Sickle cell digital discovery report

Designing better acute painful sickle cell care

January 2023

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Executive summary

In recognition of longstanding unaddressed shortcomings in acute sickle cell painful episode care, highlighted by the No-One's Listening All-Party Parliamentary Group (APPG) report, and a widespread failure to meet NICE quality standards, the NHS Race and Health Observatory developed a sickle cell program, made up of three workstreams.

The Observatory specified digital as one of the workstreams within this program, because it is widely recognised to be a part of the NHS with significant opportunities for improvement. The National Audit Office's Digital transformation in the NHS report acknowledges that the NHS has a poor track record in delivering digital transformation and achieving value for money.

The NHS Race and Health Observatory commissioned Public Digital, a digital transformation consultancy, to carry out the first part of Observatory's digital sickle cell service research. The goal has been to develop a deep understanding of the needs of patients and healthcare professionals during acute painful sickle cell episode, more commonly referred to as a crisis, with a view to identifying promising digital interventions for future testing.

We took a broad definition of digital. We don't consider 'digital' to be limited to technology based interventions, but instead see it as encompassing the impact and necessity of cultural, process and operating model change too, in order to meaningfully achieve the transformation in service delivery that technology makes possible.

To this end, the Observatory commissioned a digital discovery. This is a widely recognised phase of work in modern digital organisations, coined by the Government Digital Service. Important characteristics of a discovery team are that they:

- centre the voice and needs of the user - in this case, people with sickle cell and those that have a duty to care for them - using specific research techniques
- do not assume that they know what they solution is; rather they focus on deeply understanding the problem
- embody a concept known as 'working in the open', which means sharing the work as you are doing it. This makes it easier for others to understand what the work is, and it means you can benefit from the perspectives of many more people

By researching acute sickle cell painful episode care using modern digital user research techniques, we aimed to identify interventions that hold the potential to have tangible impact on sickle cell patients, and to demonstrate how to approach digital transformation within the NHS.

Through listening and researching with patients and healthcare professionals, we have identified a set of possible interventions. Of these interventions, our research suggests that personalised, digital care plans have the most potential to support improvements in acute sickle cell crisis care. We recommend taking this idea forwards for testing.

We know that care plans are already widely used in paper format across the NHS, including by and for people with sickle cell disease. Digital care plans do also already exist in some parts of the NHS. However, our research indicates that the NHS has not yet realised the potential of care plans - paper or digital - during a sickle cell crisis. We observed that there is no clear definition of what a care plan is and not everyone has one. Where they do exist, they are often not followed, and are dismissed.

We believe that there is value in taking a digital service design approach to care plans to answer questions like these:

- What does a care plan need in order to have authority?
- What will it take to make a clinician take it seriously during a sickle cell crisis?
- How can a care plan account for a clinician's lack of experience with and awareness of a sickle cell crisis?
- How can a care plan help to establish better accountability among healthcare professionals regarding how people are treated when they are having a crisis?

In short, we will not achieve transformation in sickle cell care simply by implementing technology. The key to change will be in taking a patient-centred, evidence-based and iterative approach to the design and implementation of any intervention in sickle cell services. We propose starting with care plans.

We also note that, taken individually, any one intervention may not make a significant difference to the experiences of people with sickle cell, in part because of the complex, systematic, and systemic nature of the problem, and a highly federated and fragmented NHS. Once again, technology alone will not address these issues. Given this context, we also recommend exploring redesigning the operating model of sickle cell services, and sickle cell service design. We propose starting with personalised, digital care plans as a potential 'front door' into sickle cell service transformation.

Finally, our research has led us to make a series of observations about sickle cell care in the NHS. From it, we developed a set of patient user needs and pain points, at each stage of a sickle cell crisis. This report goes on to describe our work, these observations, user needs and pain points. We close the report by describing our recommendations. Our central hypothesis is that it is the way any technology is designed and implemented which is fundamental to its potential to make a difference.

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Introduction

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Introduction

The goal

The NHS Race and Health Observatory commissioned Public Digital to explore the potential of digital interventions to improve acute sickle cell care pathways during an acute painful episode or crisis.

Between August and December 2022, we ran a discovery project that aimed to build a deep understanding of the challenges people with sickle cell experience in accessing adequate healthcare when they are having a crisis. Our intention was to conduct research that would identify, and begin to validate, candidate solutions for testing in a further phase of work.

> "Applying the culture, processes, business models and technologies of the internet era to respond to people's raised expectations."
>
> **Public Digital**

This is the final version of our report. You can read our interim report here, which we published online on 21 October 2022 to seek feedback on what we had learnt so far.

Many of the issues that have emerged through our research are well understood within the sickle cell community. Our goal was to build on work that has already happened, document issues from the perspective of people with lived experience, and to use this insight to inform a set of recommendations for ways in which digital interventions could help to improve acute painful sickle cell episode care. Our report describes what we learnt, it relays people's lived experience and it outlines what we believe should happen next. It explains why we believe that a digital service design approach to developing personalised, digital care plans holds the potential to truly make a difference for people with sickle cell.

No One's Listening

The sickle cell digital discovery project was commissioned as a result of an inquiry published by the All Party Parliamentary Group on Sickle Cell and Thalassaemia and the Sickle Cell Society, which found "serious care failings" in acute services and evidence of attitudes underpinned by racism. Their findings were published in a report called No One's Listening. We have referred back to the No One's Listening report regularly to help guide our work.

Our definition of digital

Public Digital's experience in delivering digital transformation leads us to recognise that digital is not just about technology, but also about the wider human change that must accompany it. Our definition of digital is: *"Applying the culture, processes, business models and technologies of the internet era to respond to people's raised expectations."*

This means that our discovery is not limited to technology interventions. While we have probed to understand how people use technology to manage their sickle cell disease, and to care for people with sickle cell disease, we have focused on understanding people's needs at the point of crisis. This was to ensure that we identified and focused on interventions that will improve outcomes and experiences for people with sickle cell during a crisis, rather than starting with our possibly mistaken assumptions about what might work.

The team

The members of the Public Digital team were: Connie van Zanten, Principal Lead; Will Roissetter, User Researcher; Victoria Betton, Researcher; Dr Teju Ademola, Clinical Adviser. With oversight from Chris Fleming, Partner.

Additional subject matter expertise, guidance and support has been provided by Dr Carl Reynolds, Sickle Cell Adviser (NHS Race and Health Observatory), David Miller (Open Healthcare UK), and Dr Sanne Lugthart, Consultant Haematologist (University Hospitals Bristol and Weston NHS Foundation Trust).

In total, we spent 14 weeks on the discovery, starting on 15 August 2022 and finishing our research, analysis and synthesis during the week commencing 14 November 2022.

We sought feedback on the report in November and December 2022. We shared the report publicly via our weeknotes. We invited and received feedback both from specific individuals and from people following our work on the internet. We are extremely grateful to everyone who helped us to make this report better - **thank you to you all**.

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Methodology

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Methodology

A discovery

A discovery is a period of time characterised by particular types of activities which are focused on research. Digital teams run discoveries before they do anything else, to enable them to build a deep understanding of the problem they are trying to solve, from the perspective of the people who they are trying to solve it for.

Ultimately, you run a discovery so that you don't immediately start designing expensive and time consuming solutions before you've understood what will truly have an impact on the people you are designing services, products and solutions for.

This section of the report provides a detailed breakdown of what we did.

Our discovery work has consisted of:

1. Orientation and kick off
2. Research
3. Prioritisation
4. Working in the open and reporting

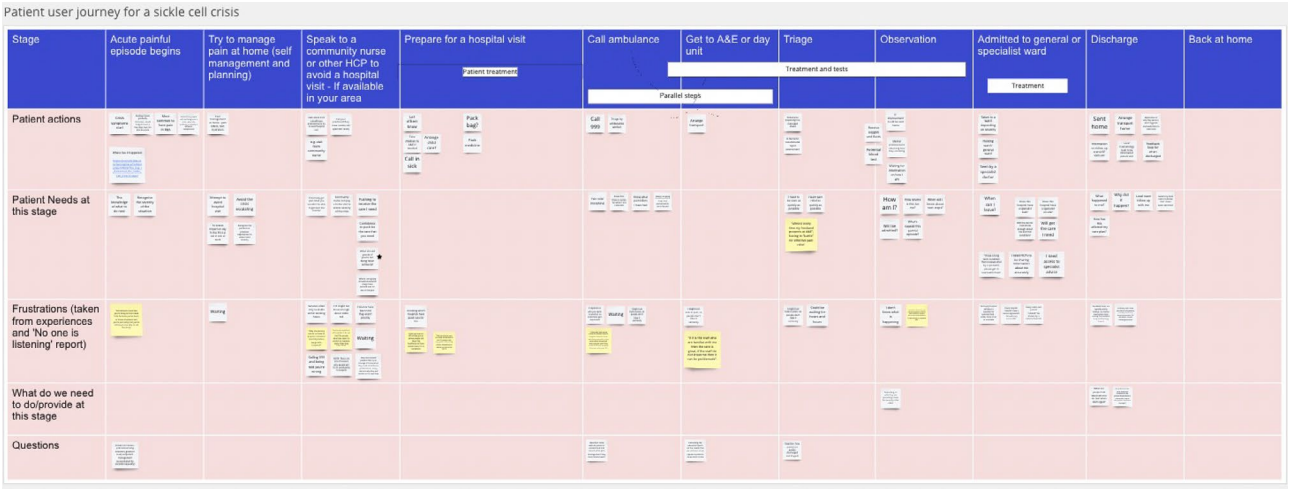
Part 01: An orientation and kick-off phase

Our team kick off at the Sickle Cell Society office on Thursday 8 September

During the orientation and kick-off phase we formed the team, launched and publicised our work externally, scoped the challenge with the Observatory, and reviewed existing documentation and research.

In this phase, we:

- Set our discovery goals in partnership with the Observatory
- Planned and delivered a kick off with important stakeholders at the Sickle Cell Society offices
- Collaborated on a press release, authored by Rose Obianwu from the Observatory
- Produced an evidence review to inform our research
- Mapped out the user experience from a clinician's perspective, to develop the Public Digital team's understanding of what happens during a crisis:



A snapshot of our first user journey map, developed with Dr Carl Reynolds (NHS Race and Health Observatory) and Dr Teju Ademola (GP and Public Digital network member)

Part 02: The research phase

During the research phase, we conducted interviews and user experience mapping with people with sickle cell, and held a range of exploratory conversations with healthcare professionals and people who are active in the sickle cell community. We also conducted a digital landscape review to help us develop a more thorough understanding of what is available to support people to manage a sickle cell crisis now, with the intention of identifying products and services that have potential for impact and scalability.

During this phase, we formed a partnership with University Hospitals Bristol and Weston NHS Foundation Trust, who we will work with to test the recommendations that come out of this discovery.

In this phase we:

- ran user research interviews with 9 people with sickle cell. 5 of these were held online; the remaining 4 were run in person, in Bristol. We spoke to people currently using a total of 3 different sickle cell services in the UK, many of which also shared their experiences of services in other parts of the UK too;
- ran 2 online interviews with non-sickle cell expert healthcare professionals;
- ran 1 online interview with 2 sickle cell expert healthcare professionals;

- held informal conversations with potential supporters and collaborators:
  - Faith Walker and Paulette Palmer, from the Friends of Cymru Sickle Cell and Thalassemia CIC
  - Harriet Smith, Innovation Lead at Yorkshire and Humber Academic Health Science Network
  - Dr Gyles Morrison, former doctor and current Clinical User Experience Specialist, with a special interest in sickle cell disease
  - A number of sickle cell advocates with lived experience
- ran a review of products and services that exist to support people with sickle cell, and those that care for them (digital landscape review).

Our user research materials for participants with lived experience of sickle cell disease:

- Our research plan and overview
- Informed consent for user research participants
- Our user research discussion guide
- User journey maps, created in collaboration with user research participants

From left to right: Dr Sanne Lugthart, Consultant Haematologist at University Hospitals Bristol and Weston NHS Foundation Trust (UHBW), Nicole Paterson, Clinical Nurse Specialist, Haemoglobinopathies at UHBW, Eugine Yafele, Chief Executive at UHBW, Connie van Zanten, consultant at Public Digital and Dr Habib Naqvi MBE, Chief Executive at the NHS Race and Health Observatory. Behind the camera: Will Roissetter, user researcher at Public Digital. This photo was taken at the Bristol Heart Institute on Monday 10 October, when we visited to conduct user research interviews.

