Rethinking Unscheduled Care:

A design investigation into people's experiences and journey through unscheduled care

2022

Summary and Research Recommendations

A design investigation into people's experiences and journey through unscheduled care

Project aim

The overall aim of this work is to use a combined approach of evidence review and collaborative user research to identify and understand insights directly from people who need (regardless of whether they get access to) unscheduled or urgent care services.

Definitions used within this work

Unscheduled care includes (but is not restricted to) urgent, emergency and out-of-hours care.

Urgent care is NHS care which cannot reasonably be foreseen or planned in advance of contact with the relevant healthcare professional.

People refers to people who need (regardless of whether they get access to) unscheduled or urgent care services.

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The system through people's eyes

"Rethinking unscheduled care" seen through people's experiences highlights that there are **three broad categories of need** that drive people to access unscheduled care. Each have different causes of **preventable (failure) demand**.

Understanding this will help us to design more effective responses to deliver a higher quality service whilst also reducing preventable demand. Below are the **key drivers of failure demand** for these three categories:

Sudden accident or illness

Uncertainty about where to go to get help and/or **lack of accessibility** of the optimal route for support.

We must design services which make it easy for people to access the right support when their need is unexpected, while recognising the impact of a crisis on their and/or their carers' cognitive load and ability to navigate systems.

Frailty, palliative and long-term conditions

Lack of or **poor quality anticipatory care planning** – including failure to involve the family support network combined **with lack of accessibility to routine support**.

We need to take opportunities for early intervention to stop people presenting to unscheduled care in a crisis.

Multiple disadvantages

Complex multiple referral pathways and **lack of access to 24/7 supportive coordinated care**. This means **police and ambulance crisis response** intervene.

We should help people to access the right service for them, instead of the only parts of the system which seem available where and when they need it.

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Background and context

- The complexity of the unscheduled care system and multiple access points results in people being uncertain about how and where to seek help. In many cases users default to the emergency department or emergency services, leading to delays for service users and unsustainable challenges to service providers.
- The current approach to the unscheduled care system is too focused on hospital services without fully considering the role of social services, primary care or community, friends and family.

- There is no comprehensive vision for the future of unscheduled care across Scotland.
- Much of the work to date has been described through the lens of the system and focused on existing services, rather than through the perspective of the person needing unscheduled or unexpected care – i.e. what they need as an individual in the moment when they experience a care or support need they had not planned for.

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Our approach

We wanted to explore how to work differently across the system and therefore undertook this work as a test of collaboration across multiple organisations using a collaborative leadership model. Leaders with expertise in seeing problems through the lens of users to bring insights into redesign formed a working group. Organisations involved:

- National delivery organisations involved in unscheduled care
- National Improvement body which interfaces with the whole system across acute to community
- Scottish Government’s design leadership

The project used **user research methods** with clear and informed rational for approaches based on analysis of current and potential future states.

Evidence review

Analysis and synthesis of existing evidence from research and grey literature, including experience data, to obtain person-centred views of people using unscheduled care.

Service co-design

Use of the literature and existing journey maps to explore people’s needs and experiences accessing services, and identify gaps in our existing knowledge and understanding.

NB. Whilst not focussing on COVID, the literature and user validation reflects learning from both pre-pandemic and pandemic experiences of people.

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Methodology – evidence synthesis and review

- The project started with a review of what the system already knows; the Evidence and Evaluation Team (EEvIT) at Healthcare Improvement Scotland undertook a rapid scoping review.
- Search terms were used as widely as possible.
- Relevant publications were mapped and described in relation to a framework developed by the Crisis Care Concordat.
- Broad thematic areas were developed in relation to the current evidence base, and gaps were articulated as questions for further exploration.

Crisis Care Concordat Framework

1) Access to support before unscheduled care
2) Urgent and emergency access to unscheduled care
3) Quality of treatment and care when in unscheduled care
4) Leaving unscheduled care services and prevention of future unscheduled care through referral to other services

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Groups more likely to experience unscheduled care – what do we know?

Groups more likely to contact unscheduled care:
People caring for children under 5, older age groups
and people from areas of socio-economic deprivation

Groups for whom accessing unscheduled care will be more complex:
Parents accessing care for young children, older people and people with long-term conditions with new or existing care needs

Groups at risk of exclusion from unscheduled care:
People whose first language is not English (including BSL)
and people from minority ethnic groups

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Groups more likely to experience unscheduled care – what are the gaps?

