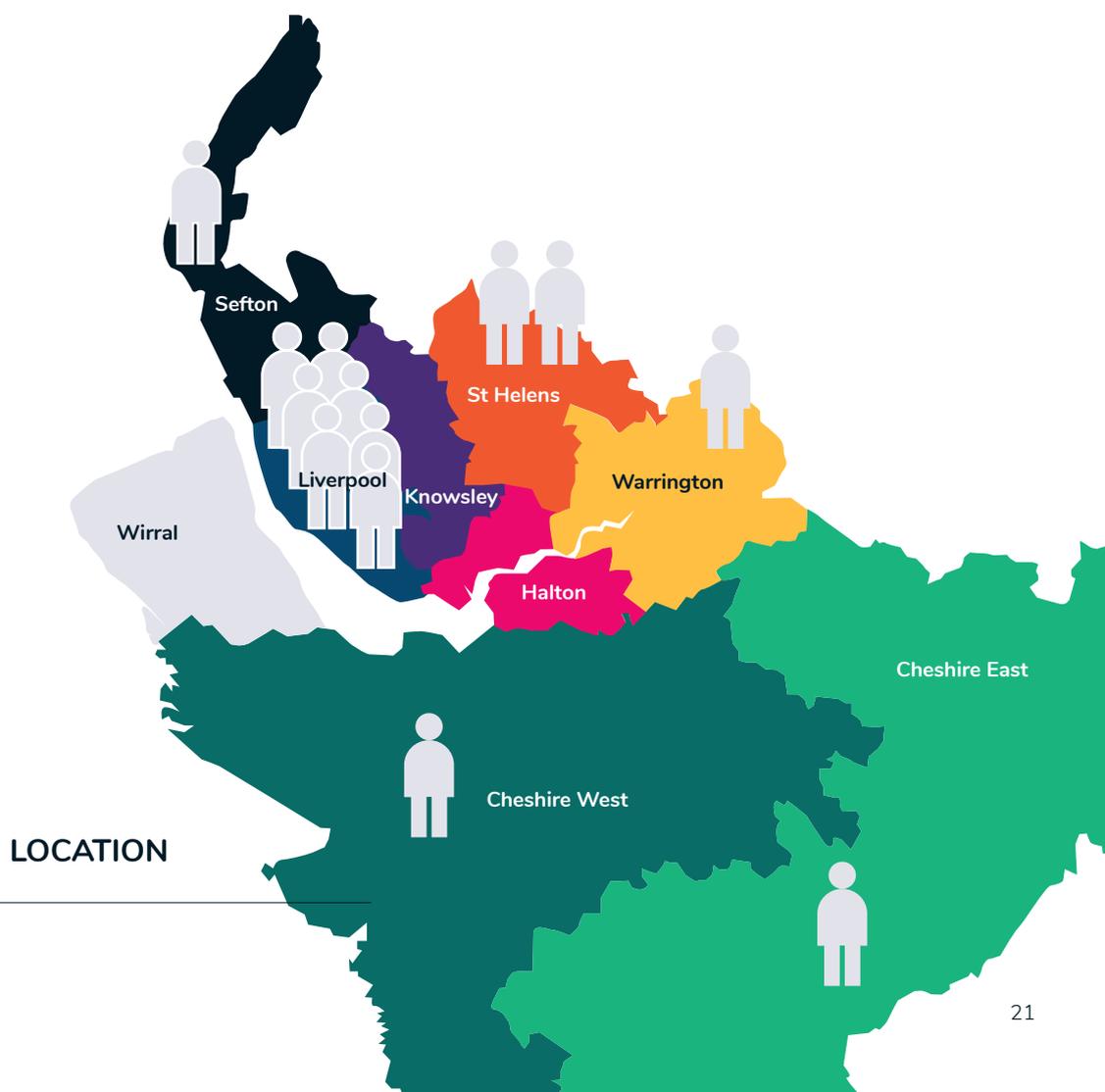
Female

AGE BREAKDOWN OF UK



AGE OF RESEARCH PARTICIPANTS

- Under 20
- 20 - 29
- 30 - 39
- 40 - 49
- 50 - 59
- 60 - 69
- 70 - 79
- 80 - 89
- 90+