Future research

Through our research, we identified a number of other areas we'd like to look at in more detail in a future phase. These are:

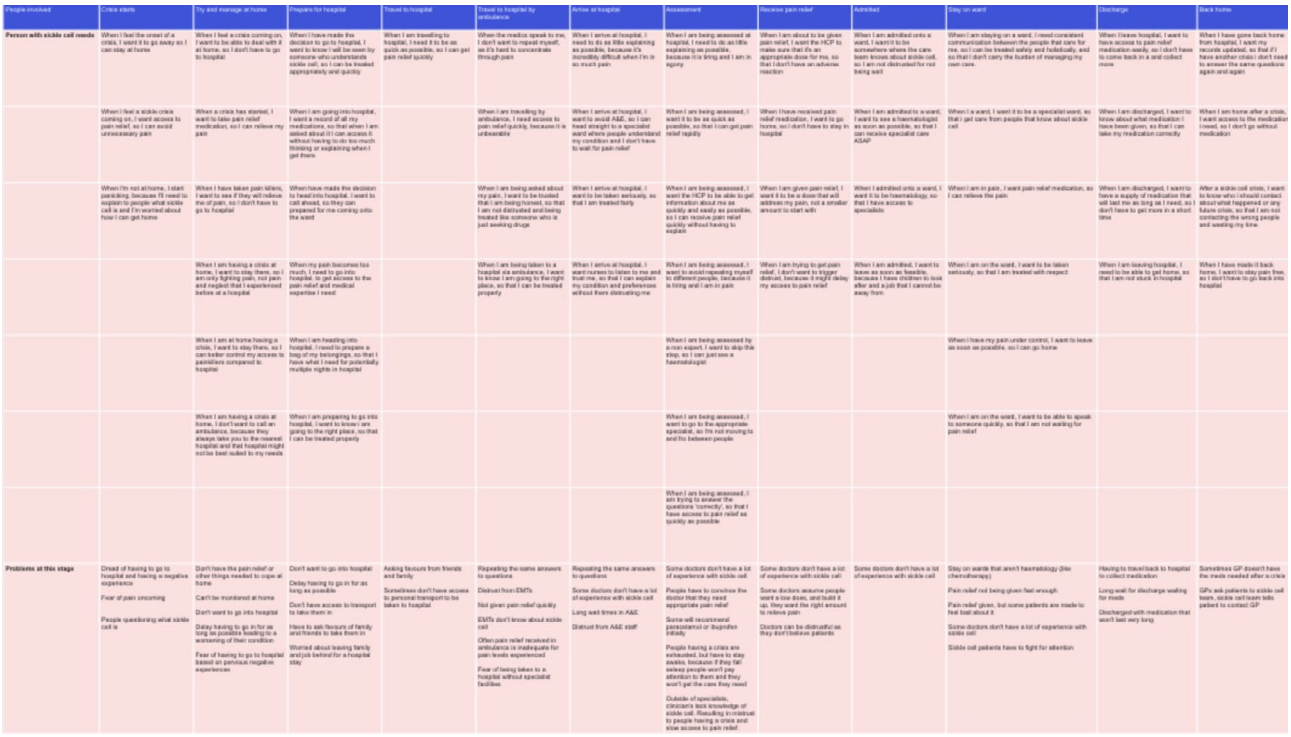
- further research with healthcare professionals to more deeply understand what enables and holds them back when treating someone during a sickle cell crisis
- further research with people with sickle cell who have less access to hospitals with specialised haemoglobinopathy services. Geographically, the people we spoke to were based in Bristol (or had a connection to Bristol Royal Infirmary) or the South East of England.

Analysis and synthesis of our user research

During the initial analysis and synthesis phase, we focused on identifying the important emergent observations from our research. We did this by:

- Recording, transcribing and note-taking at each of our interviews
- Refining and reviewing our notes from each interview, consolidating them all in one place
- Grouping and theming related statements from across all of the interviews
- Synthesising these groups into observations

We then distilled these observations into a set of clear user needs, and a summary of problems faced by people with sickle cell at each stage of their crisis experiences. You can view this summary here and in the appendix to this report.



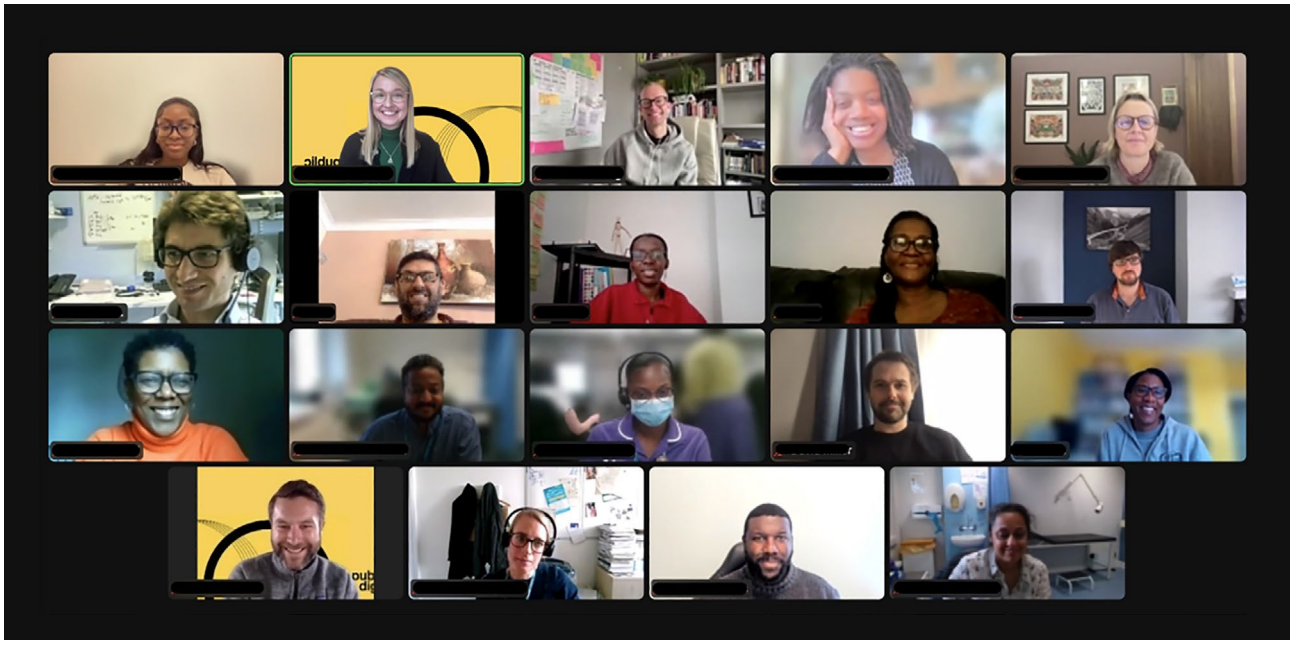
A screenshot of our synthesised user journey map representing the user needs and problems identified at each stage of a sickle cell crisis

Part 03: Prioritisation

The prioritisation phase was initially made up of a series of conversations across the team. It culminated in a productive and rich multidisciplinary, collaborative workshop where a wide range of people with intentionally different experiences, areas of expertise and relationships with sickle cell disease debated and discussed a set of four ideas that emerged from our research.

This workshop was attended by:

- People with lived experience of sickle cell, who either have sickle cell disease themselves or who help to care for people who do
- Healthcare professionals who specialise in sickle cell
- Healthcare professionals who are not expert in sickle cell, but are expert in other areas like A&E care, and General Practice - and who play an important role in caring for people with sickle cell disease
- People with experience of delivering digital services and technology in the NHS



A screenshot from our prioritisation workshop on Friday 11 November 2022

By bringing all of these different perspectives together, we were able to develop a robust appraisal of the ideas that emerged from our discovery. These were ideas that we believed might have potential to help people at the point at which they are experiencing a crisis.

We asked the workshop participants to focus on finding the weak spots in our ideas: What should we be concerned about? What might not work? What questions did our ideas spark? The point of doing this was to make sure that we don't waste time developing an intervention that isn't likely to work.

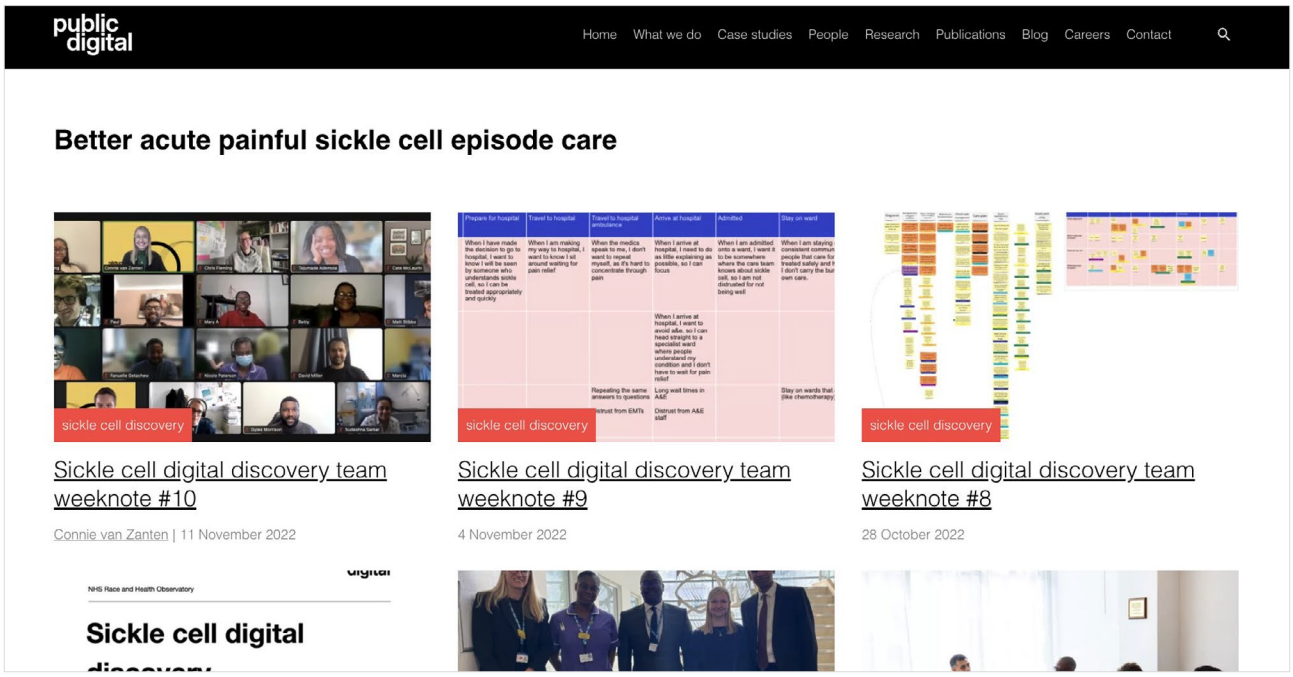
It is also important to note that many of the ideas we shared are not original. They may even already be implemented, albeit partially and imperfectly, in the health service today. They all come from the research we've been doing and the conversations we've been having with people with sickle cell disease, and healthcare professionals.

After setting the context and introducing the ideas for discussion, we split into two groups. Each group discussed the viability and potential impact of two ideas. These outputs were closely documented: you can see the details here.

Part 04: Working in the open and reporting

Working in the open

We committed to working in the open and each week we have published public weeknotes describing what we are doing and what we have learnt as we are going. These have been invaluable in helping us to meet and connect with potential supporters and collaborators for this work, and for generating interest from within the sickle cell community.



A screenshot of our weeknotes on the Public Digital website

Our interim report

We published an interim version of our report on 21 October 2022, which we shared via our public weeknotes.

Our first full draft

We published the first full draft of our report on 23 November 2022. We sought feedback on this draft during November and December 2022.

The final report

This is the final version of the report, published in January 2023.

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Our user research approach

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Our user research approach

This section of the report describes the activities that made up our user research and a brief reflection on what we found out. The next section shares the conclusions it led us to draw in terms of our observations and user needs.

Overall, our user research was made up of:

1. An evidence review
2. A digital landscape review
3. Interviews and user journey mapping

This work was in addition to numerous informal conversations and reading around sickle cell disease, services and advocacy.

Together, this led us to make a series of observations, and to identify a set of user needs.

Our evidence review

Purpose

One of the important aspects of this discovery was to make sure that we were building on research that has already been completed. Our evidence review was designed to understand and make sense of the challenges surrounding sickle cell care, and ground our research in what has been tried, proven and disproven in addressing those challenges.

Approach

To that end, we reviewed a number of different sources to gather literature and evidence related to acute painful sickle cell episodes:

1. Digital interventions: We researched key themes in respect of the use of digital interventions in the management of acute painful sickle cell episodes (predominantly technology and patient-focused). This work informed our research learning goals and user research interviews.

2. Clinical trials, randomised controlled trials, meta-analysis and systematic reviews:
   We developed an advanced PubMed search strategy, that resulted in broadly the following types of information:
   - Cochrane reviews of medicine and treatment specific interventions to improve acute painful sickle cell episodes
   - Reports of trials of drugs to improve acute painful sickle cell episodes (both drugs to reduce frequency of episodes and analgesics)
   - Reports of non-pharmaceutical interventions to improve acute painful sickle cell episodes (including different care pathways, and barriers and facilitators to care)

This review gave us useful oversight in a number of areas. There were three studies that have particularly supported and influenced our work:

- an indication of the barriers and facilitators to care during a crisis for healthcare professionals, which highlighted the potential of individualised pain plans and evidenced the importance of improving provider knowledge and mitigating provider bias.
- evidence of the impact of individualised pain plans (in children), which helps make the case for focusing on developing care plans in a way that they will be acted on.
- insight into a trial where others have used web and smartphone-based applications to improve pain self-management and functioning in youth (aged 12-18) with sickle cell disease. The results of this trial have not been published but we will be interested in its conclusions as they relate to day-to-day self-management of sickle cell pain.