The experiences of those with complex care needs, for example parents of children under 5, the LGBT+ community and people with mental health problems are often underrepresented in the published literature.

The experiences of particular groups may also be underrepresented because the literature reports findings from engagement with people at risk of unscheduled care but without direct experience of the care pathway.

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Navigation of the unscheduled care pathway – what do we know?

Awareness and perceived availability of care:
Awareness and perceived availability of services and the satisfaction and confidence in what can be provided from different services varies.

Experience of pathway access:
The pathway for accessing urgent care through the 111 service can be unclear for people.

Barriers to accessing care:
Barriers were identified for people with English not as a first language, for older people, disabled people, people experiencing transport barriers, and specific cultural barriers.

Multiple and complex needs:
The complex interplay of multiple disadvantages also increased barriers, resulting in challenges with navigating existing or redesigned services.

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Navigation of the unscheduled care pathway – what are the gaps?

It is unclear what support and information is needed for people to navigate the care pathway. People will experience different levels of urgency and uncertainty about their care needs, and services closer to home can be perceived as unavailable or poor quality.

It is unclear how people at risk of digital exclusion can be supported to access services in a 'digital first model'. The support of community organisations should be explored further.

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Improvement of the whole pathway of care – what do we know?

Uncertainty about the right care:
Reassurance and support to identify the appropriate care is described as important for people's individual circumstances.

Knowledge of alternative care pathways:
Reassurance was deemed important where people may lack confidence in the alternatives to emergency care, including the support available from community services and access to specialist care.

Previous experiences:
People's experiences of having their needs met successfully by unscheduled care influences their future use of services and use of self-care. This suggests opportunities for improving support for management of ongoing care needs.

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Improvement of the whole pathway of care – what are the gaps?

Future work could explore how the management of ongoing care needs can be integrated for people.

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Methodology – user research and collaborative sense-making with people

Sampling and recruitment of participants with lived experience

2 collaborative sense-making sessions with people

Development of problem statements using themes from these discussions

Further sense-making to revise problem statements and incorporate people’s views

Development of research questions and a recommended high level research plan

- Having completed a review of what the system already knows, **collaborative sense-making** was used to validate, organise and interpret the research data from the evidence review and pre-existing journey maps with people with lived experience.

- The evidence review informed sampling and recruitment. Participants included carers, people who’s first language wasn’t English (including British Sign Language users), older people (70 years and over) & parents of children younger than 5 years.

- **Problem statements** are short descriptions of common issues or areas of opportunity to improve the current services, based on people’s experiences.

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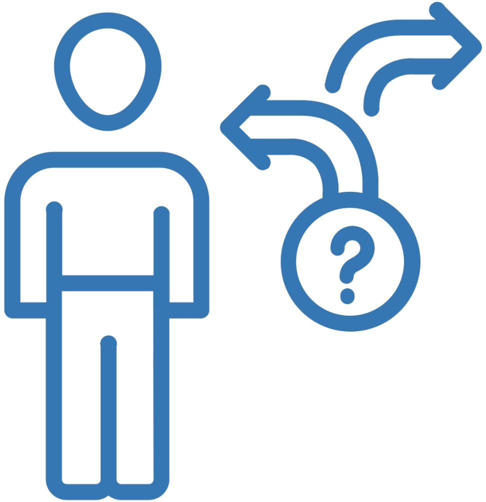
Problem Statement 1

People don't know what service to access or when to access the service.

Participants mentioned that there are different numbers to call for different issues, which causes confusion.

Participants were not entirely sure when to ring 999 versus 111.



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Problem Statement 2

People try to find workarounds based on their knowledge of the system.

One participant mentioned that they were happy to wait until help arrives if it was for them, but if it was for their children, they would go straight to hospital based on past experience.

Another participant mentioned that it was easier to turn up to Accident and Emergency (A&E) as then one becomes a *“physical problem”* who *“has to be dealt with”.*

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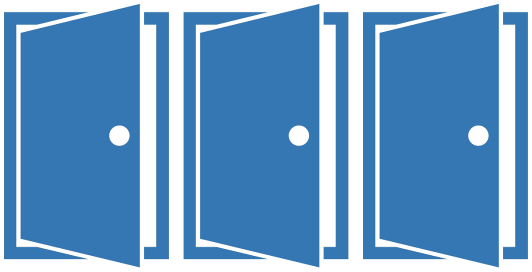
Problem Statement 3

People are not able to access services effectively because they are not entering the services through the channels the system expects them to.