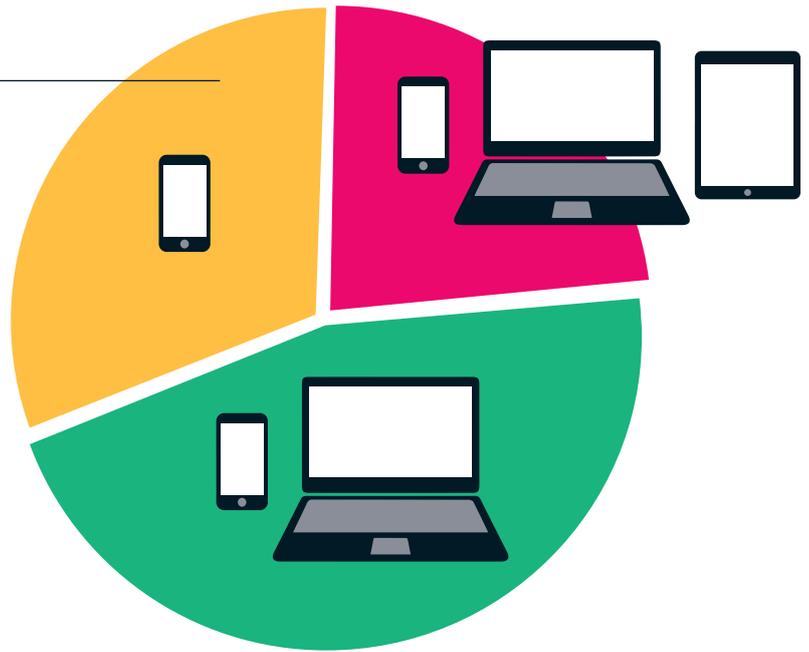


LOCATION

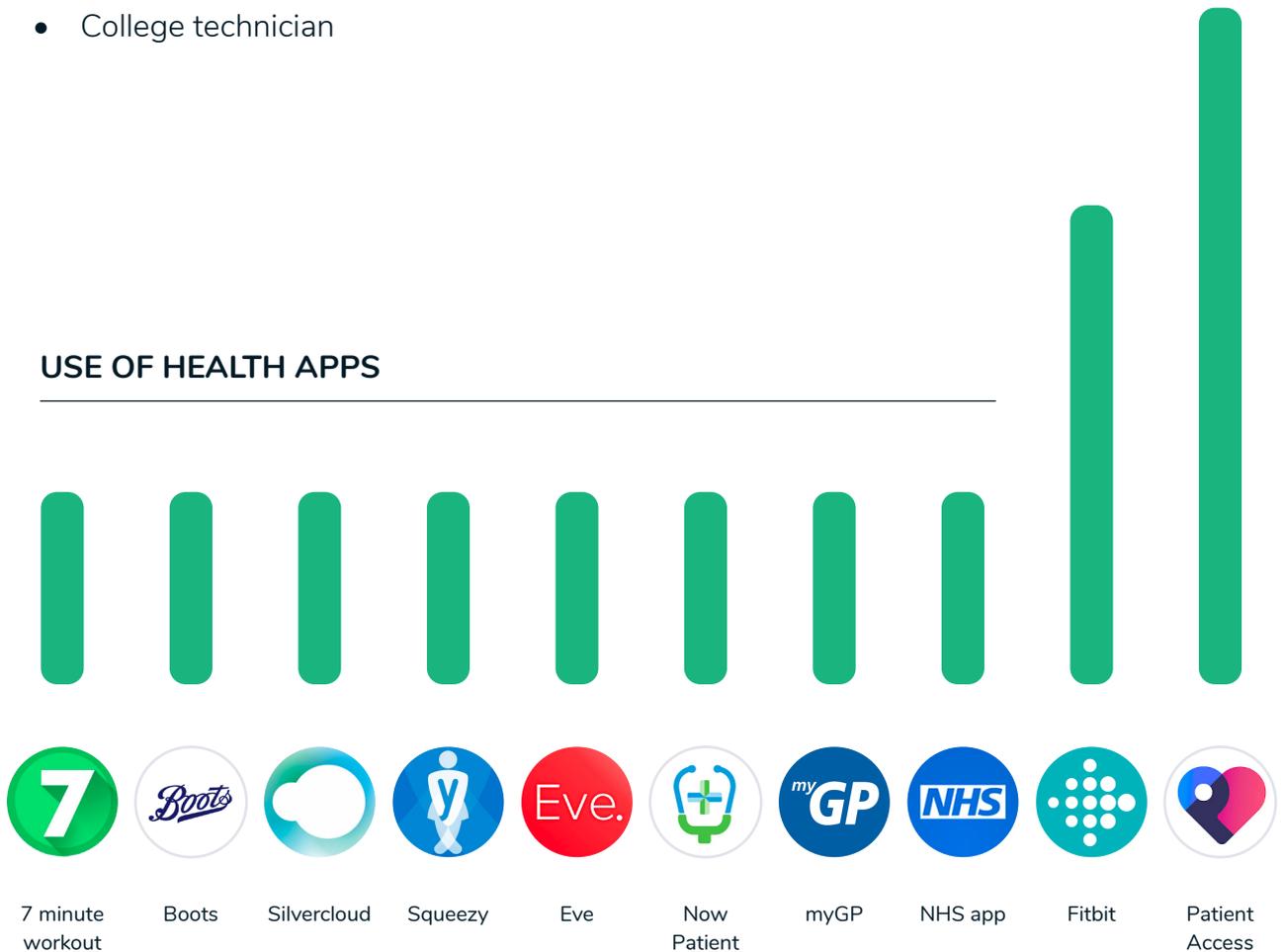
DEVICES

JOB TYPES

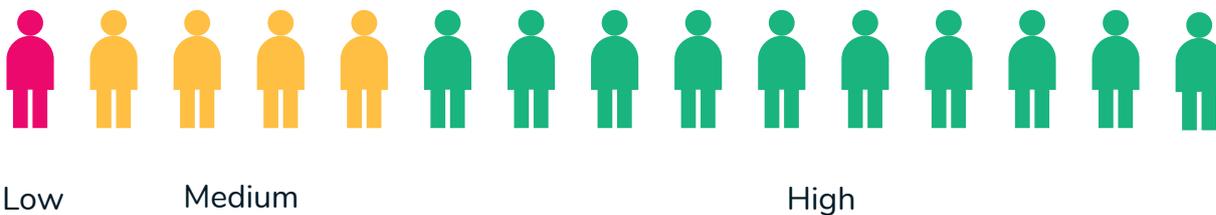
- Charity CEO
- Social worker
- University administrator
- Retired youth educator
- Examinations officer
- Full time carer
- Personal assistant
- Costume designer
- Primary school teacher
- University lecturer
- Policy and governance manager
- Software manager
- College technician



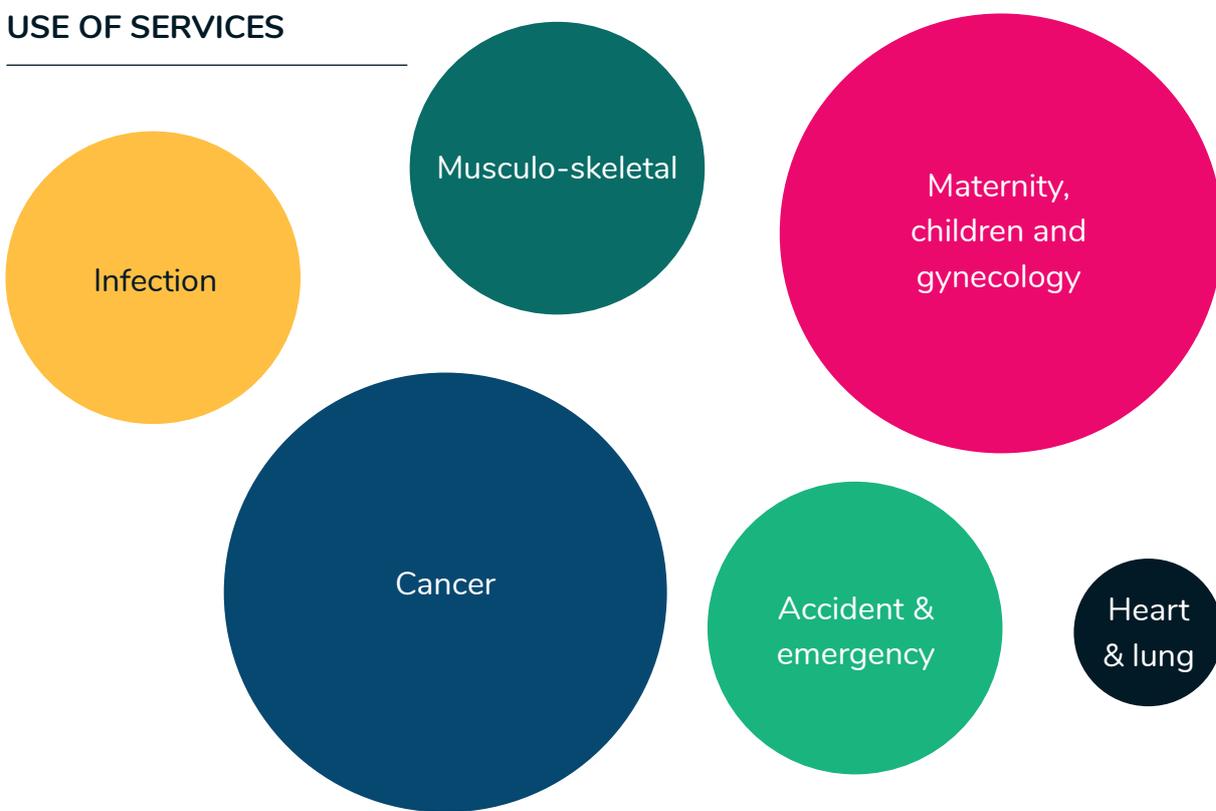
USE OF HEALTH APPS



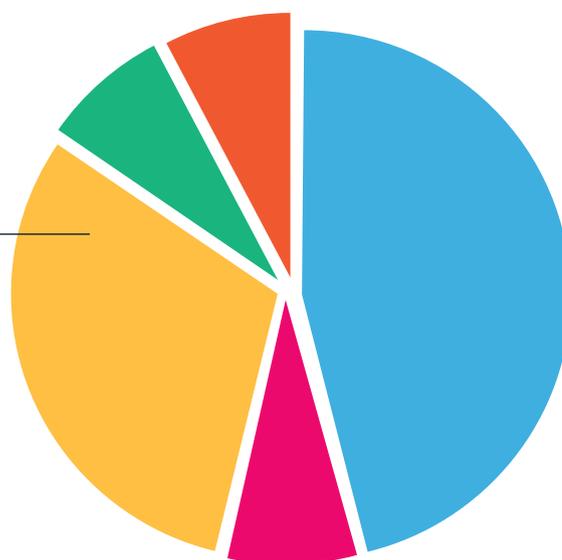
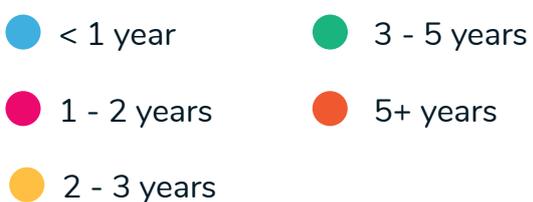
CONFIDENCE WITH TECHNOLOGY



USE OF SERVICES



TIME SPENT IN SERVICE





■ Personas

From our research, we have developed a set of personas to guide us as we progress with this project.

Personas are used to illustrate realistic, evidence based representations of our key audiences. Continuously referring back to personas and their needs, allows users to remain at the forefront of the project. This allows us to sense check that we are always working to meet the user's needs.

We want to participate in our care

TYPICAL PROFILE

This group comprises of light-hearted, caring individuals who often work in public sector roles and are used to being team players, working in the interest of humanity. Humour and personal connection are at the forefront of their interactions. They are understanding and respectful of clinicians and need to be treated as an equal.

VALUES & EXPECTATIONS

They value rapport, reassurance, patience and kindness as they believe in empathy and mutual endeavour towards a shared goal. They are progressive and expect relatability, clear guidance and choice from their engagement with services.

VIEWS & EXPERIENCE

They value the NHS and speak highly of clinicians, referring to them on an interpersonal level. They are proactive and conscientious patients, working hard to help themselves, despite this, they feel like their opinions and personal truths don't matter and they are not always listened to or taken seriously.

THE CLINICAL COLLABORATOR



“We have really amazing staff once you get in to see them and they are very down to earth; very informal in many ways, which is great. I find, once you are in the system they are good in many ways and contact you regularly. You always feel like you are the one that matters not just a number, you are a person.”

“I am quite willing to say, you know, in 95% of cases the clinician knows better than me. I haven't studied for as many years as they have but there are times when I might know, I know what's wrong, I can feel what's wrong. Just listen to *my* voice in this conversation because its a conversation, the whole thing is a conversation isn't it?”