3. We searched EThOS, the British Library's e-theses online service for thesis publications related to sickle cell, which surfaced 152 abstracts of which 15 seemed relevant to our work. This review gave us:
    - Evidence of racism in sickle cell care
    - Evidence of the link between deprivation, higher rates of readmission and in-patient mortality among those with sickle cell disease
    - Evidence and recognition of the often difficult relationship between sickle cell disease patients and healthcare professionals which has been found to prevent patients seeking medical assistance
    - Evidence to warrant pursuing different models of care for sickle cell services

Reflection

During a sickle cell crisis, the NHS does not provide sickle cell patients with a reliably good experience. Broadly this is because healthcare professionals:

- deprioritise and undermine sickle cell patient crisis pain, and subsequently frequently fail to give adequate timely analgesia;
- expose patients to negative/racist attitudes and an extreme lack of empathy;
- lack accountability when it comes to treating people with sickle cell;
- allow avoidable harm and even death to occur to patients.

This is not true of every healthcare professional, but unhappily these problems are extremely widespread.

In addition, during routine outpatient care, the NHS does not reliably provide adequate support to sickle cell patients in terms of accessing disease modifying therapies that reduce crisis frequency.

These poor experiences don't help patients adhere to treatment or encourage patient activation and self-management, and they similarly diminish trust, engagement and ultimately lead to poorer health outcomes.

With reference to the No-One's Listening report, our view of what constitutes specific barriers to timely analgesia during a crisis include:

- Low awareness of sickle cell among healthcare professionals and inadequate training
- Negative attitudes towards sickle cell patients
- Fear of the risk of administering significant quantities of analgesia
- Lack of compassion and empathy for the pain of people are from an ethnic minority

Ultimately, digital products, services, and ways of working hold some potential to make things better by reducing barriers to accessing care, putting information in the hands of patients - and healthcare professionals - enabling people to monitor and manage their symptoms and increasing accountability and trust between patients and healthcare professionals.

In practice this is best achieved with evidence-based, iterative, user-centred design. This potential hasn't been realised for healthcare professionals or patients yet.

Our digital landscape review

Purpose

The purpose of our digital landscape review was to understand what technology and products are already being used that have a meaningful impact on people with sickle cell during a crisis, and that have potential to be scaled.

Approach

There were a lot of different areas upon which we could focus, for example: specialist digital platforms (like those we started to identify in our evidence review), tools for pain management, tools for communication with healthcare professionals, and many more.

To make sure we focused on what is most important, and has the most impact, we were led by what we learnt in the user research. This resulted in us specifically reviewing what is available currently:

- To help with medication tracking
- To help with pain management
- That is specific to sickle cell disease
- In the space of digital care plans and treatment guidelines
- In the realms of wearable technology

We also heard about - but did not pursue - the role of non-specialist digital platforms like WhatsApp, which play a role in information sharing and linking up people with sickle cell disease. A number of participants cited the Sickle Cell Society's website as a useful source of information; no-one talked to us about communities on social media other than WhatsApp.

Reflections

Medication tracking and pain management

We reviewed medication tracking and pain management apps through a search of the Apple and Android App stores.

We found apps for pain management, of which the majority were for musculoskeletal conditions and none were specific to sickle cell disease. We also found generic pain apps that could be used by people living with sickle cell disease. We have done an initial appraisal of these apps but we would need to involve people living with sickle cell disease and healthcare professionals to achieve a more detailed review of their relevance and acceptability. We are also conscious that more apps may mean more work for patients. What's more, in the words of one of the sickle cell patients who we commissioned to review this report

> "The issue is not us being able to track our pain. The issue is doctors not treating and tracking our pain right."

Report reviewer

Apps related to sickle cell disease specifically

The sickle cell disease specific apps we identified appeared to be highly variable, generally had a poor user interface, and did not appear to be widely downloaded or recently updated.

For example:

- Voice Crisis Alert V2 on the App Store - app for sickle cell patients currently enrolled in the Voice Crisis Alert Study, which is looking into supporting self-management
- SCD Toolbox on the App Store - interactive resource (app) to offer up-to-date guidelines and specialist accessibility for sickle cell patient care
- Sickle-O-Scope on the App Store - a daily diary of illness and disease symptoms to sickle cell disease patients

It is worth noting that it does appear that non-specific sickle cell disease apps are being used. For example, to help people remember to stay hydrated and for mindfulness. However there doesn't appear to be anything available commercially that is being used widely in the sickle cell space.

Digital care plans

As part of our digital landscape review, we spent some time appraising the digital care plan landscape. We did this to better understand how existing solutions support people living with sickle cell disease during acute painful sickle cell episodes.

We considered Summary Care Records and their potential to be used to store sickle cell care plans. Summary Care Records hold potential because they already exist and are in use, and seem well placed to support digital personalised care plans. However, in practice this potential is limited because they don't update in a timely manner, and they are not yet easily and readily accessible..

We considered the National Haemoglobinopathy Register (NHR), which is a database of patients with red cell disorders, and the National Institute for Health and Care Excellence (NICE) guidelines for managing acute painful episodes in hospital. There is further work to do to increase our understanding of the extent to which healthcare professionals are aware that these tools exist, and of their usability. However, we do know that the NHR is not accessible to patients and, anecdotally, we have heard concerns from healthcare professionals that the NHR is not fit for purpose. We've also heard that both the NHR and the NICE guidelines are not tools that healthcare professionals are readily accessing. This is an area which we would investigate more robustly in a further phase of work.

Finally, we considered Coordinate My Care (CMC), a digital NHS service that allows end of life care plans to be created and shared digitally across London between all healthcare professionals to ensure they are connected at all times. Our initial research indicates that this model holds potential for digital personalised care plans, in terms of the patient needs it seeks to address. Namely, facilitating coordinated care across healthcare professionals to enable patient access to appropriate and patient-informed care.

Wearable technology

During our research, we heard about people using wearable technology to help them to manage their sickle cell.

Notably, we came across Sanius Health, a health technology organisation working to support people with rare and chronic diseases, including sickle cell disease. They are developing an online community for people with chronic diseases, and they are researching how to help people improve their own wellbeing by giving them personalised predictions and instant access to their full medical history. This is made possible by users inputting wellbeing data into an app and through continuous biometric tracking via a smartwatch. This is live research. We are interested to see the results of this research, and were keen to discuss perceptions of the value of wearable technology with people with sickle cell and those that care for them, which we did in our prioritisation workshop.

Reflection

Overall, we were struck by the relatively small amount of technology and web or app-based tools that exist which are specific to sickle cell disease. Other than the concept of personalised, digital care plans, we did not find anything which currently exists which appears to be well designed and/or widely used which would meet the needs of people experiencing acute painful episodes.

Interviews and user journey mapping

People involved	Crisis starts	Try and manage at home	Prepare for hospital	Travel to hospital	Travel to hospital by ambulance	Arrive at hospital	Assessment	Receive pain relief	Admitted	Stay on ward	Discharge	Back home
Person with sickle cell needs	When I feel the onset of a crisis, I want it to go away so I can stay at home	When I feel a crisis coming on, I want to be able to deal with it at home, so I don't have to go to hospital	When I have made the decision to go to hospital, I want to know I will be seen by someone who understands sickle cell, so I can be treated appropriately and quickly	When I am travelling to hospital, I need it to be as quick as possible, so I can get pain relief quickly	When the medics speak to me, I don't want to repeat myself, as it's hard to concentrate through pain	When I arrive at hospital, I need to do as little explaining as possible, because it's incredibly difficult when I'm in so much pain	When I am being assessed at hospital, I need to do as little explaining as possible, because it is tiring and I am in agony	When I am about to be given pain relief, I want the HCP to make sure that it's an appropriate dose for me, so that I don't have an adverse reaction	When I am admitted onto a ward, I want it to be somewhere where the care team knows about sickle cell, so I am not distrusted for not being well	When I am staying on a ward, I need consistent communication between the people that care for me, so I can be treated safely and holistically, and so that I don't carry the burden of managing my own care.	When I leave hospital, I want to have access to pain relief medication easily, so I don't have to come back in a and collect more.	When I have gone back home from hospital, I want my records updated, so that if I have another crisis I don't need to answer the same questions again and again
	When I feel a sickle crisis coming on, I want access to pain relief, so I can avoid unnecessary pain	When a crisis has started, I want to take pain relief medication, so I can relieve my pain	When I am going into hospital, I want a record of all my medications, so that when I am asked about it I can access it without having to do too much thinking or explaining when I get there		When I am travelling by ambulance, I need access to pain relief quickly, because it is unbearable	When I arrive at hospital, I want to avoid A&E, so I can head straight to a specialist ward where people understand my condition and I don't have to wait for pain relief	When I am being assessed, I want it to be as quick as possible, so that I can get pain relief rapidly	When I have received pain relief medication, I want to go home, so I don't have to stay in hospital	When I am admitted to a ward, I want to see a haematologist as soon as possible, so that I can receive specialist care ASAP	When I a ward, I want it to be a specialist ward, so that I get care from people that know about sickle cell	When I am discharged, I want to know about what medication I have been given, so that I can take my medication correctly	When I am home after a crisis, I want access to the medication I need, so I don't go without medication
	When I'm not at home, I start panicking, because I'll need to explain to people what sickle cell is and I'm worried about how I can get home	When I have taken pain killers, I want to see if they will relieve me of pain, so I don't have to go to hospital	When have made the decision to head into hospital, I want to call ahead, so they can prepared for me coming onto the ward		When I am being asked about my pain, I want to be trusted that I am being honest, so that I am not distrusted and being treated like someone who is just seeking drugs	When I arrive at hospital, I want to be taken seriously, so that I am treated fairly	When I am being assessed, I want the HCP to be able to get information about me as quickly and easily as possible, so I can receive pain relief quickly without having to explain	When I am given pain relief, I want it to be a dose that will address my pain, not a smaller amount to start with	When I admitted onto a ward, I want it to be haematology, so that I have access to specialists	When I am in pain, I want pain relief medication, so I can relieve the pain	When I am discharged, I want to have a supply of medication that will last me as long as I need, so I don't have to get more in a short time.	After a sickle cell crisis, I want to know who I should contact about what happened or any future crisis, so that I am not contacting the wrong people and wasting my time
		When I am having a crisis at home, I want to stay there, so I am only fighting pain, not pain and neglect that I experienced before at a hospital	When my pain becomes too much, I need to go into hospital, to get access to the pain relief and medical expertise I need		When I am being taken to a hospital via ambulance, I want to know I am going to the right place, so that I can be treated properly	When I arrive at hospital, I want nurses to listen to me and trust me, so that I can explain my condition and preferences without them distrusting me	When I am being assessed, I want to avoid repeating myself to different people, because it is tiring and I am in pain	When I am trying to get pain relief, I don't want to trigger distrust, because it might delay my access to pain relief	When I am admitted, I want to leave as soon as feasible, because I have children to look after and a job that I cannot be away from	When I am on the ward, I want to be taken seriously, so that I am treated with respect	When I am leaving hospital, I need to be able to get home, so that I am not stuck in hospital	When I have made it back home, I want to stay pain free, so I don't have to go back into hospital
		When I am at home having a crisis, I want to stay there, so I can better control my access to painkillers compared to hospital	When I am heading into hospital, I need to prepare a bag of my belongings, so that I have what I need for potentially multiple nights in hospital				When I am being assessed by a non expert, I want to skip this step, so I can just see a haematologist			When I have my pain under control, I want to leave as soon as possible, so I can go home		
		When I am having a crisis at home, I don't want to call an ambulance, because they always take you to the nearest hospital and that hospital might not be best suited to my needs	When I am preparing to go into hospital, I want to know I am going to the right place, so that I can be treated properly				When I am being assessed, I want to go to the appropriate specialist, so I'm not moving to and fro between people			When I am on the ward, I want to be able to speak to someone quickly, so that I am not waiting for pain relief		
							When I am being assessed, I am trying to answer the questions 'correctly', so that I have access to pain relief as quickly as possible					
Problems at this stage	Dread of having to go to hospital and having a negative experience Fear of pain oncoming People questioning what sickle cell is	Don't have the pain relief or other things needed to cope at home Can't be monitored at home Don't want to go into hospital Delay having to go in for as long as possible leading to a worsening of their condition Fear of having to go to hospital based on pervious negative experiences	Don't want to go into hospital Delay having to go in for as long as possible Don't have access to transport to take them in Have to ask favours of family and friends to take them in Worried about leaving family and job behind for a hospital stay	Asking favours from friends and family Sometimes don't have access to personal transport to be taken to hospital	Repeating the same answers to questions Distrust from EMTs Not given pain relief quickly EMTs don't know about sickle cell Often pain relief received in ambulance is inadequate for pain levels experienced Fear of being taken to a hospital without specialist facilities	Repeating the same answers to questions Some doctors don't have a lot of experience with sickle cell Long wait times in A&E Distrust from A&E staff	Some doctors don't have a lot of experience with sickle cell People have to convince the doctor that they need appropriate pain relief Some will recommend paracetamol or ibuprofen initially People having a crisis are exhausted, but have to stay awake, because if they fall asleep people won't pay attention to them and they won't get the care they need Outside of specialists, clinician's lack knowledge of sickle cell. Resulting in mistrust to people having a crisis and slow access to pain relief.	Some doctors don't have a lot of experience with sickle cell Some doctors assume people want a low dose, and build it up, they want the right amount to relieve pain Doctors can be distrustful as they don't believe patients	Some doctors don't have a lot of experience with sickle cell	Stay on wards that aren't haematology (like chemotherapy) Pain relief not being given fast enough Pain relief given, but some patients are made to feel bad about it Some doctors don't have a lot of experience with sickle cell Sickle cell patients have to fight for attention	Having to travel back to hospital to collect medication Long wait for discharge waiting for meds Discharged with medication that won't last very long	Sometimes GP doesn't have the meds needed after a crisis GPs ask patients to sickle cell team, sickle cell team tells patient to contact GP

A screenshot of our synthesised user journey map representing the user needs and problems identified at each stage of a sickle cell crisis. You can view the map here, or read the list in the appendix.