Participants suggested that people can enter unscheduled services through different channels to get the service they need.

A participant described someone accessing health and social care services by ringing the police in a situation where they felt that they’d get more attention than if they rang the NHS.



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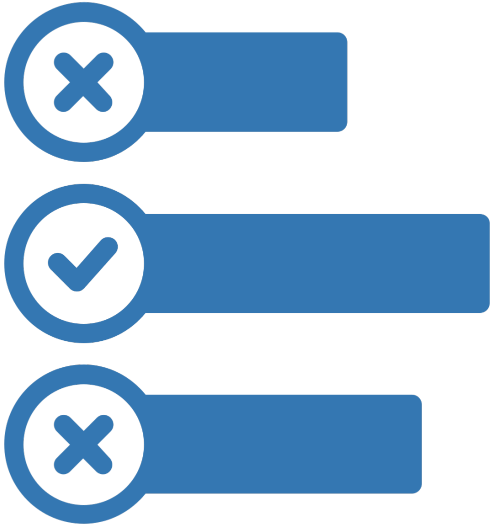
Problem Statement 4

People don’t have the opportunity to tell services all of the information they feel is important, and this impacts care.

Participants felt that when contacting health and social care services to access care, they are asked very structured questions that do not allow them to provide information about their condition that might be relevant.

A participant with a child highlighted their frustration at being sent away when they knew their child was not okay.



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Problem Statement 5

People accessing urgent care are often under extreme stress, which can impact their ability to process information, make decisions or follow advice.

A participant remembered finding it very hard to focus on answering a series of questions via phone when they were in immense pain.

Another participant said that they were too stressed to remember the instructions given to them over the phone by the advisor.

Problem Statement 6

People feel the information they are asked for in initial contact is not always relevant to their situation, slowing down the process of care.

Participants felt that when they contacted health and social care services for help, the questions they were asked followed a standard script and some questions were deemed not relevant.

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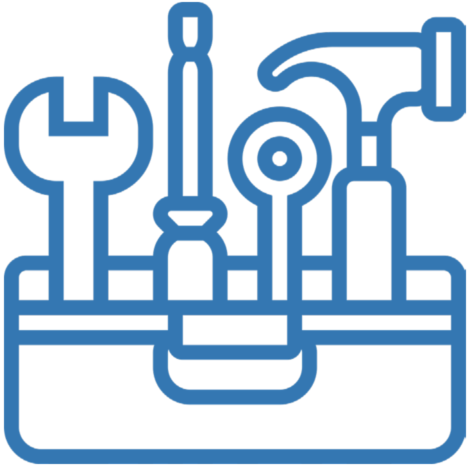
Problem Statement 7

People often don't have the tools to describe what they need to ensure equity of access.



Participants described that not everyone Is equipped to handle the current processes.

Participants suggested that there could be a different care experience if they had support around them in the form of family or friends, in comparison to those living alone.

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Problem Statement 8

People often repeatedly share information or experience delays because information is sometimes inconsistently shared or used across services.

Participants felt that communication between different parts of the system could be complicated.

Participants highlighted that they were asked for the same information on multiple occasions, which caused delays to them receiving care.

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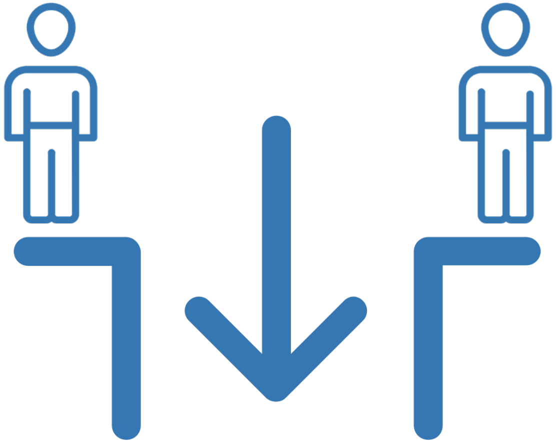
Problem Statement 9

There is a gap between patient expectations and the expectations of service providers.