THE POWERLESS PRAGMATIST



We feel like we are being ignored

VALUES & EXPECTATIONS

They value control, common sense, practicality and accountability. They want to be independent and take control of their recovery, but feel that the systems are confused and that their basic emotional and physical needs cannot be met.

VIEWS & EXPERIENCE

They feel distrusted, undermined and poorly equipped by inflexible and unfriendly NHS people and processes. They can clearly articulate the pitfalls and are often left feeling angry that their experiences felt cold and uncivilised.

TYPICAL PROFILE

This group consists of widely educated people of various age and income groups with first hand experience of serious conditions, accidents and illnesses.

Many are systematic observers as carers or family members who take healthcare seriously, recognise clinical expertise and hold the system accountable when things go wrong.

“We were told the medication was available and then we went to get it at the local pharmacy and they said we couldn't have it because we didn't have our children with us. My husband explained that they were sick at home and she said they needed evidence that we had a child.”

“Some questions were left unanswered and I got no responses from nurses. The junior doctors were like scared rabbits, all behind computer screens or looking at the patient via a computer screen and not going and looking at them in the bed.”

A&E is not for me!

THE VULNERABLE VICTIM

TYPICAL PROFILE

This group is made up of younger adults, connected to caring roles and professions who feel empathy for NHS employees. As irregular users of services, they are unfamiliar with what is available, what to expect and what is most appropriate for their needs. They generally do not want to access services unless absolutely necessary.



VALUES & EXPECTATIONS

They value safety, fairness and comfort, they recognise the challenges to the system, but feel that abused services place them at risk without a mechanism for protection. As such they demand only the basics and would rather recover independently where possible.

VIEWS & EXPERIENCE

They often feel guilty for accessing services. Because of this, they resent misuse and mismanagement. They feel hostile towards hospital environments and can place themselves at risk in attempting to avoid treatment.

“But I felt awful going to A&E. I’ve never been to A&E before. It was my own internal guilt for like, too many people are taking up places in A&E.”

“That waiting room is not appropriate for the elderly. I was there with my mum and dad and you could 100% see that if they’d have been on their own they would’ve felt so vulnerable. It was, as there would be, drug addicts, drunks, people lying on the floor, shouting.”

THE BATTLING BRAVE



TYPICAL PROFILE

This group typically represents cancer patients or carers of people at the end of life pathways. They have very hard times ahead of them and are grateful for the support that they receive from staff and services. They are intrepid, yet quietly overwhelmed; this makes them appear generally trusting and compliant, believing all decisions made on their behalf to be in their best interests.

We need to know our options

VALUES & EXPECTATIONS

They value dignity, sensitivity, calm and control. They want their care to be well explained, customisable, easy to understand and a stress-free process.

VIEWS & EXPERIENCE

They view the NHS as a higher power that should not be questioned, they are also often unable to come to terms with the decisions they face. As such, they accept what they are told or rely on others to help them navigate things. This means that they are often unaware of the pathways and options available to them.

“When you first hear the scary word and you are told you’ve got cancer then there’s that visible reaction. But from that generation they were fairly stoic as well so he really put a brave face on. The thing we need most would actually be a one-point contact. One person that understands the whole journey. Someone who keeps it simple with access to all the data and knowledge of where she is on the journey.”

“They are very good at just giving you the information that you need, at the time, feeding you the bits that you need to know. But there is a huge amount of information and I have had to draw a sort of flow diagram for my husband so he has a simplified version.”

Getting an appointment is impossible

TYPICAL PROFILE

This group usually comprises of older, busy, independent, hard-working individuals. They have a decent income, are used to having information at hand, being in control and like getting what they need on demand.

VALUES & EXPECTATIONS

This group values formalities and systemisation (when it works in their favour) as it is predictable and assists with planning. They expect clarity, organisation, speed and support from their engagement with services.

VIEWS & EXPERIENCE

This group trusts the NHS and view it as a public service that they have some ownership of. They consider that it should be at their disposal, working in their favour at all times.

Despite reports of fast effective treatment in specialist areas, much of their recent, acute care experience reflects confusion, frustration, anger and disappointment, with particular reference to accessibility and communication.

THE IMPATIENT PATIENT



“Just trying to get an appointment was absolute hell. I couldn’t get one by phoning, you couldn’t get through, and you can only book for that day. Couldn’t get through via their website, so twice I actually went and queued up at quarter to eight for when the doors opened at 8 o’clock. The first time I was tenth in the queue and all the appointments had gone by the time I got in.”

“You get different letters and doctors and they refer you on... then you get a letter which you think is going to be your appointment; it’s not. You then have to phone and book it... and they’ve said, oh well there’s a waiting list, so contact if you haven’t heard from us in four weeks. I did contact them after four weeks and they said, there’s still a waiting list. So it’s like barriers along the way.”

“Just trying to get an appointment was absolute hell. I couldn't get one by phoning, you couldn't get through, and you can only book for that day.”



The Rows Cafe

Mr. Old Boot
Dinn
Est 1842

THE LEATHER SHOP

Carphone Warehouse

kenneymoore
TO LET
01244 345600

Bella Italia

CAFE

MOSS BROS.

ST. WERBURGH STREET

SOLE TRADER

next

Outcomes insights, AND USER STORIES

This section of the report combines the discovery work conducted with participants and desktop research. Findings have been discussed and analysed, and sorted into six key insights.

These insights are all interlinked, with common themes running through them - particularly around communication and access to information. Proposed solutions often bridge more than one finding.

Providing the right content to the right people at the right time, will be key to addressing most of the insights discussed in this report.

Not all of the requirements and user needs will be within scope for this project, but are listed to keep in mind for future work.

■ User's stories

User stories are structured not necessarily to define specific features or functionality, but to show how the development of a product or service will give value back to the user.

These stories take generalised insights and recommendations and start to make sense of them; developing them into specific requirements, focusing on the outcome that the user wants to achieve.

Some user requirements have already been discussed - and developed - in Mindwave's PHR platform (see page 8 of this report), and some requirements will appear under more than one insight heading.

At this point in the project, the primary focus is on patients and service users, and so all user stories are written from their point of view. Further work will include user stories from carers, clinicians and clinical staff.

1. Entering the system is one of the biggest challenges

Not only is it difficult to know where to go, who to speak to and when, actually getting onto a care pathway - in whichever system may be relevant - is found to be very challenging also. There are a number of reasons for this. You may have:

- Gone to the wrong place.
- Spoken to the wrong person.
- Not had the "right" symptoms.
- Not been believed (or have felt this way at least).
- Managed to get a referral, but it has been lost, postponed or rejected.
- The wrong demographic for the condition.
- Tests or scans that "prove you're fine".

Or, there may simply be a long waiting list for a patients to be seen.

“So you can be talking two, three weeks before you can get an appointment. If you want a phone call, it can be at least a week before you can get a phone call even. And that’s why one of the things I love is now being able to go onto an app and actually say, I will pick that appointment.”

Work has already been done across the NHS to try and help potential patients and service users appropriately triage themselves and find the right place to go to, for example 111 and posters within clinical services:

Stay well : Guide to help you choose the right service for you and your NHS

NHS

Self-care	Pharmacy	GP	Minor Injuries	A&E/999
<p>Hangover. Cough. Colds. Grazes. Small cuts. Sore throat.</p>	<p>Diarrhoea. Earache. Painful cough. Sticky eye. Teething. Rashes.</p>	<p>Arthritis. Asthma. Back pain. Vomiting. Stomach ache.</p>	<p>Cuts. Sprains. Strain. Bruises. Itchy rash. Minor burns.</p>	<p>Severe bleeding. Breathing difficulties. Severe chest pain. Loss of consciousness.</p>
<p>Self-care is the best choice to treat minor illnesses and injuries.</p> <p>A large range of common illnesses and injuries can be treated at home simply with over-the-counter medicines and plenty of rest.</p>	<p>Pharmacists advise and treat a range of symptoms. This can avoid unnecessary trips to your GP or A&E department, and save time.</p> <p>No appointment is needed and most pharmacies have private consulting areas.</p>	<p>GPs and nurses have an excellent understanding of general health issues and can deal with a whole range of health problems.</p>	<p>Minor Injuries Units, Walk-in Centres and Urgent Care Centres provide non-urgent services for a range of conditions.</p> <p>They are usually led by nurses and an appointment is not necessary.</p>	<p>A&E or 999 are best used in an emergency for serious or life-threatening situations.</p>
<p>NHS 111</p>	<p>If you're feeling unwell, unsure or if you want health advice and guidance for non-life threatening emergencies call NHS 111.</p>			<p>24 hours a day 7 days a week</p>
<p>NHS Choices</p>	<p>You can also access health advice and guidance or find your nearest service online through NHS Choices.</p>			<p>Visit www.nhs.uk</p>

Produced by NHS Northern, Eastern and Western Devon Clinical Commissioning Group

However, these methods of communication are only really available to you once you have already reached a clinical service.