Purpose

The purpose of our one-to-one research with people with sickle cell was to centre and elevate the voices and experiences of people with sickle cell in this work, and to develop a deep understanding of what happens when people experience a crisis.

Approach

We ran nine interviews with people from three sickle cell services, most of whom had also used sickle cell services in other parts of the UK. In these interviews, we asked participants to talk about their day-to-day experiences with sickle cell disease, and we mapped out their most recent experience of a crisis.

Reflection

This research led us to make a set of observations about the experiences that people with sickle cell have when they are having a crisis. We will describe and evidence these observations in more depth in the next chapter of this report.

1. Sickle cell patients often have additional needs which are not picked up on by healthcare professionals in the moment of crisis, meaning they must stay alert and monitor the treatment they are receiving.

2. Care plans are used inconsistently, and vary widely in their format and in how they are interpreted by patients and healthcare professionals. This means they do not currently result in consistently good care, or improve accountability and auditability of care and supporting research.

3. Tracking the medication a sickle cell patient is taking is an arduous, daily task, and it becomes particularly difficult in the context of a painful crisis.

4. People with sickle cell disease who are experiencing a crisis regularly have poor experiences with ambulance care and in A&E and avoid seeking professional help for as long as possible.

5. Directly accessing care by sickle cell nurses or similar specialist care teams can completely change the experience of a crisis for the better.

6. There is a stark imbalance between the level of mistrust people with sickle cell face from healthcare professionals, and the simultaneous pressure on them to manage much of their own care.

7. There is a persistent lack of communication and collaboration across healthcare professionals in hospitals and across different settings, which results in an administrative burden for people with sickle cell, and contributes to poor experience and treatment when in crisis.

8. Different people would like a different level of input from healthcare professionals in managing their condition day-to-day, and when they are in crisis.

9. Outside of specialists, clinicians' lack knowledge of sickle cell. This results in mistrust of people having a crisis and slow access to pain relief.

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Our observations

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Our observations

Our observations are split into two categories:

- A prioritised set of observations, selected for their relevance to what happens when a person with sickle cell disease is having a crisis
- A further set of observations which we think are useful and important but haven't focused on during the discovery.

Instead, we're capturing and sharing them in the hope that they can be of benefit to others working in this space.

Observations related to what happens during a crisis

01 Sickle cell patients often have additional needs which are not picked up on by healthcare professionals in the moment of crisis, meaning they must stay alert and monitor the treatment they are receiving.

We heard evidence from numerous user research participants of times when they have had to stop a healthcare professional from giving them certain types of pain relief, or treatment.

> "Too much morphine can make me stop breathing…I have to ask them 'how much is that?'. I have to be conscious, I have to prompt them."
>
> **User research participant**

> "The hospital needs to be aware of this [my details and history] when I am being treated so that I don't get given the wrong medicines…I have diabetes as well, and this is crucial for them to know."
>
> **User research participant**

This is dangerous, and it translates into additional stress and anxiety for people who are experiencing a crisis. It also contributes to a pervading sense of not feeling important, or respected. We believe there is an opportunity to explore how to make this information more readily available, and relieve the burden on the person who is experiencing a crisis.

02 Care plans are used inconsistently, and vary widely in their format and in how they are interpreted by patients and healthcare professionals, meaning they do not currently result in consistently good care.

We heard mixed responses when we asked people about care plans. Some had never heard of them, some didn't know if they had one. One participant had developed one with their consultant recently, which they have used once. One participant has one which is iterated in collaboration with their haematologist after each crisis.

> "The care plan was created with feedback from me. So it's not like she kind of went off and created it…and it was in development after every hospital admission… [My haematologist] would say how was A&E? How was it coming through ED? What changed? What was different this time? What didn't work for for you? What do you think worked for you?…So I've used it, and I've usually given it to the ambulance crew. They've actually started to ask me now and it's so easy."

User research participant

Others had received credit-card sized cards in the post, which they thought might be care plans and which they thought came from their local sickle cell service. This was true, but they weren't sure that was the case. They had to fill the cards out with important personal information themselves. We observed that these cards were more akin to statements of fact about a person, rather than a personalised plan for how to treat them in crisis. People's perception of the usefulness and validity of these cards were mixed.

We also heard mixed views on how care plans are used, when they exist. Some people find them to be a useful way of sharing information with healthcare professionals. Others do not.

> "My care plan is fine - it's more about getting the caregivers to actually listen to you… It would be easier if there was an e-element, so I could get it up on an app or something. There's one thing having a physical copy. If anyone and everyone can have access to it then it can easily be updated every time."

User research participant

One participant felt that sometimes their care plan is followed too rigidly, meaning that the ultimate goal, to manage their pain, takes longer to achieve.

> "It has some disadvantages as well, because sometimes some, like nurses, for example, will be super rigid about it, and they will not want to give you anything, you know, outside of what's in there."

User research participant

This concern was echoed by one of the healthcare professionals we spoke to.

> "The goal is to get on top of each individual's pain - so clinicians still need to think, in the moment. The uncertainty is you don't know how the patient will respond to pain or pain management"

Healthcare professional

On balance, we believe that there is potential in digital, personalised care plans that would be worth exploring further as a way of relieving the pressure on the individual experiencing a crisis. We would like to understand whether or not they improve health outcomes for patients, where poor outcomes include avoidable death and comorbidity, frequency of sickle cell crisis, and negative patient-reported outcome measures. In the future, we think there is an opportunity to look at the success of care plans used in other conditions to identify what has and hasn't worked e.g. dementia.

03 Tracking the medication a sickle cell patient is taking is an arduous, daily task, and it becomes particularly difficult in the context of a painful crisis.

Many of our participants talked to us about the effort it takes to keep track of their medication, and we heard about many different techniques for doing so. Lots of people with sickle cell rely on family members to help them with their medication.

All participants remarked how difficult it is to remember what you've taken, particularly when you're in pain. At the point of crisis, the healthcare professionals treating you need to know what you take regularly, and what you have already taken for the crisis pain.

> "So quite often, they'll ask you what medications are you on? And I just can't talk at that point."
>
> **User research participant**

> "When it comes to painkillers it's hard to manage that, hard to keep track of those, you do get a bit loopy and out of it, to remember what time you took it is impossible. Someone has to manage it for me - usually my mum. Or I'll take too much or not enough."
>
> **User research participant**

> "I've got to take all the medication I'm on [to hospital], I'm keeping hold of medicine boxes - just in case…I've got a cupboard, it's just for me"
>
> **User research participant**

> "One of the things I really, really hate, is to constantly repeat this while you're screaming and crying in agony…If the first person took it down, and put it on the system, so the next person that comes to see us [has that information already]."
>
> **User research participant**

We also heard a positive report of monitoring prescriptions via an app that both the patient and GP have access to, which made the patient feel they were being better cared for. We are interested in exploring the extent to which this problem could be resolved or eased via a digital intervention.

04 People with sickle cell disease who are experiencing a crisis regularly have poor experiences with ambulance care and in A&E and avoid seeking professional help for as long as possible.

All of our research participants were unanimous in their desire to avoid going to hospital for as long as possible when they are having a crisis. Where there was variation was in people's threshold for when they feel that hospital is unavoidable.

The reasons cited for avoiding going to hospital were varied. Not many people enjoy going to hospital. For some of the people we spoke to, it's simply more comfortable to stay at home. For some, the reasons are more negative.

> "I'm fighting for access to the things that I need - I have to fight to get the attention of the nurse - for six hours, I press the bell 100 times, no-one comes to you. Then they come and say let me give you some paracetamol. You get exhausted, tired, the entire experience is very negative…They always try to make you take paracetamol and ibuprofen. I didn't come here for that, I've got that in my bag… At least at home I'm just fighting the pain - not the neglect."
>
> **User research participant**

One of the people we spoke to, a parent, shared:

> "I considered going in, but I couldn't…I've got two kids, a job, my partner works nights most of the time. There was no-one to be in with the kids."
>
> **User research participant**

We heard reports of healthcare professionals doubting and questioning pain levels:

> "[I'm] speak[ing] to mum on the phone and being accused of being 'fine'."
>
> **User research participant**

Waiting for long periods of time for pain relief:

> "Getting pain relief is really difficult…I didn't get the painkillers needed. Ended up getting one-to-one care because I didn't get my pain meds."
>
> **User research participant**

Being moved in and out of different wards:

> "I have a lot of anxiety - if I do have to go in, I don't know where I'm going to end up - so I'd rather not [go in]."
>
> **User research participant**

"[I was] moved from the haematology ward to chemo ward as there weren't enough beds in haematology…After I was yo-yoed around a bit I was discharged from the chemo ward."
User research participant

"There is never enough space in the haematology ward."
User research participant

We heard from some people that their experiences of emergency care were negative in that they were perceived as being drug seekers.

"With ambulance and A&E they can also see you as a drug seeker, or not really believe you're in as much pain as you're saying." **User research participant**

We also heard that ambulances don't take people straight to haematology wards, even when they could. They will only take them to A&E, and quite possibly to a hospital that doesn't have a haematology ward.

"Ambulance crew insist on taking to A&E as they don't feel comfortable taking (me) to haematology."

What is clear is that people's experiences in hospitals vary widely. However, there are consistent negative themes around being made to feel unimportant, not being trusted, and being moved around a lot.

This was clearly evidenced in the No One's Listening Report, and we believe a radical reformation of the way sickle cell services are delivered will be necessary to truly tackle this problem. One of our user research participants put it very clearly:

"It's because of the way the NHS is run - [the] ER experience is not designed for us and our frequency of visits."
User research participant

05 Directly accessing care by sickle cell nurses or similar specialist care teams can completely change the experience of a crisis for the better.

"[It's] frustrating not to be able to skip all these steps and just see the haematologist."
User research participant

"If I'm not at home [when a crisis starts] I'm panicking. I'll need to explain sickle cell to people, how am I going to get home?."
User research participant

"It helps a lot when the nurses recognise you. I feel comfortable that I'm in the right place and they know what they're doing"

User research participant

"Not having to go to A&E is a big deal for me…Makes me feel relief, and happy… There was a bed ready… They were on top of it right away"

User research participant

"They said whenever I'm in pain I should call that number…[When I arrived] I had pain relief before I'd even completed the story."

User research participant

This serves as a useful counterpoint to the previous observation about the challenges people experience in ambulances and A&E. Being able to access sickle cell experts directly makes a significant difference to how people feel about accessing help.

06 There is a stark imbalance between the level of mistrust people with sickle cell face from healthcare professionals, and the simultaneous pressure on them to manage much of their own care.

People with sickle cell are constantly faced with mistrust and a lack of compassion from healthcare professionals. This is not new insight.

"I remember a healthcare professional asking me 'why are you crying?'"

User research participant

"It's my body and I know what would happen to me…I don't think doctors understand me. I know they spend years training and they see lots of patients, but I've always felt they don't really listen to what I'm saying because they have a set pattern for what they want to do with you."

User research participant

"[I was] told by the nurse that cancer patients are more important than sickle cell patients."

User research participant

Within this, there is a tension between the widely recognised expertise of people with sickle cell to understand what they need when they are having a crisis, in contrast with the level of mistrust they receive from healthcare professionals when they are in crisis.

One of the impacts of this is that people with sickle cell are disproportionately expected to be able to manage aspects of their care:

"When I go into hospital or I go in to have a blood test…They ask me: What blood tests are we doing today? When I went for the last one, they didn't take the right blood tests. This time I took a photo on my phone."

User research participant

While simultaneously not being trusted in the moment they are being treated in crisis.

> "You're the expert in your health - but only with certain things. When I'm telling you [a healthcare professional] this pain I'm feeling is not sickle pain, I know if it's infection pain or sickle cell…[They tell me] 'Well your infection markers aren't up, and your temperature isn't up." I've fainted in hospital going to the toilet, I've deteriorated really quickly…I did tell you. I just wish that there was a note there to say that, just to highlight certain things...Don't just brush it off."
>
> **User research participant**

This is deeply frustrating for people with sickle cell disease. We are keen to explore the extent to which we could ease this problem with digital interventions, for example an individual, shared (between healthcare professionals and people with sickle cell) care plan.