Some participants highlighted the care system does not take into account individual circumstances.

Some participants felt that the system expects people to take care of themselves or be able to access help after they received their treatment.

Participants described challenges in accessing pharmacy services, for example, due to living alone or financial constraints.

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Summary of problem statements and research themes

Theme 1:
Access to and navigation of unscheduled care

Theme 2:
Information provision during unscheduled care

Theme 3:
Individual context and experiences

Access uncertainty	Workarounds	Entry routes
Information provision	Information sharing	Information relevancy
Available tools	Extreme stress	Expectation gap

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Recommended Research Theme 1. Access to and navigation of unscheduled care

- How do different user groups decide which services to use and when?
- How do they make those decisions? What are the key factors that influence people's choices when making this decision?
- What common workarounds or coping strategies to accessing unscheduled care have people developed?

Potential Methodologies

Systematic literature review, Semi-structured interviews,
Contextual inquiries (home or care settings)

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Recommended Research Theme 2. Information provision during unscheduled care

- How do providers request and collect information from people accessing services?

- What is the experience of service users providing their personal information during access to unscheduled care?

- What information do service users feel is relevant to the delivery of their care?

Potential Methodologies

Ethnography, Surveys, Journey mapping, Process mapping

Recommended Research Theme 3. Individual context and experiences

- How do people's individual contexts and backgrounds impact how they experience unscheduled care?

- How does this affect the following:
    - Accessing the services
    - Making decisions such as following instructions
    - Navigating the unscheduled care journey

Potential Methodologies

Ethnography, In-depth interviews, Journey mapping, Co-design sessions

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Planning for future service co-design

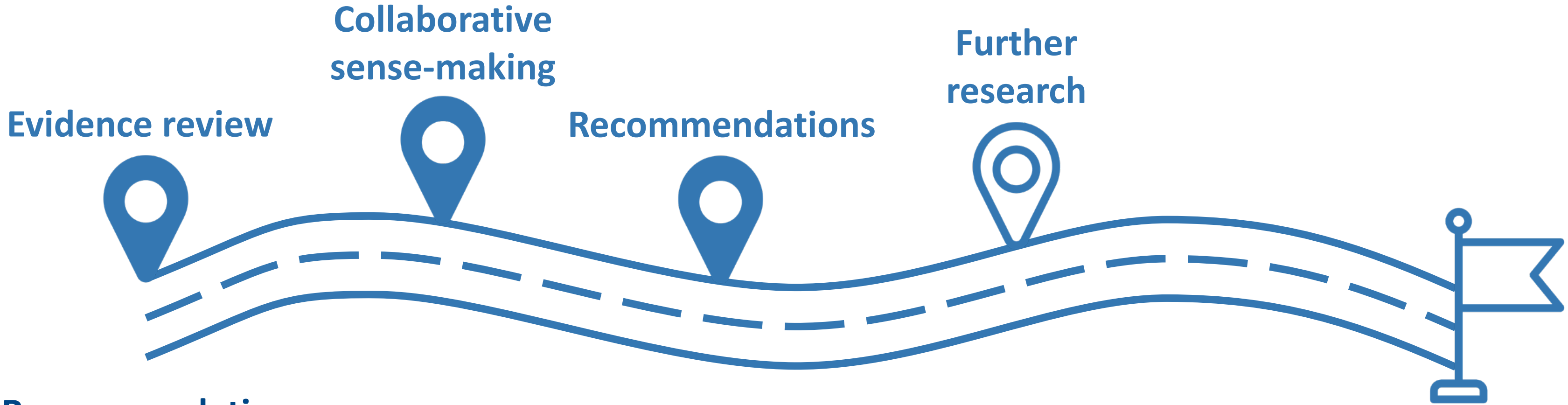
- How might we co-design a service that takes people’s individual contexts (before, during and after experiencing care) into account?

Identifying subject matter experts (SMEs) such as policy professionals and clinicians

Journey mapping with SMEs and people with lived experience

Collaborative sense-making sessions with people with lived experience

Next steps and recommendations for future research



Recommendations

1. Research is required to address the research questions and understand the implications of these for emergency and unscheduled care services.
2. Future work should explore preventative strategies in the context of accessing emergency and unscheduled care.
3. Not all problem statements apply to all cohorts of people using or needing services. A bespoke and inclusive approach should be taken to engagement.