Once you are on a care pathway with a diagnosis, the service care is felt to be excellent. (There is still some uncertainty for users what their care pathway looks like. This will be addressed in the final insight.)

RECOMMENDATIONS:

Clinical services making better use of digital booking systems so that patients can manage their appointments online would help reduce a lot of frustration and anxiety - particularly with making an initial GP appointment, and changing appointment dates that are given to them by hospitals.

Make the following really clear to users:

How: should you go about finding help? Can you look online? NHS A-Z? Do you need to speak to someone?

Who: is the initial person you should be speaking to? A GP? 111? A&E? A pharmacist?

What: should you tell them?

Where: should you do this? Over the phone? Out of hours? Walk in centre?

When: should you speak to someone? Is it urgent? Can you wait 2 weeks for an appointment?

The appropriateness of the clinical service for each service user and/or patient is key. Making comms materials that have been produced by the NHS more visible and highlighting to users what each type of clinical service and/or clinician can help with, in an easy-to-access, easy-to-use, engaging, digital format, could help to reduce the problem.

Surfacing information and advice on health conditions, who does what in a clinical system, and providing appropriate and useful contact details would also be helpful.

Some of the following insights will also contribute towards addressing this issue, particularly around A&E, and communicating with clinical staff.

IN SUMMARY:

- Online appointment management will help to reduce frustrations.
- Providing/signposting to accessible information on which clinical service (online or offline) is most appropriate for different circumstances, with appropriate contact information, will help patients and service users get access to the right care faster.

USER'S STORIES:

- Give me health and care information so that I can understand my symptoms better, and be more informed when I make a decision to book an appointment or call a clinical service.
- Provide me with basic triaging tools so that I can self-assess the seriousness of my condition.
- Help me to understand what each clinical service does and who I might see there, so that I can assess which is the most appropriate for me to contact.
- Provide me with appropriate contact information so that I can ask relevant questions before accessing a service.
- Let me book and change my appointments online so that I have instant confirmation of when I can see somebody.

2. Clinical services (particularly A&E) are sometimes misused by patients - and can be perceived to be mismanaged

User research participants stated feeling vulnerable and unsafe in their visits to A&E departments in the region.

The A&E departments were described as “hostels for drunks” with reports of people drinking and smoking outside the doors and then coming in and lying down on rows of chairs.

Waiting times for patients to be seen in A&E were presumed by participants to have been misrepresented over the phone. They felt as though they were being lied to, incentivising them not to come in, when they simply wanted to find out which was the least congested department to visit. How to access emergency services was also found to be challenging; information and advice given felt to be misleading:

“If it’s logged as an ambulance call we should’ve gone to the ambulance section, not in the waiting room. I’ve only brought him here myself because the ambulance said they’d be 20 minutes. When we got there, we had to wait 40 minutes before someone came for triage and then we had to wait over an hour longer. If they’d have told me this, because there’s a difference isn’t there from walk-in to triage to treatment? I would have waited for the ambulance... I mean my Dad couldn’t breathe!”

It was felt that a minority of “drunk people” and “drug users” were negatively impacting the experience and service for those who were in need and potentially vulnerable - particularly by increasing waiting times, and making other patients feel unsafe.

Participants often felt that a majority of people in the waiting room did not need to be there and were potentially wasting the time of the clinicians and increasing the waiting time for other people.

“I went to A&E and there were people in there who didn’t need to be in there, like going in just to charge their phones and stuff and lying on the bed. She plugged her phone in and lay down on one of the beds in there who I assume to be a drug addict, her and her boyfriend, it just wasn’t a nice place to be.”

Patients reported “checking in” to the A&E departments without giving any symptoms or reason to the receptionists which was felt to be a missed opportunity to start the triage process.

As discussed, desktop research showed that the Cheshire & Merseyside region has a disproportionate issue with alcohol, and that the population also has a higher than average rate of MRSA.

Research also told us that in a push to move more care into the community and out of hospitals, a large number of beds had been removed from hospitals. Rather than helping to move care back into the community, patients ended up in emergency beds.

Anecdotal reports of “playing” the system (eg on calls to 111 and 999) to ensure an ambulance or hospital visit have also been heard. Terms such as “frequent flyers” were being used by clinical staff such as paramedics, nurses and doctors.

In summary, the key issues around A&E and hospitals in the region that our research highlighted are as follows:

- Vulnerability
- Inefficiency
- Alcohol use on hospital sites
- MRSA
- Antimicrobial resistance
- Not enough beds

RECOMMENDATIONS:

A large proportion of the issues discussed are out of the remit of this project, however, as discussed in the previous insight, providing education, information and advice around the appropriateness of a clinical service is key, and signposting to alternatives will be useful here.

Some examples of ways in which a digital platform could potentially address some of the issues are as follows:

- Self-reported triage system (in the first instance, we would recommend using existing NHS triage systems and comms to ensure adherence to clinical safety guidelines).
- Although creating a triage system is out of scope for this project, particularly with issues around medical device compliance, we would recommend that a quick and simple online system - at a much higher level than 111 - is developed to encourage the patient to consider the following things:
 - Whether the issue is sudden onset/accident or related to an ongoing condition.
 - The level of pain and discomfort.
 - Fears and concerns that the patient has.

NB: This triage system would not necessarily need to provide medical advice or suggested diagnosis: as discussed in the previous insight, it could simply link to advice around appropriateness of clinical services and practitioners based on the user's answers.

- Education around appropriateness of using A&E and other clinical services.
- Show live waiting times online for all relevant clinical services, eg A&E, walk in centres etc (relies on some interoperability with a hospital system).
- Useful information around accessibility (eg how far it is to walk from the department to the main entrance), parking (eg cost, do machines take card payments?).

Further ideas were discussed around a “scan-in” system using a digital platform such as PHR which already holds patient’s details (out of scope for this project but useful to keep in mind). The system would hold their self-triage information and provide their data to the hospital EHR system. Users could scan into “quiet zones”, and by using their device to open doors to check-in, they could reduce the spread of germs.

IN SUMMARY:

- Surfacing and developing existing content from the NHS on self-triage and what different clinical services provide, could help to reduce inappropriate use.
- Provision of additional content, such as live waiting times and information on parking facilities will help to reduce frustrations that patients/service users have with services.

USER'S STORIES

- Provide me with basic triaging tools so that I can self-assess the seriousness of my condition and whether A&E is the right place for me to go.
- Show me all the relevant information about a clinical service (walk-in centres and A&E) in real-time, so that I can make an informed decision about where and when to go.
- Let me share information about my condition with hospital systems, to help them manage their initial triage process.
- As a vulnerable person, give me a place within the A&E department, similar to paediatrics, so that I don't feel unsafe.

3. Communication can be felt by patients and service users to be dismissive, distrusting and impersonal. Systems are often inefficient

First and foremost, written communication was reported to be impersonal, sometimes difficult to understand, outdated and dismissive. Communication via letter and electronic system is widely known to be inefficient. Letters aren't received in a timely manner, or don't get received at all. GP records are not linked with hospital records. Patient records cannot currently be instantaneously shared across clinical services.

Additionally, participants reported feeling as though clinicians didn't always trust what they were saying - with some believing that the clinician had already made up their mind about what was wrong, disregarded any new symptoms, ultimately leading to misdiagnosis or delayed care.

"I was told that I should feel fortunate that the NHS was going to do a cosmetic breast surgery for mastectomy. The way I was treated, was kind of rude to be honest with you.

Another surgeon looked at my scars and the first thing she said to me is are you on testosterone. I was like why would you ask if I was on testosterone? So I thought that was really odd that the surgeon formed some type of speculation about me and the way I physically look, I don't know if she was assuming I was a trans person or something like that...

Then there was the GP, I was losing weight and I went to go see him and he was like, when's the last time you've had AIDs test done. I mean weight loss yes but erm... it's a little bit ridiculous. I filed a formal complaint with the GP surgery after that."