07 There is a persistent lack of communication and collaboration across healthcare professionals in hospitals and across different settings, which results in an administrative burden for people with sickle cell, and contributes to poor experience and treatment when in crisis.

Navigating the healthcare system is the patient's burden - many of the people we spoke to cited communication failures and breakdowns as a significant source of frustration and anxiety.

> "That's why I don't call an ambulance, because they always take you to the closest hospital…I live quite far - I choose to go [a different hospital that is further away] - easier than having to start my story all over again."
>
> **User research participant**

> "My GP [doesn't] know anything about sickle cell disease. And I don't think that it's their fault. I just think that it's a specialist condition... But sometimes they have to be the first point of contact."
>
> **User research participant**

> "It was over a week that I was being yo-yoed [while in crisis]. [I had to] act as the go between between the GP and the sickle cell team. [I was] pushed away to a GP, pushed back to sickle cell team, no-one had answers. I want to turn somewhere I won't be yo-yoed away."
>
> **User research participant**

> "Also between GPs and the hospital. Either of them won't have an update on something. Our memory isn't always that good, our concentration as well. They'll ask what I had on my last inpatient stay, I struggle to remember. Even with the GP you know, to have...`Because sometimes I'll go to the GP whether it's about my sickle cell or chronic pain - the hospital lowered my dose of gabapentin, they didn't tell the GP…I wish there was more communication between the medical staff."
>
> **User research participant**

We also heard about challenges in communication within the same hospital setting, and the same crisis.

> "The patients have to do the comms between the different parts of the services."
>
> **User research participant**

> "If [the information about me] was all in one place, I wouldn't have to dread the curtain being open"
>
> **User research participant**

> "[I had to] get [my sickle cell nurse] to explain to the nurse [taking my blood tests]."
>
> **User research participant**

This only worked because the participant's sickle cell nurse happened to work upstairs from where the blood tests were being taken on this occasion.

Another participant shared a positive experience they'd had with their GP when their GP was playing a more active role in their care:

> "Being able to monitor opioid intake as it can be difficult when you're in pain…[When my GP could see what medication I was ordering, via an app] it felt like I was being more cared for…I know how easy it can be to fall into the spiral of 'Oh, I need something stronger than paracetamol'…You can find yourself depending on it to function…It gave me a bit more control…I'd rather have someone watching and seeing what I'm ordering and being able to say, 'Okay do we need to review how you're managing your pain?'"
>
> **User research participant**

We also heard about opportunity for collaboration with other specialties, for example haematology teams and acute pain teams:

> "[The] problem would benefit from expertise more widely, from different specialities [like the acute pain team]. I don't want to have to give high dose opioids to manage that pain, there must be another way."
>
> **Healthcare professional**

We believe there is lots of potential to explore how digital interventions - in the broadest sense, from online care plans to multidisciplinary ways of working - could help address these problems.

08 Different people would like a different level of input from healthcare professionals in managing their condition day-to-day, and when they are in crisis.

Some people will do everything within their power to self-manage their sickle cell disease as much as possible. For many, this is because they have had such poor experiences that they opt to stay at home until the pain is unbearable.

> "[I'm] really asking myself if I have to go to the hospital. It takes me longer to make that decision now…[My] pain level [is] 9 or 10 for 48 hours before making a decision."
>
> **User research participant**

Some feel that - despite the challenges - being in hospital and under that kind of care is for the best.

> "I feel comfortable that I'm in the right place and they know what they're doing."
>
> **User research participant**

> "They're not going to let me go until I feel better - and I'm fine with that."
>
> **User research participant**

Some talked about the need to be monitored, and the extent to which that can be done from home.

> "It makes me feel so frustrated because I can't be monitored at home."
>
> **User research participant**

> "I can monitor oxygen levels which I've got a watch for now. If I'm feeling a little bit funny in myself, I can see [check my levels]. That's really good."
>
> **User research participant**

Much like the previous observation, this seems like a problem that could be explored and possibly addressed with different digital interventions - from wearable technology, to a redesigned sickle cell service operating model.

09 Outside of specialists, clinicians' lack knowledge of sickle cell. This results in mistrust of people having a crisis and slow access to pain relief.

We heard from multiple user research participants that they felt mistrusted by specialists who didn't know about sickle cell and therefore had to prove their pain to get relief.

> "I've had experiences where I'm sharing a room, part of the ward, with other people with other illnesses like sickle cell - sickle cell is not seen as important with people like cancer - things like ringing the bell and asking for medication. You'll be waiting for ages. There's not the same quality of care for us as there is towards people with cancer."

User research participant

> "Even if they [healthcare professionals] don't physically say it, you can tell that they think we're just there for the pain meds. It happens more often than not. It's weird cos I'm quite - I suffer with anxiety - so I'll be anxious of the nurses reaction to request pain meds, puts you off wanting ask for more"

User research participant

Healthcare professionals also talked about the importance of being able to access specialists and specific guidance directly when treating someone in crisis.

> "[We have a] newly developed sickle cell A&E guideline - accessible via mobile phone [via] an app to which the hospital subscribes. [Sickle cell crises are] not a common presentation - so much so that people may not even have awareness of it…The haematology department approached us - 'We'd like to develop a guideline - are you interested to collaborate?'...In this era of digitalism I think it's the way forward."

Healthcare professional

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User needs

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User needs

Well-understood and clearly stated user needs are the foundation of good service design. We have used the research we have conducted to articulate the needs of people with sickle cell, taking into account both planned and unplanned events that people experience and have to deal with in their lives. In addition, we have considered the needs people with sickle cell have at each stage of a sickle cell crisis, to indicate the necessary functional elements of a sickle cell crisis service.

We have captured both the emotional and functional needs of the people we have spoken to. Emotional needs come from problems like not being trusted by healthcare professionals during a crisis. Functional needs are practical challenges like arranging getting to a hospital during a crisis when in pain.

Having an in-depth understanding of people's emotional needs helps us design the functional elements of a service better.

Emotional needs of people with sickle cell:

- When I'm having a crisis, I need to be trusted that I am the expert in my condition, because I live it every day.
- When I'm having a crisis, I need to have confidence in the people caring for me, so that I know I am receiving appropriate care.
- When I am having a crisis, I want to be treated fairly, like everybody else, so that I am not judged, looked down upon or discriminated against.
- As a person with sickle cell disease, I need to understand how my care will change when I transition from child to adult services, so that I can avoid the trauma of finding myself in an adult ward with a new team who don't know me.

Needs during specific stages of a crisis

To identify and articulate these needs, we divided up the stages of a sickle cell crisis as described to us by people living with sickle cell. They are

1. Crisis starts
2. Try and manage at home
3. Prepare for hospital
4. Travel to hospital
5. Travel to hospital by ambulance
6. Arrive at hospital
7. Assessment
8. Receive pain relief
9. Admitted to hospital
10. Stay on ward
11. Discharge
12. Back home

For each stage we have put needs we have heard from our participants as well as problems described at each stage. You can read the user needs and problems identified here, or written as a list in the appendix.

Further observations

These are a set of additional observations that we made during our research, which we weren't able to focus on during our discovery. We want to share them for the benefit of others who are working towards improving sickle cell care.

- Preparing young people for adult care can be a trauma inducing experience when done badly. For three of the participants we spoke to, their first interaction with the adult service was when they were in crisis.

  Participants talked to us about how different the atmosphere is on a children's ward in comparison to e.g. an adult's cancer ward, or an adult's haematology ward. They described it as jarring moving between those two settings. They talked about how hard it was when their first interaction with the adult service was when they were having a crisis and they suddenly found themselves on an adult's ward where everything works very differently. It's much less friendly and all of a sudden people didn't seem to believe them. Participants talked about not understanding where they were or what was happening, or knowing who anyone was. Beyond all the issues we already know about, when a person is not introduced properly and onboarded onto the adult service outside of crisis, in a routine way, it's particularly unpleasant when they first start using it.

  We propose that addressing and improving the transition phase from paediatric to adult services could have a significant impact on people with sickle cell, for the better.

- People with sickle cell and those who care for them benefit from sharing and listening to each other's experiences. Those without that community feel lonely and isolated, and miss out on useful information that would help them manage their condition and navigate day-to-day life with sickle cell. While we think there is enormous opportunity for digital to support this, it is less relevant to the experience in the moment of crisis, which is our focus.

- People's experiences with their GPs are mixed. Those that have better experiences are those whose GPs work with their sickle cell team, and who take a more active role in their care.

- Many people with sickle cell are forced to rely on their family and friends for care and support, including transport and encouragement to go to hospital. Those that don't have this support structure around them suffer in additional ways.

- Many of the people that we spoke to shared that they haven't had the opportunity to speak up and talk about their experiences before, especially in a setting where they are not currently having a crisis. These people similarly reported that they appreciated the opportunity to do so.

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Digital interventions

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Digital interventions

Innovation is not invention

This section of the report talks about possible solutions to the challenges we identified during the discovery. Many are based on existing technologies that people may recognise. They all came from our research, and exist already in some form. Our central thesis, however, is that it is the way these technologies are designed and implemented that is fundamental to their potential to make a difference. To truly realise the potential of any of these ideas, it will be necessary to take a design-led, user-centred, evidence-based approach to designing, testing and delivering them.

Developing these ideas

We debated and refined these ideas at our prioritisation workshop, where we benefited from a multidisciplinary and collaborative appraisal of their potential for impact, viability and scalability. What follows is a detailed overview of what we learnt and the conclusions we reached.

The ideas that emerged from our research, and which we asked participants to discuss and debate, were as follows:

- **Personalised, digital care plans** for people with sickle cell disease, to instruct people who are unfamiliar with sickle cell disease in how to address a person's pain quickly, build trust between patient and healthcare professionals, and increase professional accountability.
- **How to design useful sickle cell care guidelines**, developed in collaboration between sickle cell experts and A&E specialists, for use in emergency settings and during a crisis, to provide healthcare professionals with good practice for the management of a crisis.
- **Using technology to track medication**, to reduce the in-the-moment burden on people experiencing a crisis to remember and report how they manage their pain on a daily basis, and what they've taken so far to manage their crisis.
- **Using wearable technology to monitor relevant stats** e.g. oxygen saturation levels, blood pressure, pulse and temperature, to help people with sickle cell disease to understand if they are going into/are in crisis and to provide information to healthcare professionals about people's stats in the run up to a crisis.

Below, we describe each of these ideas in more detail, covering their:

- Context
- Intended outcomes
- Our hypotheses
- How it might work
- How we might test it
- Where this idea came from

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Personalised, digital care plans

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Personalised, digital care plans

Context

Care plans are a familiar concept within the NHS, and they exist already for multiple conditions. They are designed to provide tailored care instructions for a specific patient's needs. There is already technology in place to make care plans accessible, for example, MyCarePlan.

All sickle cell patients should have a care plan that has been co-produced between the patient, primary care and specialist multidisciplinary teams. This is mandated in the specialised commissioning service specification. It is also already possible for an individual's care plan to be uploaded into the National Haemoglobinopathy Registry (NHR). However, it is not currently the case that every sickle cell patient has a care plan and the NHR is not consistently used.

As we have described, there isn't currently a singular approach to sickle cell care plans, so the term means different things to different people and, when a person does have a care plan, their experience of how it's used varies widely. Across the course of our research, we learnt about the myriad ways in which care plans are currently not used and are often dismissed.

Intended outcomes

The intention of designing and testing personalised digital care plans is:

- to instruct people who aren't expert in sickle cell disease in managing pain, for example by administering appropriate levels of analgesia quickly in the moment of crisis;
- to build trust between patient and healthcare professionals;
- to increase professional accountability i.e. to provide a mechanism whereby access to and/or use of the care plan is recorded.

Our hypothesis

We believe that a personalised, digital care plan will result in better experiences and outcomes for people with sickle cell when they are experiencing a crisis.

In order to be effective, we expect it will need to be:

- co-produced by a multidisciplinary team, including patients, GPs, A&E staff, paramedics and haematologists so that all potential perspectives and needs are accounted for, thereby reducing barriers to use;
- available via the internet and offline, to both the patient and healthcare professionals in the moment of crisis, to increase accessibility and trust in the tool;
- regularly iterated in a collaborative way e.g. through outpatient appointments with a patient's haematologist, after a crisis has occurred so that the tool remains effective and up to date for the person with sickle cell;
- capable of recording that a healthcare professional has seen it during the moment of crisis, to increase professional accountability around how it is used.

We believe the most important questions to answer - with the exception of measuring the impact of the care plan - will be:

- What does the care plan need in order to have authority?
- What will it take to make a clinician take it seriously?
- How can a care plan account for a clinician's lack of experience with and awareness of a sickle cell crisis?

These questions will be best answered through a process of co-design, prototyping and testing.

Personalised, digital care plans will not solve all of the complex issues surrounding sickle cell care, but we do hypothesise that they will meaningfully contribute to improving people's experience of acute care. We have both qualitative (from our user research interviews) and quantitative data (from our evidence review) to support this hypothesis. We believe that taking a user-centred and design-led approach to care plan development will enable us to understand the extent to which they can be designed to meaningfully overcome common barriers in sickle cell care.