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Concluding leadership reflections of this project

- Our starting point was a recognition that the system’s knowledge of itself is rarely challenged by the insights and views of those with lived experience of using it.

- The system’s knowledge of itself is based on data the system feels relevant, and the interpretation of that data is undertaken by those in the system.

- By involving people with lived experience not just as sources of data but as sources of insight into what that data is telling us, and what is missing from that data, we increased the chances of *‘finding out about things we did not know we needed to find out about’*

- This **person-centred understanding of care** revealed areas for further research rarely addressed in existing evidence:
  - the role of communities, friends and families needs to be better understood and built into service thinking
  - the vital importance of ‘gatekeepers’ to the system not just in gaining in access to care but in how people feel about the unexpected care system
  - how people’s personal lives and contexts/situations impact their needs and experience of unexpected care

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Concluding leadership reflections of this project

- We used this work as an opportunity to explore working differently as researchers and designers.
- By working across a range of organisations in an informal way we were able to:
  - Effectively combine and make use of scarce design and research resources
  - Draw on widespread system experience from different perspectives to complement the addition of the perspectives of those with lived experience
  - Share views and learning throughout to open up new ideas and areas for investigation
- The leadership group around the team of researchers and designers played a key role to:
  - Unblock barriers within individual organisations
  - Support each other to work differently
  - Build a rich understanding of the barriers to and opportunities for this way of working

KEY LESSONS

Working across organisations allowed us to mutually challenge and support each other

Working outside a formal delivery programme allowed us to build a richer understanding, following ideas and issues we had not expected as they emerged

- We would like to continue involving the perspectives of wider disciplines. Healthcare Improvement Scotland are developing a companion piece, which considers unscheduled care for strategic planners.

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Collaborators

Scottish Government

- Office of the Chief Designer

Healthcare Improvement Scotland

- ihub
- Evidence and Evaluation for Improvement Team
- Community Engagement Directorate

NHS 24

- Stakeholder Engagement and Insights Team

Police Scotland

Scottish Ambulance Service

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Appendix – Full Recommended Research Plan (Theme 1)

Research questions	1. How do people currently try to access unscheduled care services? a) How do different user groups decide which services to use and when b) How do they make those decisions? What are the key factors that influence people's choices when making this decision? c) What common workarounds / coping strategies to accessing unscheduled care have people developed? Why?
What we plan to do	Desk Research; Semi-structured interviews; Contextual enquiries (home or care settings)
What will this give us?	Sampling and recruitment strategy; In depth understanding of key drivers, motivations and influences as well as journeys / workarounds users have established
Who do we need to involve?	End users (diverse sample informed by desk research)
Who do we need to deliver?	User Researchers; Social Researchers

Appendix – Full Recommended Research Plan (Theme 2)

Research questions	2. What information do people have to provide when accessing unscheduled care? a) How is information currently asked for by the providers? b) When and how many times? c) What is the experience of being asked the question for users? Why? d) What information do users feel is relevant to their care? Why?
What we plan to do	Ethnographies; Call-listening / shadowing?; Survey; Journey mapping workshops; Process mapping
What will this give us?	An understanding of different as-is journeys that users take highlighting key pain points and opportunities such as in terms of information exchange
Who do we need to involve?	End users (different care needs and outcomes); Protected characteristics; Pharmacies; GPs; NHS-24 contact centres; Police and Ambulance contact centres
Who do we need to deliver?	User Researchers; Service Designers; Business Analysts

Appendix – Full Recommended Research Plan (Theme 3)

Research questions	3. How do people's individual contexts and backgrounds impact how they experience unscheduled care? a) How does this affect the following: - Accessing the services - Making decisions such as following instructions - Navigating the unscheduled care journey
What we plan to do	Ethnographies; In-depth interviews; Journey Mapping workshops; Co-design sessions
What will this give us?	A clearer picture of the As-Is Journey for different user groups combined to form a composite story. A co-designed view of problems and opportunities A plan for subsequent phases of design work including resource required
Who do we need to involve?	End users (different care needs and outcomes); Pharmacies; GPs; NHS-24 contact centres; Police and Ambulance contact centres
Who do we need to deliver?	User Researchers; Service Designers; Graphic Designers