It was also felt that rules and bureaucracy, in many cases, overruled common sense, for example where referrals have been made about a specific part of the body yet

since the referral was made, the condition had evolved to another. Doctors are bound by the referral. For example:

“So, eventually, so I was referred to physio at the end of January and saw a physio for the first time in June and it was one of the junior physios and she wouldn’t listen to me, so I was saying to her, yes, I’ve been referred with the knee but actually I’ve got a real problem with my hip right now and that’s what I need some help with. But whether she is bound by the referral and couldn’t look at another part, I don’t know but she was only able to focus on the knee. And at that point I was using a walking stick permanently. Absolutely couldn’t do without it. I was in a lot of pain.”

Participants stated an understanding for the lack of time and resource within clinical services, and the fact that clinicians are often under a lot of pressure. They also felt, however, that if they were trusted by clinicians to be experts in their own health care needs, the available time and resource could be used more efficiently.

At this moment in time, clinicians ultimately have the power - they have the power to listen to you, refer you, medicate you, dismiss you.

Methods of providing feedback to the clinical services were also felt to be inadequate. A text message is usually sent that says:

“Thinking about your recent visit to RLBUHT’s A&E department: How likely are you to recommend your experience to friends and family if they needed similar care or treatment? 1 Extremely likely, 2 Likely, 3 Neither likely nor unlikely, 4 Unlikely, 5 Extremely unlikely, 6 Don’t know. Your feedback is anonymous and important in helping improve services. Contrary to warnings that may appear on your phone ALL REPLIES ARE FREE. Reply STOP to opt out. Thanks”

The text messages do not provide the option to give any more detailed feedback, and participants felt that therefore this method did not provide them with the opportunity to share their views, and would not be useful for a service to take on board and improve.

RECOMMENDATIONS:

The challenge in addressing this issue arises from the fact that we cannot change a clinician's way of working and/or their experience of "time-wasting patients". This project cannot fundamentally reduce the workload, or address the lack of resources available in clinical services.

What the project can do, is provide advice and information on how to communicate most effectively with a clinician. The most effective way that a digital solution can address this issue, is by tracking and storing long-term health data, to which a patient or service user can refer to within an appointment. If a patient or service user can easily demonstrate when they have been better/worse over a period of time in the past, a clinician can gain a better informed long-term view of the patient, rather than the specific moment in which they see them. This can include evaluating side effects from medication, pain levels, anxiety levels, temperature, blood pressure, alcohol intake, exercise, etc.

Additional research with clinicians and clinical staff (eg 111 and 999 responders, GP receptionists) to find out how a patient could provide the most useful information in the most succinct way is also recommended.

Additionally, by providing the most appropriate and up-to-date contact information and allowing connection with clinical services and clinicians in more efficient ways, barriers are reduced, and patients, service users and carers can become more empowered to take responsibility for their own health and care.

A piece of work ("XDS" or "Health Information Exchange"; part of the Share2Care programme) is currently being developed to allow patients to access their clinic letters via an online portal. Once this has been deployed, the delay in receiving letters via post, and any issue with letters being lost will be vastly reduced.

Additionally, this project could provide insight into improving or providing more effective methods of feedback and communication that could be fed to the clinical services that we are working with.

The opportunity to collect feedback would also contribute towards reducing patient frustrations - giving patients and service users a mechanism in which to provide feedback on their experiences will allow them to feel heard. This type of solution

could extend to connect PROMS and PREMS with other electronic patient data, such as goals and treatment plans, and could even connect with CROMS to create a view of the whole patient story.

IN SUMMARY:

- Reduce clinician frustrations by providing templates/suggestions to patients on how to communicate effectively.
- Give patients access to clinic letters in a digital platform so they are always accessible.
- Provide better feedback mechanisms to give patients a voice.
- Allow patients and service users to track their health and wellbeing over time so that they can be informed and evidence based in conversation with their clinicians.



USER'S STORIES

- Let me track and store all of my health data in one place, so that I can feel more confident and provide “evidence” when speaking with a clinician.
- Give me access to my clinic letters online, so that I don't have to wait for post which is often delayed and sometimes lost. If possible, let me communicate mistakes with what has been written, as documented errors can sometimes prove problematic in future appointments or with diagnoses.
- Provide me with information on how to communicate the most important information to my clinicians succinctly and efficiently so that I feel confident I have told them everything they need to know.
- Give me better methods of feedback so that I feel listened to when something goes wrong - and when something goes right! I want my feedback to be taken into consideration, and a scale from 0 - 10 does not allow this to happen.
- Let me put a face to a name when I am meeting clinical staff so that I feel better able to establish my potential care team in my mind.



4. Record keeping systems are seen by some as antiquated and scrapbook-esque

Following on from the issues with paper communication previously discussed, participants in our research also reported issues with medical record keeping.

More than one participant reported that all of their records were kept on paper, and that they were responsible for not only updating them, but also keeping them and bringing them to every appointment.

“Why in 2019 is my documentation antiquated? All my notes about my treatment is handwritten in like a scrapbook for want of a better word.”

“So every time you go for an appointment with your baby you’d always take that with you. They say have you got your red book? I was like god I haven’t used that red book for about a year now because once they hit two I’ve not really been to see them for anything; but every time we went that was always in the bag. It’s like a bible really to the Doctors when they’re small.”

“You get a file, at the hospital when you book in. It’s this big file, a folder, like a lever arch file, and you have to take it everywhere with you. You put your birth plan in it and at every appointment, they put all your scans and letters in it and they go to your midwife. Everything is all done on paper. In this day and age, we are talking about paper copies of everything which doesn’t make much sense. Well, you’re not supposed to forget it. Like towards the end of your pregnancy they say take it everywhere with you. You know like if you were going to the shops, have it in the boot of the car or wherever. Don’t go into labour without your file. What is the point? They didn’t even look at my birth plan!”

Other patients also were shown paper records, but these records were then kept by the clinical service.

The other key issue with clinical record systems is that they tend to be stand-alone - not only on a trust-by-trust basis, but departments within trusts also have their own systems that often don't connect with one another. For example, a maternity team would not be able to view a patient/service user's mental health records. Our research has shown that clinicians, patients, service users and carers want all of their health data to be visible to their entire care team, in one easily accessible place.

“There was a cross over period between going from the retina to the cornea unit. The cornea people thought I should still be with the retina specialists. The retina specialists had signed me off to go to the cornea specialists and that is where I thought something was not working between these two departments. So I felt that was kind of like a waste of time because you are just telling me I should be back with a department they have told me to leave. I was in a kind of like transition between two and as a patient, I just thought don't they talk, don't they communicate?”

Aside from preventing a “whole person”-centred approach to care, the burden is predominantly on patients, service users and carers to remember everything about their medical history, which can be a huge challenge. This is especially true for those who have co-morbidities and often need to repeat their entire history every time they meet a new clinician.

RECOMMENDATIONS:

A number of trusts are making the move to a “paperless” system. There is still reluctance from some areas due to perceived risk around data safety and also whether digital systems might reduce levels of access for some users who don't necessarily have access to devices or internet connections.

Departments and staff are being educated on how becoming paperless will be more secure and more efficient.

Personal Health Record platforms (such as Mindwave's “MyPHR”, Parsek's “Vitaly” and PKB's PHR) that aim to connect with electronic health records within trusts, will help to solve this problem. Patients and service users will have “always on”

access to their medical records that can be shared with clinicians across clinical services. Clinicians and/or clinical services will therefore also be able to view and share additional data such as forms, treatment plans, and information leaflets, with patients and service users. The goal is to show all of a patient or service user's health data in one place - **and allow the user to choose where that place is.**

The ability to include carers in a patient or service user's health platform (such as a PHR) to allow the sharing of content and data with them, will move towards tackling the issue of accessibility to device and internet. It is particularly important to address older generations with younger carers, but also with patients/service users that lack capacity to use such systems.

IN SUMMARY:

- Some education is required to ease the transition into “paperless” record keeping. The benefits to fully electronic health records, such as physical safety (not getting lost or damaged) and always having them hand, are clear.
- Allow the user to choose the platform that best suits their needs - create a safe and open marketplace where data and learning can be shared is beneficial for all.

USER'S STORIES

- If clinical systems cannot interoperate, let me collect all of my own health data in one place so that a holistic view is available. Allow me to share this with my clinicians so that they have access to all of my health information.
- Make sure that my data is always accessible via a digital device, so that I do not run the risk of losing or damaging paper records.

- Provide clinicians or clinical services with access to an online system that can integrate with mine, so that new health data can be seen in real-time by all relevant parties.
- Give me a way to keep notes against appointments, so that when discrepancies occur I can easily refer back to what has been previously said.
- Give me a choice of platforms that where I can access, store and track my health and care data, so that I am not forced to use a system that doesn't meet my personal preferences.
- Let me share data across platforms where relevant, so that I can make the most of the functionalities and options available to me.
- Let me share data across platforms where relevant, so that I can make the most of the functionalities and options available to me.