How it might work

There are various options for delivering this, such as leveraging existing commodity tooling and products, creating a bespoke developed solution specifically with sickle cell patients in mind, or working with partners to introduce new features into existing national tools or commercial products. We recommend looking into the most viable and scalable way of approaching this as part of testing the value and answering the questions outlined above in the next phase of work. It is worth noting that we are interested in exploring how digital and physical interventions might work together to increase accessibility and mitigate against the risk of digital exclusion.

How we might test it

We propose starting small and testing within a specific area or care system. Provided there is sufficient evidence to indicate that personalised, digital care plans have potential for impact and scalability, and are viable, we can then begin to experiment across care boundaries.

We propose identifying a cohort of patients who are visiting A&E regularly, and prototyping a care plan that is written for and targeted at clinicians, assuming no prior knowledge of the condition or of the patient. We would look to test with healthcare professionals who are more and less aware of sickle cell disease and how to treat it, in order to better understand how this knowledge influences their behaviour and to inform the design of the care plan.

Where this idea came from

- We spoke to a number of people during our user research who have and use a care plan;
- There is evidence that having a personalised care plan helps with pain management;
- We met with Dr Gyles Morrison, who published a thesis in 2018 in which he explored personalised care plans. Dr Morrison found significant and promising evidence for the effectiveness of this as a tool, and went a significant way into prototyping what that could look like.

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Medication tracking

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Medication tracking

Context

When people present in crisis, the healthcare professionals treating them need to know what they usually take to manage their pain, and what they've taken to manage their pain in this instance.

It's difficult - especially when you are in pain - to share this information and keep track of what you've taken. We were curious as to whether there might be a way of making that information more readily accessible, and stopping patients from having to repeat themselves.

Intended outcomes

- To reduce the burden on people who are experiencing a crisis to self-report
- To increase healthcare professionals' confidence in what might help with the pain
- To increase transparency and build trust between the patient and healthcare professional

Our hypothesis

We hypothesise that having this information readily available to both patient and healthcare professionals could help to:

- reduce healthcare professional scepticism of drug seeking behaviours;
- accelerate access to more powerful painkillers, avoiding people in crisis having to start at the bottom of the pain management ladder.

How it might work

In hospital, the electronic drug chart serves to document drug and treatment administration e.g. doctor prescribes 5mg oramorph 2-4 hourly as needed for pain. Then the nurse records each time they give it to the patient. It might be helpful for patients to have something similar on their phone to share with healthcare professionals. This could be an extension of the care plan that describes the routine treatment and pain management regime that a patient is following.

GP prescriptions are transactions that are routinely captured and are already made available to secondary healthcare professionals via Health Information Exchange (HIE), and to patients via the NHS app. There could be value in sharing information like the average dose of opiates a patient is prescribed per month. We think there could be value in better sharing and using this kind of data, as opposed to asking patients to enter it again somewhere else.

How we might test it

It will be important to understand:

- how this impacts clinician behaviour - they need to remain empowered and able to use their clinical judgement in the moment;
- if this puts an unnecessary and unreasonable burden on people with sickle cell. Does it suit them to track their medication in this way on a day-to-day basis? Might there be a way of tracking medication that doesn't rely on the patient e.g. a way of automatically recording what medication they order and are prescribed? It should also be noted that when they are in pain, it's unlikely that they will be able to track what they're taking;
- is this something that has existed prior to technology? Is the tracking of medication established as a useful concept?

Where this idea came from

A number of our user research participants talked about the challenge of tracking their medication. One participant mentioned an app - LloydsDirect NHS Prescriptions - that they used to be able to use which they and their GP had access to, which helped them to track what they were taking and also meant that they felt they were being better cared for because their GP was able to see when the patient was ordering new medication. We wondered if this could be built upon to be useful during a crisis.

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Accessible NHS-wide guidance on managing a sickle cell crisis for clinicians

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Accessible NHS-wide guidance on managing a sickle cell crisis for clinicians

Context

There is already an NHS-wide NICE guideline on managing a sickle cell crisis. However, this has arguably not been designed for an ambulance, A&E and emergency setting, and it has been proven that this guideline is not being used and adhered to consistently. What's more, during our research with healthcare professionals, we came across a number of other documents that act as guidelines for healthcare providers to use to help them take care of people experiencing a sickle cell crisis. It seems that there is an opportunity to rethink sickle cell crisis care guidance - both the guidance itself, and how people know it's there.

Intended outcomes

- To provide healthcare professionals in good practice for the management of a crisis
- To mitigate against the existing problem that healthcare professionals who are not familiar with sickle cell crises don't know how to treat a crisis appropriately
- To understand how to make guidance - especially that which already exists - more effective, accessible and prominent during the moment of crisis

Our hypothesis

We believe that sickle cell crisis guidelines could be improved in terms of their usability in a high-pressure emergency setting, and in terms of promoting access to them. Many healthcare professionals will only treat people experiencing a sickle cell crisis infrequently. This lack of real experience of dealing with patient crisis episodes can impact the effectiveness of the guidance. In particular, we suspect this solution may not be effective in areas with a low prevalence of sickle cell. We would like to test the extent to which guidelines can be adapted to make them easier to follow for healthcare professionals who are not familiar with sickle cell disease. We would also like to test the extent to which standardised guidelines are effective when the sickle cell service is likely to be different in every hospital.

How it might work

In our research, we found two instances of sickle cell care guidelines that had been developed for a particular locality, and in collaboration across organisations and different healthcare specialisms. We are interested in the extent to which the value is in the fact that the guidelines have been developed collaboratively, and are specific to sickle cell services in a particular part of the country. We also believe that making these guidelines more accessible e.g. open to all, so that patients, healthcare professionals, loved ones and carers alike can access it, might go some way to improve transparency, trust and accountability.

How we might test it

We propose taking a similar approach as to that which we have outlined for personalised, digital care plans. We'd start by bringing together existing guidelines and a collaborative, multidisciplinary team to co-design what information is most important at the point of crisis. Then, we would ask a small cohort of healthcare professionals to use the guidance. We would scale out from there, depending on what we learn.

Where this idea came from

This kind of tool is in use at University Hospitals Bristol and Weston NHS Foundation Trust. It is one of a much bigger set of guidelines, which staff have access to via an app. It was developed in partnership by resident sickle cell experts and A&E specialists.

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Wearable monitoring technology

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Wearable monitoring technology

Context

Currently, a clinical trial is being undertaken (by Sanius Health) which is exploring the role of wearables in sickle cell disease management. We were curious to discuss this idea with our multidisciplinary group, to understand how people felt about wearable technology as a possible intervention to help manage their acute painful episodes.

Intended outcomes

- To help people with sickle cell understand if they are going into/are in crisis
- To provide information to healthcare professionals about people's stats in the run up to crisis and enable them to treat the person in crisis more quickly

Our hypothesis

We believe that there may be value in consistently tracking people's relevant stats e.g. their heart rate, oxygen saturation levels, blood pressure, and temperature. We heard a positive report during our research of how access to this information may help people with sickle cell learn more about their condition and how to read what they are feeling.

However, we also heard much more frequently and consistently that people with sickle cell know - without external validation - when they are going into a crisis. We also heard scepticism about the usefulness of this intervention in the management of an acute painful episode.

> "If you haven't improved other aspects of care, what difference will a smart watch make?"
>
> **Workshop participant**

We believe that wearable monitoring technology might be a useful adjunctive tool for managing sickle cell, but it does not seem like an essential idea to test in respect of managing crises.

We propose keeping track of the Sanius Health clinical trial, to understand the potential role of wearable monitoring technology as part of a wider suite of supporting sickle cell services and to help successfully amplify promising results.

Given the mixed responses we've heard from people with sickle cell about this idea, and the promising early results, should this prove to be a service that is scaled for people with sickle cell, it will be important to design the service end-to-end to enable it to have the most impact.

We are also interested to understand if the data prompts somebody with sickle cell to make a decision to go to hospital to seek professional care sooner.

How it might work

People with sickle cell wear a smartwatch that measures their relevant stats. Patients and healthcare professionals involved in their care routinely have access to this information. Healthcare professionals involved in a person's care at a point of crisis are able to access this information via the patient's watch.

Where this idea came from

There are promising studies already on this - it has been a success so far. One of our user research participants is part of a clinical trial in which they have given participants smart watches which track their stats. This participant talked about how this was useful when they started to feel unwell, as a way of confirming whether or not it was likely they were experiencing the onset of a crisis. However, people's way of monitoring themselves varies, and it was clear from our research that most people tend to know when they are going into crisis.

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Our recommendations

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Our recommendations

Based on this work, and our experience in designing and delivering effective digital services, we recommend that the NHS Race and Health Observatory takes this work forward with the following areas of focus: testing at least one practical intervention, and exploring wider transformation in sickle cell services.

The goal of this discovery was to identify practical interventions that hold the potential to make a tangible difference for people with sickle cell when they are accessing healthcare services at the point of crisis. We have identified a set of pain points that people with sickle cell regularly experience when they are enduring a sickle cell crisis. We have identified a set of solutions that we believe - if we take a digital approach to them - could go some way towards tackling these pain points. However, it is clear that the issues experienced by people with sickle cell using the NHS go far beyond the challenges experienced at the point of crisis.

We also believe that, taken individually, these interventions may not make a significant difference to the experiences of people with sickle cell, because of the complex, systematic, and systemic nature of the problem, and the highly federated and fragmented nature of the NHS. Technology alone will not solve these problems.

Given this context, we recommend exploring redesigning the operating model of sickle cell services and sickle cell service design. We envisage a future in which a suite of services, designed, developed and iterated with ongoing learning and feedback loops in place, is overseen by a central, digitally-skilled and multidisciplinary team.

This work would explore questions like:

- How might we remove or reduce the need for people experiencing a sickle cell crisis to attend A&E?
- How might we safely keep people in crisis at home for as long as possible? Are home visits to prevent hospital admissions appropriate and possible?
- How might we improve pain management by increasing access to pain specialists at the point of crisis?
- How might we support and increase access to haematologists and red cell specialists during a crisis?

What follows is a recommendation for practical interventions to test, and a service design-led approach to the transformation of sickle cell services in the UK.

We recommend the following:

- work to develop personalised, digital care plans in a trust-generating way that addresses specific, common barriers in sickle cell care. This could include exploring medication tracking between patients and professionals;
- consideration is given to testing, developing and using national sickle cell care guidelines alongside this intervention, with a particular focus on how to address healthcare professionals' lack of awareness of sickle cell disease and how that impacts crisis treatment;
- a service design approach is taken to investigating wholesale redesign of sickle cell care pathways, to establish a national standard that takes into account different levels of prevalence in different places:
- existing digital interventions that have potential e.g. personalised, digital care plans, guidelines, wearables are fully examined
- a focus on investigating new approaches e.g. access to pain specialists during a crisis an exploration of different models of care
- deep-dives are conducted with the aim of improving the transition between paediatric and adult services

Given its independent status and operating model, the NHS Race and Health Observatory may be well-placed to take these recommendations forward.

The next phase of work will be most impactful if it focuses on testing and learning. The two questions to work towards are:

- What can we do sooner that will have a material impact on people experiencing a sickle cell crisis?
- Longer term, how can we transform the way sickle cell care is designed and delivered for the better?

Learning by doing: what next

Based on our research, we believe that:

- the solution will not be a one-size-fits-all approach. Different people manage their condition differently; different parts of the UK have widely varying prevalence of sickle cell. An effective sickle cell service will accommodate differences like these;

- interventions need to be made at a national level in order to be truly effective. We propose starting small and testing locally to prove (or disprove) the viability and potential of any possible intervention. However, an element of standardisation will improve accountability and experience;

- in order to truly create benefit from any of the interventions that are taken forward, it will be essential to apply the practice and principles of service design in order to ensure that what results is based on user needs (of both people with sickle cell and those varying groups that are charged with their care) solves a whole problem and robustly measures and iterates towards meaningful change for people with sickle cell.

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Looking to the future: how interventions can come together as a platform

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Looking to the future: how interventions can come together as a platform

The NHS has a mandate and the levers to set and deliver a bold vision for the treatment of sickle cell disease. This could be:

> **To deliver a nationally available technology-enabled support offering, operated by trusted partners, that supports people in a crisis, aids day-to-day condition management and crisis prevention and improves health outcomes for people with sickle cell.**

We have proposed a series of potential interventions as part of this discovery and we recommend starting with personalised, digital care plans. However, instead of specifying just one transactional service, we believe there is benefit in starting to see this as a combined "platform" of capabilities supported by underpinning activities and initiatives. These are a combination of improvements and optimisations and the building of new services under the powerful NHS brand.

We propose starting by prototyping and testing personalised, digital care plans and exploring and validating their potential role in enabling this way of working, as a front door to a wider sickle cell service platform.

What do we mean by 'a platform'?

A platform in this sense is a set of common capabilities that provide the infrastructure to enable others to fulfil their needs when it comes to using technology to help themselves or others to manage sickle cell disease.

A platform generally mediates the exchange of value between individuals or entities, also providing benefit for the platform operator. For example, a platform that has the capability to help individuals or entities learn about what works when it comes to sickle cell and inform others of this information affords a value exchange between those parties. The platform operator monitoring this value exchange does so in the service of finding ways to enhance and optimise this capability for the greater good of all involved.