5. There are blurred lines around who is accountable and/or responsible for a patient/service user's health and care.

Our research showed that there is often confusion on the part of patients and service users, as to when they are responsible for taking action vs when their clinical team might be responsible - particularly in regards to chasing referrals and appointments.

“So, again, I think it’s really important that everybody can see that those things are happening because that would save me phoning the surgery, taking up the time of the receptionists who need to be dealing with the people in front of them, saying, have you sent this letter, has it gone to the right person? But for me, I’m, I like to be in control, I like to know what is going on.”

Linking directly with our previous insight around communication, the confusion is exasperated by the feeling that clinicians are “king” and hold all of the power. As discussed, this piece of work aims to empower patients, service users and carers to take action with their own care.

Currently, as a patient or service user, you are treated episodically by condition; as discussed previously, a maternity team cannot see a patient’s mental health records, which can often leave patients and service users confused, particularly if they receive conflicting advice. Who is the most responsible clinician?

RECOMMENDATIONS:

Showing a patient’s journey - past, present and future - with actions attached to it, and who is responsible for those actions, could start to relieve some of the confusion around accountability and responsibility.

Additionally, providing information to a patient, service user or carer on the options that they have available to them would be useful. For example, how long should you expect to wait for a referral to go through? What can you do if you haven’t received a referral in this time?

Surfacing key people in your health care journey could also be useful - photos of clinicians and clinical staff, easy-to-access contact details of departments and services, and a clear indication of who is responsible for what (for example, a clinician’s secretary or a service’s receptionist). Simply being able to put a face to a name will help to reduce some of the mystery around a health care journey. A way to escalate errors or mistakes in clinic letters would help patients and services users to feel more in control.

By surfacing all of a patient or service user's data in one place, person centred care as opposed to episodic care, can start to become a reality.

IN SUMMARY:

- Providing clear information on clinical service roles and escalation processes, will relieve some of the mystery around accountability.
- Platforms that will show all patient data in one place will be integral to empowering patients and service users to take control of their own care.

USER'S STORIES

- Give me information on what each clinician or member of clinical staff (including receptionists, secretaries etc) does, so that I am able to understand who has what remit with regards to my health and care.
- Let me put a face to a name when I am meeting clinical staff, so that I feel better able to establish my potential care team in my mind.
- Give me information and advice on how to escalate problems, so that I feel empowered to make changes when my health and care is not being appropriately managed.
- Give me a way to track actions and "events" along my health care journey, so that accountability and responsibility for each is clear.

6. There is a lack of clarity and future visibility around an individual's care pathway

Participants reported feeling unsure about what to expect when they start on a care pathway, from the physical locations they'll be visiting, to who they will see there; from what side effects to expect from treatments, to how long the whole process might take.

“When you are in a situation like I am where your body is basically failing you, you need to be able to take control of something and the only thing that I can take control of is making sure that I see the right people at the right time and that everybody is doing the jobs that they say they are going to do when they have done them. And while I trust everyone to do that, in the middle of the night, when its going around in your mind, being able to log onto an app and say, actually yes that it happening, that is so important. “

As with all of the insights, this finding links closely with the others, particularly around communication and access to information - patients and service users aren't able to see how departments connect to one another or communicate with one another, or who is responsible for what.

RECOMMENDATION:

Provide a visual representation that patients, service users and carers can easily access that shows them where they have been and where they might go.

If a clinical service's digital system could log "events" and push them into a patient held record, this would ensure that the patient's visual map was up-to-date in real time.

This could include appointments, admissions, diagnoses being made, collecting prescriptions, etc.

Further research with all user groups is recommended to create a definitive list of all “events” on a care pathway and all of the actions that might go alongside it. Could a system track “referral made”, who it is made by, and “referral seen” and who has seen it? Additionally, adding potential waiting times in between each “event” would help to reduce some of the anxiety that we know patients, service users and carers feel when they are waiting for the next stage in their care.

Often not knowing how long a wait might be, can be much worse than knowing you have a long wait ahead! By providing a clear view of a health and care pathway, users will feel less excluded from their own journey. By showing what has already happened, there is the additional benefit of communication with clinicians newly involved in a journey, as key dates and events are easy to access and therefore share. This removes some of the challenges patients and service users often face when asked to repeat their history multiple times to multiple people.

IN SUMMARY:

- Giving a patient, service user or carer a longer-term view of what their care might look like, would help reduce the uncertainty and nervousness around their health care journey and interactions with clinical services.
- Clearly showing the journey up until the present will help patients and service users to communicate key dates and events with new clinicians.

- Show me a visual representation of my health and care - for example, a journey map - of where I've been and where I might go, so that I can be clear about my history, and less anxious about my future.
- Let me (or my clinicians) tick off "key events" in my health and care journey so that I can be clear about what has been achieved and what I am still waiting for.
- Show me the status of actions that need to be completed, eg referrals being seen or actioned, to reduce my anxieties around when certain things will happen for me.
- Suggest questions for me to ask at key events, so that I feel less alone in my journey and more confident in knowing what I could ask.
- Link to other patient/service user/carer stories at key events, so that I feel less alone in my journey, and can be better prepared for managing the impact of the event.
- Let me add notes or escalate issues if they become worse and require urgent attention, so that I do not have to battle through current communication channels.
- Give me a way to keep a record of who has taken and will take action along my health care journey, so that I can contact the right person if there is a problem.
- Let me choose to use geolocation on a digital system, so that I can find real-time maps, directions, photographs and information about a clinical service.
- Show me photographs and descriptions of who I might meet at different locations, so that I feel less anxious about my appointments.
- Inform me of predicted waiting times along my journey, so that my expectations are managed.
- Tell me how much parking might cost and whether the machines take cash or card, so that I can be prepared for my visit to a clinical service.
- Inform me of accessibility information at clinical services, so that I can be prepared with assistance or alternative options if necessary.

7. Local community culture contributes to chronic conditions

Research clearly showed a disproportionate problem with alcohol and alcohol related diseases in Cheshire and Merseyside. Anecdotal reports told us that there is a large drinking culture in the region, which was attributed to community; and social activities predominantly focusing around alcohol consumption. The social culture in Cheshire and Merseyside was compared to that in London:

“In London, people drink because they’re stressed. In Liverpool, we drink because we want to be connected; to our roots, to our past, to each other.”

RECOMMENDATION:

The most obvious recommendation would be to signpost users to alcohol monitoring apps and resources to help reduce alcohol intake.

Research told us that the culture and social aspect of drinking alcohol is fiercely protected - community and connection is a hugely important part of people’s lives, perhaps more so in this region than some others. Therefore, alongside signposting to the aforementioned apps, social prescribing should also become a large part of any offering attempting to address this issue. In order to encourage positive behaviour change, combining education around alcohol related harm with practical alternatives for social and community based activities should be provided in an engaging, personalised, and easy to access format.

IN SUMMARY:

- Provide healthy and personalised alternatives to social drinking alongside alcohol cessation advice.

- Show me personalised, fun and healthier ways to socialise than drinking so that I feel encouraged to change my behaviour.
- Help me to reduce my alcohol intake so that I can reduce my risk of alcohol related disease.





No entry

These doors
are alarmed

N

rs
bd

Service roadmap

This is a suggested roadmap and is subject to change following the first pilot.

The PHR platform that Mindwave is built in a modular way so that elements and features can be easily moved and “switched off and on”, to accommodate such changes.