An online example of a platform would be Amazon's Marketplace. Amazon makes it possible for sellers to use a common set of capabilities such as listing products, purchasing, fulfilment and delivery which the seller would otherwise have to provide themselves. This allows the seller to concentrate on selling their products. On the other side, the buyer has access to products they would like to buy, meaning they benefit from the same capabilities as the seller.

Amazon, as the platform operator, uses data generated from each interaction to learn about what works best for buyers and sellers to improve its capabilities. This allows Amazon to further strengthen its offer and provide greater value to both sellers and buyers.

A platform for management of sickle cell disease

A platform for management of sickle cell disease is one that prioritises learning.

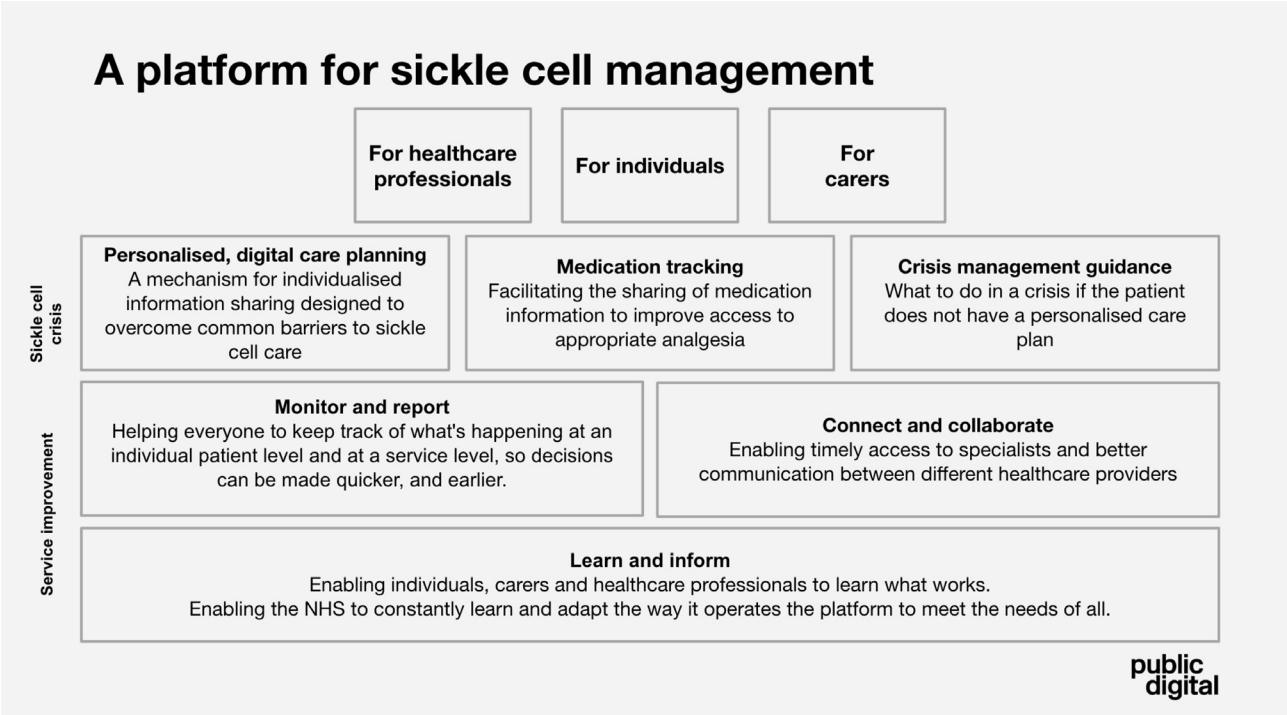
A platform that supports everyone to:

- Learn about what works
- Learn about the needs of individuals
- Learn about how to prevent issues in the future

The platform should build on the strengths of capabilities that already exist in the NHS to manage sickle cell. Those capabilities should support individuals, carers and healthcare professionals to manage the disease.

Key platform capabilities

Based on our research, we propose the following key platform capabilities as our starting point.



Learn and inform: One of the fundamental elements of a definition of digital that takes into account the culture, processes, and business models of the internet-era is a mechanism that enables, and is able to act on, learning. By making sure such a mechanism underpins sickle cell services, we can enable individuals, carers, and healthcare professionals to learn what works when it comes to sickle cell management. As the key decision makers and owners of the platform model, the NHS will need to constantly learn, adapt, and scale the way it operates the platform to meet the needs of all.

Monitor and report: Building on the concept of short, constant feedback loops, clear, structured information on how individuals are doing, and how well the service is performing, will help everyone to keep track of what's going on so decisions can be made quicker, and earlier. Wearable technology to collect patient data - at the discretion of patients - may possibly form part of this capability with regards to an individual's care.

Connect and collaborate: We know that the quicker people experiencing a crisis get access to specialists, the better their experience. We propose a capability to connect specialists and non-specialists and enable them to collaborate in the direct care and treatment of people with sickle cell, both at the point of crisis and throughout the day-to-day management of the condition. This capability would work towards enabling timely access to specialist knowledge, enabled by better technology and information flow.

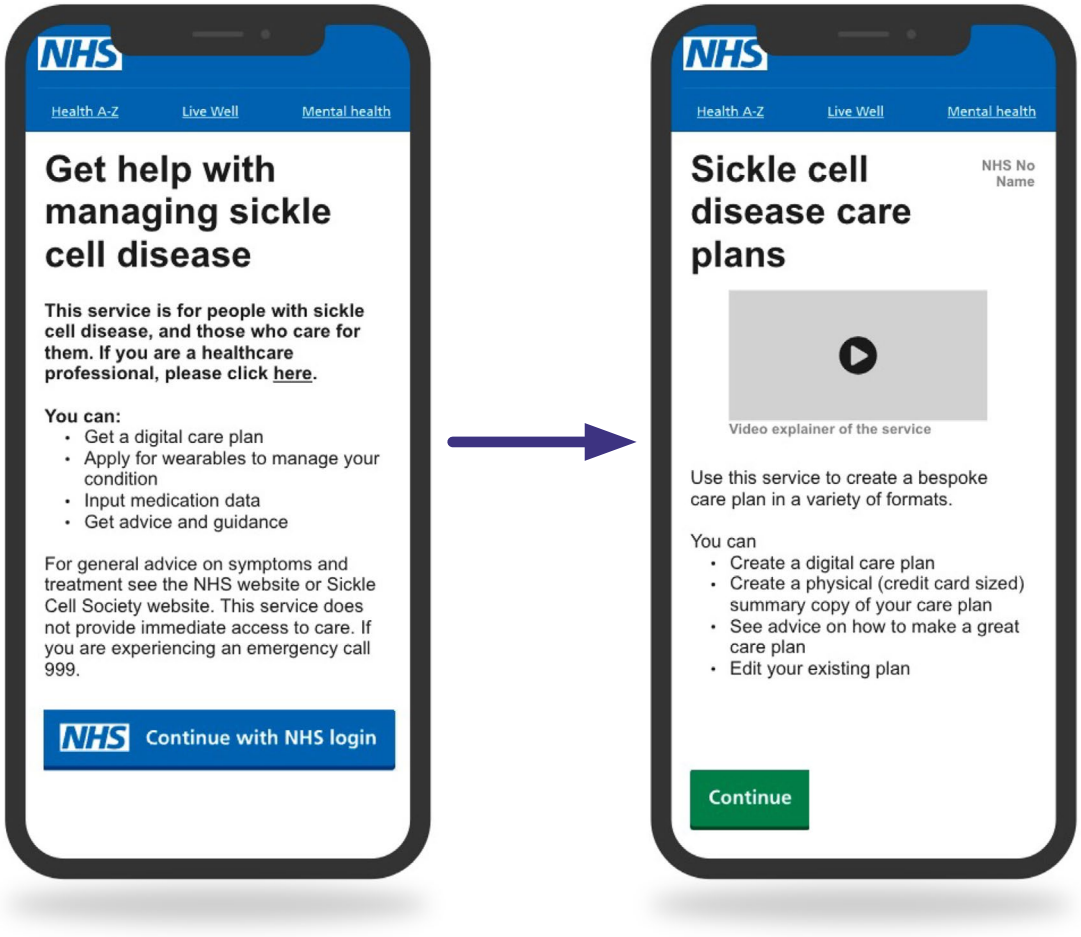
Personalised, digital care planning: By providing individuals and healthcare professionals with a mechanism for information sharing that is designed and tested to overcome common barriers to better sickle cell crisis care, we can start to materially improve the experience for people with sickle cell sooner.

Medication tracking: Facilitating the sharing of medication information between patients and healthcare professionals to improve access to appropriate analgesia at the point of crisis, likely as part of a personalised care plan.

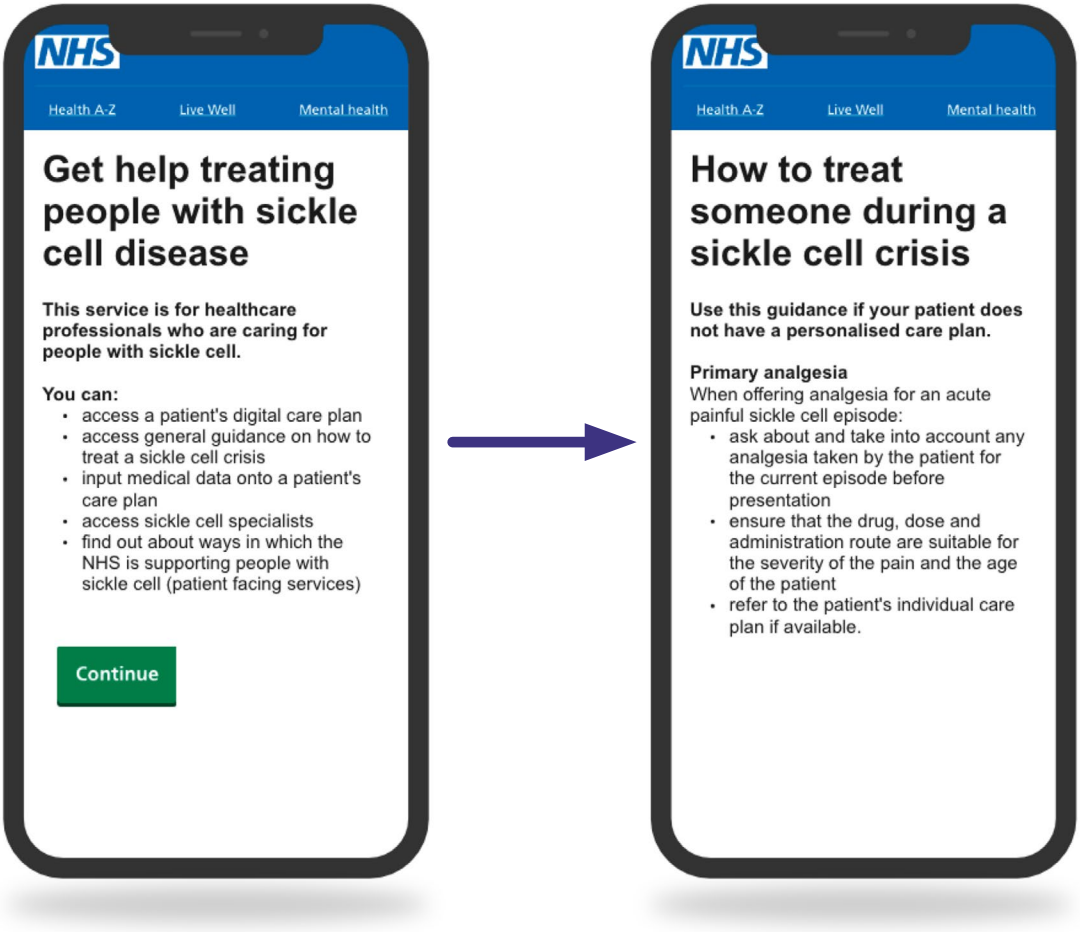
Crisis management guidance: Guidance for what to do in a crisis when a person doesn't have a personalised, digital care plan that is specifically tailored and tested to overcome barriers to healthcare professionals administering timely analgesia.

Illustrating the user experience

To illustrate what the user experience might look like for users of the platform (both patient and clinician) we have mocked up a series of screenshots.