This is a suggested roadmap and is subject to change following the first pilot. All of the features and functionality within this roadmap are based on the insights and learnings that we have gathered during the course of our research, for example:

The “**Documents**” feature within the “**Access**” section of the roadmap meets the following user need: *“give me access to my clinic letters online so that I don’t have to wait for post, which is often delayed and sometimes lost. If possible, let me communicate mistakes with what has been written, as documented errors can sometimes prove problematic in future appointments or with diagnoses.”*

The “**Track**” section of the platform provides opportunity to *“let [users] track and store all of [their] health data in one place so that [they] can feel more confident, and provide “evidence” when speaking with a clinician.”*

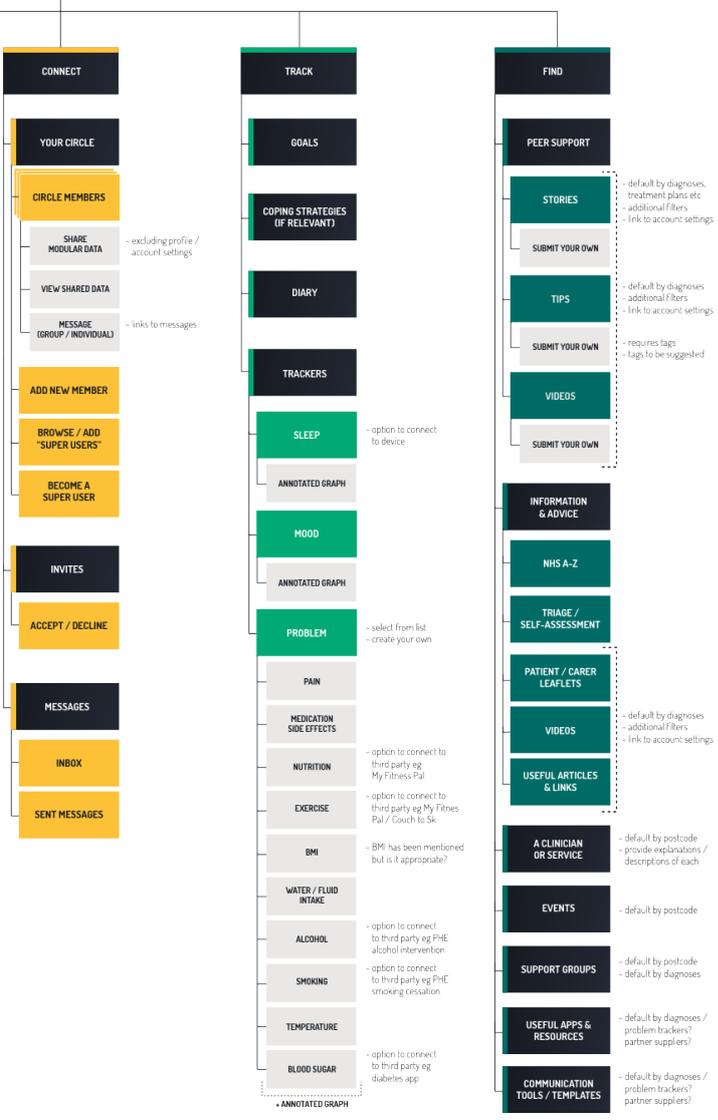
Some of the user needs will not be in scope for this project, for example, *“as a vulnerable person, give me a place within the A&E department, similar to paediatrics, so that I don’t feel unsafe.”*

The PHR platforms from Mindwave are built in a modular way so that elements and features can be easily moved and “switched off and on” to accommodate changing priorities across different trusts and regions.



Service roadmap Cheshire & Merseyside

HEADER LINKS: FEEDBACK FORM LOG IN / LOG OUT



- ability to escalate if actions are delayed or condition worsens
 - link to peer support / clinician directory
 - geolocation / directions / parking info

Brand guidelines

The following guidelines are high level suggestions based on our user research and prototype testing. They will be developed further as the project progresses.

PURPOSE:

Provide users with the tools and connections to make supported and informed health choices and stay well for longer.

TOE OF VOICE:

Clear, understandable and concise wording with good signposting. Approachable, calm and caring language. Minimal adjectives – stick to the facts.

THE NAME SHOULD BE:

- Relatable
- Simple
- Memorable
- Link to health and wellbeing
- Suggestive of transformation and care
- Emotive
- Not clinical
- Easy to say
- Feel kind

The name should not be an acronym - unless the letters stand for something meaningful and memorable.

VISUAL BRANDING

- Day and night mode options
- Friendly but professional
- Accessible
- Formal
- Use the NHS logo
- Calm and natural colour ways
- Soft and rounded lines and features
- Strong, friendly, welcoming and legible typeface
- Lots of icons/imagery
- Colour coding to strengthen navigation throughout

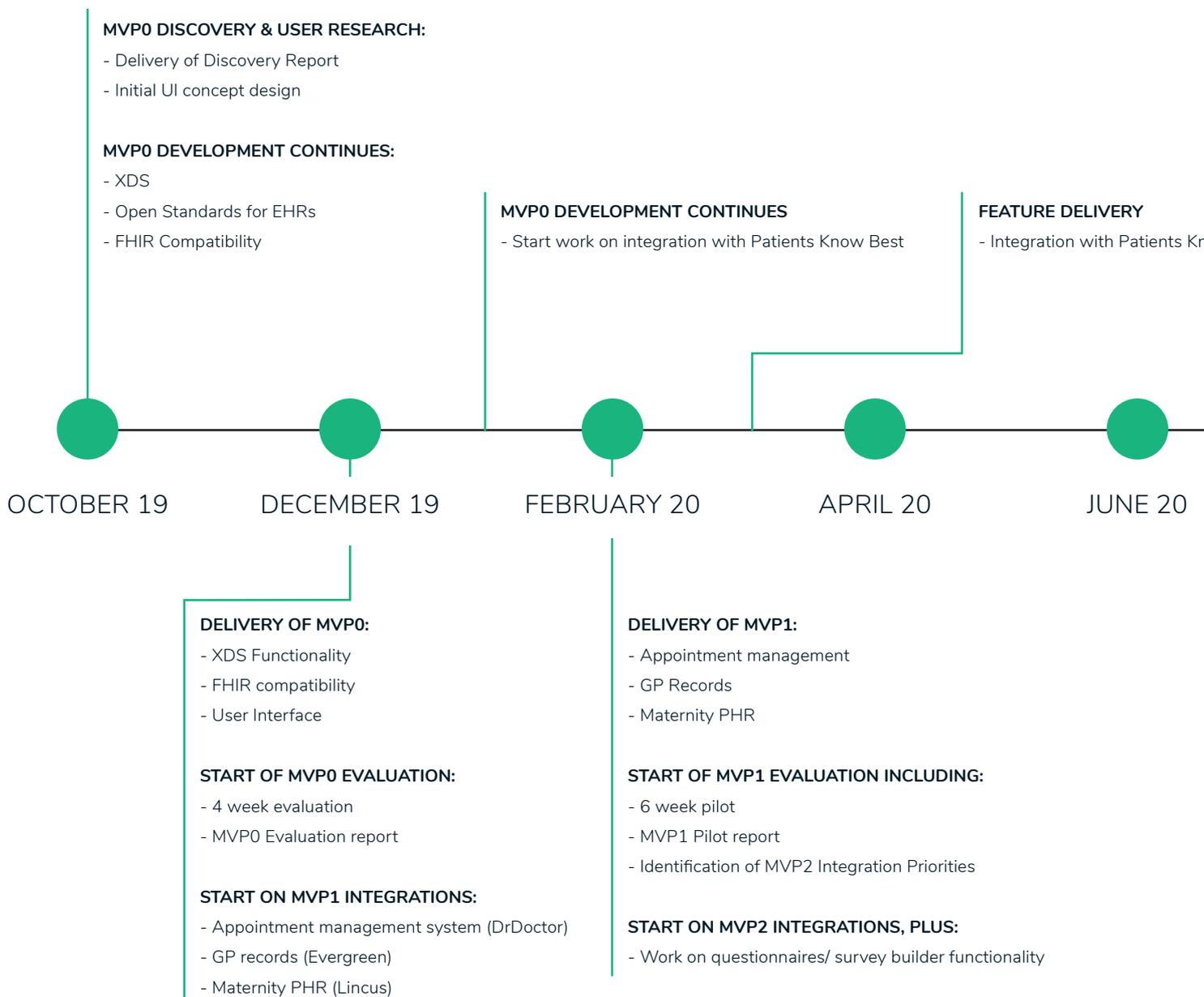
IMAGES SHOULD BE:

- Inspiring
- Fresh
- Active and alive
- Suggestive of strength
- Suggestive of possibility and imagination

IMAGES SHOULD CONVEY:

- Nourishment
- Hope
- Ownership
- Empowerment
- Independence

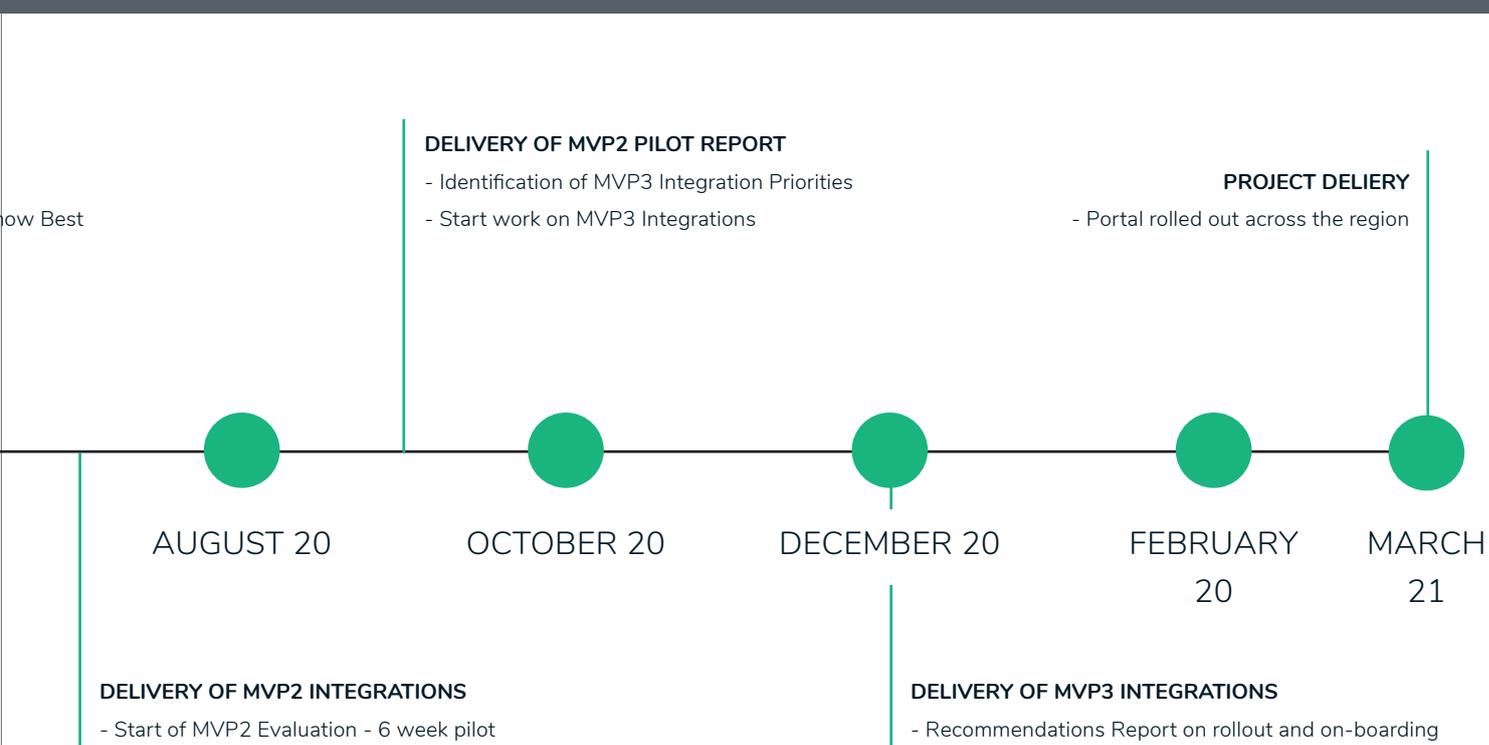
Proposals & TIMELINES



CONTINUED RESEARCH

We recommend that user research should continue for the lifespan of this project, in the form of pilots, user testing (both one-to-one and with groups) of prototypes, visual design and content, depth interviews, and surveys. Continued persona development would also be beneficial when discussing user journeys. Other methodologies could be used, such as card sorting and Treejack architecture validation to determine labelling of features and sections, and navigation of the platform.

User testing should include any past research participants who expressed a desire to continue with this project, as well as new participants - with the addition of carers and clinicians in future phases.



Measuring Success: PROJECT KPIS

RECOMMENDATION

Each MVP phase will be thoroughly evaluated through pilots and/or user testing and analysis. Each evaluation phase will gather qualitative and quantitative data to inform the next phase of design and development. From this data, we can build SMART KPIS for the following phase of the design and build. These KPIS could include goals such as “reduce frustrations around waiting times”, or “help patients and service users to feel more involved in their health and care”. The SMART (Specific, Measurable, Achievable, Realistic and Timely) aspect of these will need to be determined through each MVP phase.

USER SATISFACTION - QUANTITATIVE & QUALITATIVE

- What percentage of users are satisfied with their experience of using the service?
- How helpful have users found the service?
- Test via pilot questionnaires, user testing, workshops, depth-interviews etc.

“Each MVP

COMPLETION RATE

- What percentage of actions do users successfully complete?
(eg more appointments attended due to the platform, monitoring health and wellbeing, accessing care plans, finding resources etc)

DIGITAL TAKE-UP

- What percentage of users choose the digital service to complete their task over other digital and non-digital channels? (eg reduction in phone calls to services, tracking health data, keeping a diary, checking appointments, finding information and services via the platform etc)

phase will be thoroughly evaluated..."

Project definitions & PROCESSES

Minimum Viable Product: MVP

A Minimum Viable Product is the first version of a new product. It is a “skeleton” product which uses the minimum amount of functionality and content to provide a user with a complete journey and experience. This enables a team to collect the maximum amount of validated learning about their users in order to develop and iterate the product into a fully functioning and populated solution that successfully meets their audience’s needs.

The reason for using this method is to ensure that no time, money or work is wasted; each assumption, insight and decision is thoroughly tested, validated and built upon.

MVPO

Proof of concept to demonstrate how various kinds of clinical documents can be displayed in the citizen portal.

MVP1

Release of the citizen portal, including integrations with appointment management, GP records, Maternity PHR and clinical documents. This phase will include a pilot.

MVP2

Taking the results of the MVP1 pilot and initial discovery work, to implement additional functionality integrations.

Agile

By employing Agile thinking, and Scrum methodology, we can allow for rapid development, testing and iteration to ensure a quick and effective method of creating a successful product.

”THE END USER FIRST.

Scrum is not about the team. It is not about the client. It is not even about the product. It is about being relevant to the end-users.

THE AGILE MANIFESTO

We have come to value:

- **Individuals and interactions** *over processes and tools*
- **Working software** *over comprehensive documentation*
- **Customer collaboration**
over contract negotiation
- **Responding to change**
over following a [set] plan

While the *italic* items of this list carry value, we value the **bold** items more.”

Clinical & INFORMATION GOVERNANCE

Caldicott Principles

All MVPs and the resulting platform, will adhere to the **7 Caldicott principles**.

- Justify the purpose.
- Don't use patient-identifiable information unless it is absolutely necessary.
- Use the minimum necessary patient-identifiable information.
- Access to patient-identifiable information should be on a strict need to know basis.
- Everyone should be aware of their responsibilities.
- Understand and comply with the law.
- The duty to share information can be as important as the duty to protect patient confidentiality.

The users of the service must at all times be aware of how their data is being collected and used, and be clear on the consents they give and withdraw. They need to be in control and have confidence in the system. Where users are able to share their own data with one another, this will be with specific consent. They will be able to withdraw consent at any time.

The platform will be integrating with third party services, such as the NHS widget and login, Dr Doctor's appointment management system. All parties must adhere to the project's clinical and information governance guidelines and regulations.

A clear and robust consent model will be implemented as part of the service.

Privacy and security notices will be provided, in context.

Whilst the service is open to all, it will not be targeted at children and adolescents. However, the necessary safeguards for those under 18 and those under 16 will be implemented.

Various reports that will be required for proper evaluation of the service following deployment of the MVP, will avoid the use of personally identifiable data in almost all circumstances. Where it is unavoidable to use the data, all appropriate safeguards and protocols will be put in place.

A suitable IG Toolkit will be developed in alignment within existing IG frameworks with C&M as part of the platform deployment to ensure clear and consistent assessment by the project teams and also to be transparent with users.

Users will be kept informed throughout their journey on how their data is being used and why.

Privacy, security & CONFIDENTIALITY

Ethos

In the National Data Guardian (NDG) Review, in summer 2016, Dame Fiona Caldicott said: “people’s confidential data should be treated with the same respect as their care”.

The service will be architected and developed with this principle at its core.

PRIVACY

All users are entitled to their privacy and must be in control at all times.

SECURITY

All systems and processes will be designed to meet all extant security standards. These will need to be published and be available to all users and stakeholders.

The security systems must be fully tested and results published to ensure that the public, users and potential users have full confidence in the service.

CONFIDENTIALITY

All staff who are part of the service delivery team will be appropriately trained in the laws and regulations governing confidentiality. It is most important that everyone is able to correctly interpret the rules to ensure confidentiality whilst providing the best possible personalised self-management support. The system will be carefully designed so as to allow for the appropriate confidentiality and use of personal data to tailor services, route maps and directions.

“people's confidential
data should be treated
with the same respect
as their care”.

MINDWAVE

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