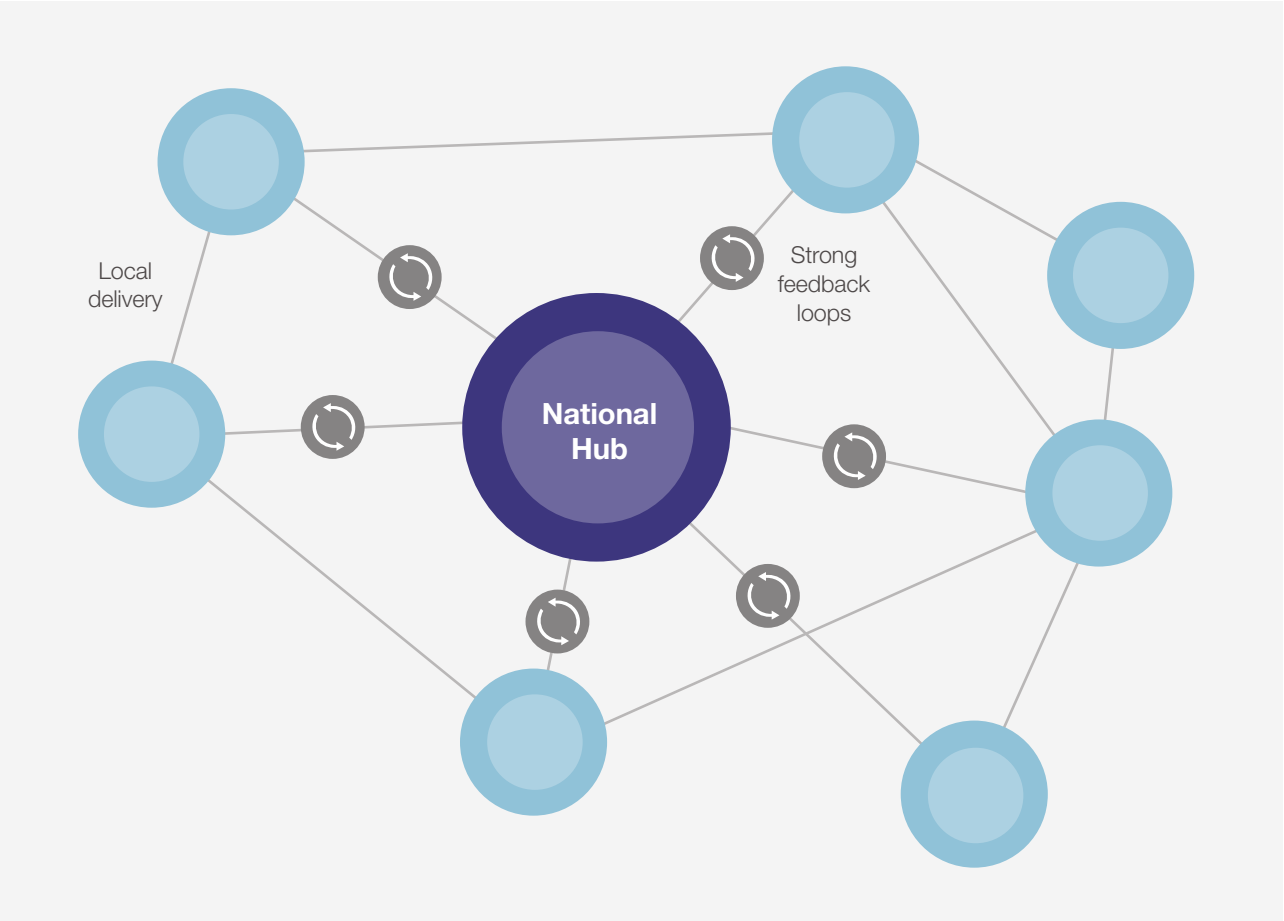
The patient experience (illustrated above) is accessible through a responsive website on any device. It is integrated with NHS Login to provide access to demographics data and other records. The user is able to access a variety of services to meet the user needs identified in the discovery.



There is also potential for a corresponding clinician experience although, as with the patient, this would need to be weighed up against the multiple platforms and services clinicians already have to access. Other options like integration with existing systems could be preferable, subject to further testing. These screenshots are illustrative only.

How this might be resourced and operated

Operating this service requires multiple partners working in tandem, with potentially a networked ‘hub and spoke’ model.



Central unit accountable for: Running national offers, managing a feedback loop with local providers, curating and publishing evidence on what works, managing the community of practitioners and scaling successful interventions.

Local teams accountable for: Running local experiments, publishing insights, iterating and delivering services and solutions.

The model is predicated on strong feedback loops and networks, facilitated by technology.

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What next?

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What next?

Our sickle cell digital discovery has identified a series of needs and challenges faced by people with sickle cell during a crisis. Through this research, a set of possible interventions and a new approach to sickle cell service design and delivery have emerged.

The next step is to test these interventions for their impact, viability, and scalability in what is often referred to as an 'alpha' phase. During an alpha phase, a team will usually prototype and test ideas, run experiments and generally look for different ways of solving problems.

We propose that the NHS Race and Health Observatory commissions an alpha that:

- develops and tests the concept of personalised, digital care plans, with both people with sickle cell and healthcare professionals;
- continues to research and define what good looks like with regards to the overarching operating model that underpins sickle cell care in the UK, with a view to addressing wider issues in sickle cell care, including and beyond the moment of crisis.

It is important to note that an alpha does not involve building a real, working service. The focus in this phase is on testing and validation.

After this phase of work, and provided that at least one intervention is validated and deemed worth further exploration, this should be taken into a 'beta' phase.

A beta is when you start to build the intervention and release it for use with a small cohort of users, so that you can continue to validate that it is solving the problem it is intended to solve. It is after this point we recommend scaling the intervention for wider use.

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Appendix

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Appendix

User needs during different stages of a crisis

1. Crisis starts

Needs

- When the beginning of a crisis starts, I want it to go away, so I can stay at home
- When the beginning of a crisis starts, I want access to pain relief, so I can avoid unnecessary pain
- When I am out of the house and a crisis starts, I want to get home as quickly as possible, so I am in a safe space and have access to my medication

Problems at this stage

- Dread of having to go to hospital and having a negative experience
- Fear of oncoming pain
- People questioning what sickle cell is
- Panic about a crisis beginning far away from home

2. Try and manage at home

Needs

- When a crisis has started, I want to take pain relief medication, so I can relieve my pain
- When I have taken painkillers, I want to see if they will relieve me of pain, so I don't have to go to hospital
- When I am having a crisis at home, I want to stay there, so I am only fighting pain, not pain and negative experience I've had at hospital before
- When I am at home having a crisis, I want to stay there, so I can better control my access to painkillers compared to hospital
- When I am having a crisis at home, I don't want to call an ambulance, because they may take me to the nearest hospital and that hospital might not be best suited to my needs

Problems at this stage

- People don't have the pain relief or other things needed to cope at home
- People can't be monitored at home
- People don't want to go into hospital
- People are delaying having to go in for as long as possible leading to a worsening of their condition
- People have a fear of having to go to hospital based on previous negative experiences

3. Prepare for hospital

Needs

- When I have made the decision to go to hospital, I want to know I will be seen by someone who understands sickle cell, so I can be treated appropriately and quickly
- When I am going into hospital, I want a record of all my medications, so that when I am asked about it I can access it without having to do too much thinking or explaining when I get there
- When I have made the decision to go to hospital, I want the ward notified that I am coming in, so they can prepare for me coming onto the ward and I don't have to wait
- When my pain becomes too much to bear, I need to go into hospital, to get access to the pain relief and medical expertise I need
- When I am heading into hospital, I need to prepare a bag of my belongings, so that I have what I need for potentially multiple nights in hospital
- When I am preparing to go into hospital, I want to know I am going to the right place, so that I can be treated properly

Problems at this stage

- People don't want to go into hospital
- They delay having to go in for as long as possible
- Some people don't have access to transport to take them in
- People have to ask favours of family and friends to take them in
- People worry about leaving family and job behind for a hospital stay

4. Travel to hospital

Needs

- When I am travelling to hospital, I need it to be as quick as possible, so I can get pain relief quickly

Problems at this stage

- Asking favours from friends and family for a lift
- Sometimes don't have access to personal transport to be taken to hospital
- People feel like they are a burden on others asking for favours

5. Travel to ambulance by hospital

Needs

- When the medics speak to me, I don't want to repeat myself, as it's hard to concentrate through pain
- When I am travelling by ambulance, I need access to pain relief quickly, because it is unbearable
- When I am being asked about my pain, I want to be trusted that I am being honest, so that I am not distrusted and being treated like someone who is just seeking drugs
- When I am being taken to a hospital via ambulance, I want to know I am going to the right place, so that I can be treated properly

Problems at this stage

- Repeating the same answers to questions
- Distrust from Emergency Medical Technicians (EMTs)
- Not given pain relief quickly
- EMTs often don't know about sickle cell
- Often pain relief received in ambulance is inadequate for pain levels experienced
- Fear of being taken to a hospital without specialist facilities

6. Arrive at hospital

Needs

- When I arrive at hospital, I need to do as little explaining as possible, because it's incredibly difficult when I'm in so much pain
- When I arrive at hospital, I want to avoid A&E, so I can head straight to a specialist ward where people understand my condition and I don't have to wait for pain relief
- When I arrive at hospital, I want to be taken seriously, so that I am treated fairly
- When I arrive at hospital, I want people to listen to me and trust me, so that I can explain my condition and preferences without them distrusting me

Problems at this stage

- Some doctors don't have a lot of experience with sickle cell
- Long wait times in A&E
- Distrust from A&E staff
- A&E staff don't know about NICE guidance

7. Assessment

Needs

- When I am being assessed at hospital, I need to do as little explaining as possible, because it is tiring and I am in agony
- When I am being assessed, I want it to be as quick as possible, so that I can get pain relief rapidly
- When I am being assessed, I want the healthcare professional to be able to get information about me as quickly and easily as possible, so I can receive pain relief quickly without having to explain
- When I am being assessed, I want to avoid repeating myself to different people, because it is tiring and I am in pain
- When I am being assessed by a non-expert, I want to skip this step, so I can just see a specialist
- When I am being assessed, I want to go to the appropriate specialist, so I'm not moving to and fro between people

Problems at this stage

- Repeating the same answers to same questions
- Trying to answer the questions 'correctly', so that I have access to pain relief as quickly as possible
- People have to convince the doctor that they need appropriate pain relief
- Some will recommend paracetamol or ibuprofen initially, which is inappropriate
- People having a crisis are exhausted, but have to stay awake, because if they fall asleep people won't pay attention to them and they won't get the care they need
- Outside of specialists, clinician's lack knowledge of sickle cell. Resulting in mistrust to people having a crisis and slow access to pain relief

8. Receive pain relief

Needs

- When I am about to be given pain relief, I want the clinician to make sure that it's an appropriate dose for me, so that I don't have an adverse reaction
- When I have received pain relief medication, I want to go home, so I don't have to stay in hospital
- When I am given pain relief, I want it to be a dose that will address my pain, not a smaller amount 'to start with'
- When I am trying to get pain relief, I don't want to trigger distrust, because it might delay my access to pain relief

Problems at this stage

- Some doctors don't have a lot of experience with sickle cell
- Some doctors assume people want a low dose, and build it up: what they want is the right amount to relieve pain
- Doctors can be distrustful as they don't believe patients

9. Admitted to hospital

Needs

- When I am admitted onto a ward, I want it to be somewhere where the care team knows about sickle cell, so I am not distrusted for not being well
- When I am admitted to a ward, I want to see a haematologist as soon as possible, so that I can receive specialist care as soon as possible
- When I admitted onto a ward, I want it to be a specialist one, so that I have access to specialist doctors and nurses
- When I am admitted, I want to leave as soon as feasible, because I have children to look after and a job that I cannot be away from

Problems at this stage

- People have lives to lead and a stay in hospital impacts this negatively
- People get placed onto wards with little to no knowledge of sickle cell resulting in poor care

10. Stay on ward

Needs

- When I am staying on a ward, I need consistent communication between the people that care for me, so I can be treated safely and holistically, and so that I don't carry the burden of managing my own care
- When I am staying on a ward, I want it to be a specialist ward, so that I get care from people that know about sickle cell
- When I am in pain, I want pain relief medication, so I can relieve the pain
- When I am on the ward, I want to be taken seriously, so that I am treated with respect
- When I have my pain under control, I want to leave as soon as possible, so I can go home
- When I am on the ward, I want to be able to speak to someone quickly, so that I am not waiting for pain relief

Problems at this stage

- Stay on wards that aren't haematology (like oncology)
- Pain relief not being given fast enough
- Pain relief given, but some patients are made to feel bad about it
- Some doctors don't have a lot of experience with sickle cell
- Sickle cell patients have to fight for attention on a busy, understaffed ward

11. Discharge

Needs

- When I leave hospital, I want to have access to pain relief medication easily, so I don't have to come back in and collect more
- When I am discharged, I want to know about what medication I have been given, so that I can take my medication correctly
- When I am discharged, I want to have a supply of medication that will last me as long as I need, so I don't have to get more in a short time
- When I am leaving hospital, I need to be able to get home, so that I am not stuck in hospital
- When I am told I will be leaving hospital, I want to leave hospital quickly, so I am not waiting around

Problems at this stage

- Long wait for discharge waiting for meds
- Discharged with medication that won't last very long
- Nobody available to take them home

12. Back home

Needs

- When I have gone back home from hospital, I want my records updated, so that if I have another crisis I don't need to answer the same questions again and again
- When I am home after a crisis, I want access to the medication I need, so I don't go without medication
- After a sickle cell crisis, I want to know who I should contact about what happened or any future crisis, so that I am not contacting the wrong people and wasting my time
- When I have made it back home, I want to stay pain free, so I don't have to go back into hospital

Problems at this stage

- Sometimes GP doesn't have the meds needed after a crisis
- GPs ask patients to talk to sickle cell team, sickle cell team tells patient to contact GP

Sickle cell digital discovery report

For more information please visit: www.nhsrho.org

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