



Digital Health Passport for Sickle Cell Anaemia

Co-design, prototype and
interoperability blueprint

TinyMedicalApps.



We believe that the Digital Health Passport (DHP) for sickle cell disease will offer significant benefits to empower individuals with the disease and their caregivers to take control of their health, leading to an enhancement in their quality of life.

PROJECT LEAD

Olayinka Sholaja brings her experience as a project manager in clinical research to now lead the Digital Health Passport for Sickle Cell Anaemia.

Yinka's expertise lies in ensuring the smooth execution of studies, maintaining quality standards and fostering collaboration between key stakeholders. She is dedicated to driving impactful results and contributing to advancements in the field of healthcare through project management and strategic leadership.



“My journey began with deep empathy and a desire to make a tangible difference in the lives of those affected by sickle cell disease. Initially, I was drawn to this cause after witnessing my late uncle struggle with the condition in a rural area of Lagos, Nigeria. This motivated me to learn more about the disease, leading me to complete a dissertation titled “The overall Assessment of the Pharmacological and Clinical profiles of Conventional Supplements in the Treatments of SCD, and Assessment of Socioeconomic status on the Severity of Sickle Cell Disease in Africa and Dubai” during my MSc program at Queen Mary University of London in 2017.

Working on the Digital Health Passport project for sickle cell has been an insightful and empowering experience. It has allowed me to expand my contributions and collaborate with others who share the same dedication. Ultimately, our goal is to improve outcomes and quality of life for those living with sickle cell disease through effective self management of the condition.”

Olayinka Sholaja, Project Director

INTRODUCTION

Tiny Medical Apps (TMA) is at the forefront of healthcare innovation with its Digital Health Passport, supporting children's asthma management across 10 Integrated Care Boards (ICB).

The Digital Health Passport is now expanding its scope to cover epilepsy and more Core20PLUS5 priority areas for children in collaboration with Greater Manchester NHS ICB. A partnership with the Young Epilepsy Charity and the Caribbean and African Health Network (CAHN) will ensure the end product meets the needs of all users.

In 2023 the Digital Health Passport team secured National Institute for Health and Care Research (NIHR) funding to develop support for children, young people and their carers, with sickle cell anaemia. The project has involved extensive PPIE work alongside CAHN and the demonstration of interoperability with OpenEHR care plan systems used in London.

With more than eight years of development within the NHS, TMA is exploring further public health prevention features, including educational resources and self management tools for mental well-being, childhood obesity (prevention of type 2 diabetes), good dental care and reducing digital exclusion for people with mild to moderate learning disabilities.

Dr Greg Burch is joint CEO and clinical director. Greg is a practising Specialty Doctor in Emergency Medicine. Over the last seven years he has delivered the Digital Health Passport through clinical co-production with the NHS and patient co-design.

Matt Bourne is joint CEO and chief technology officer. Matt has 25 years of experience developing software within and for the NHS. Matt has successfully delivered the company's ISO/IEC 27001 certification, DTAC approval and NHS Login assurance.



The DHP has an ORCHA rating of 88%.

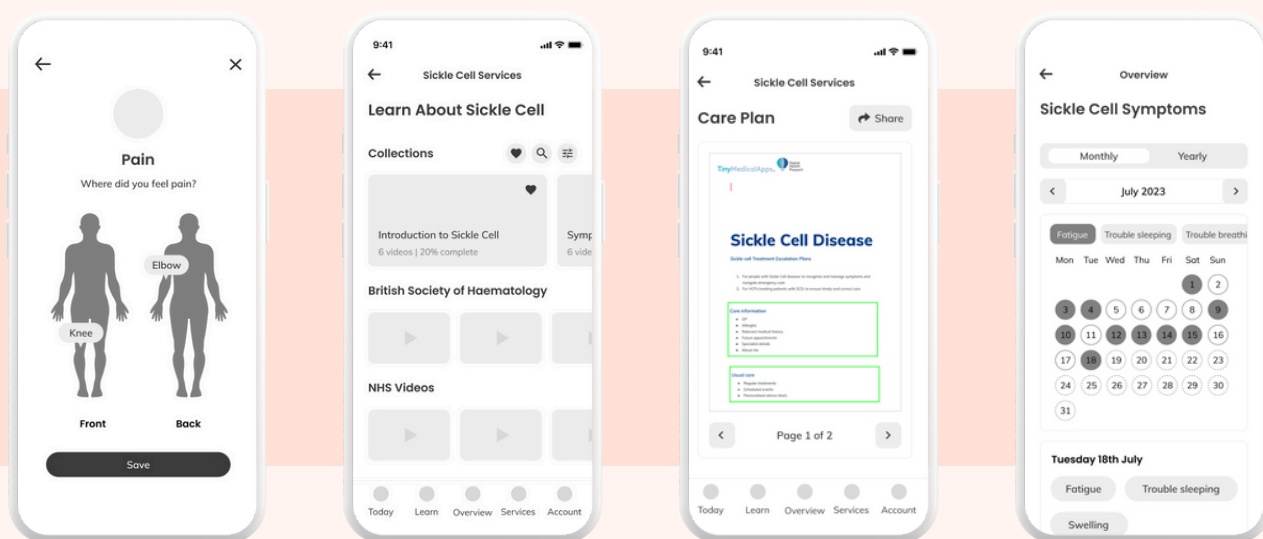
PURPOSE

This document supports the case for a hybrid model of funding. We recommend that national funding is provided to rapidly scale the Digital Health Passport for sickle cell anaemia to meet the immediate needs of thousands of families. We believe regional funding should be provided for the integration with regional care planning systems that would further improve patient experience and outcomes.

The Sickle Cell Digital Discovery report: ‘Designing better acute painful sickle cell care (2022)’ commissioned by the NHS Race and Health Observatory set out to understand the broad availability of digital products and services that currently exist.

Researchers were struck by the limited amount of technology, dedicated health sites and web or digital tools that currently exist to support patients at the point of crisis and for managing the condition at home.

When apps for sickle cell anaemia were identified, these were considered to be highly variable in quality and subject to poor user interaction, not widely downloaded nor regularly updated.



Digital Health Passport for Sickle Cell Anaemia

The objectives of the NIHR i4i Fast grant project were to:



Explore challenges, needs and ideas for how and where a digital service could help people with sickle cell anaemia



Design the prototype features and content for a Digital Health Passport (DHP) for sickle cell anaemia



Demonstrate interoperability between the DHP and the Universal Care Plan for London

UNDERSTANDING REQUIREMENTS

The workshops led by the Caribbean and African Health Network (CAHN) identified several pain points experienced by sickle cell patients and their carers:



Difficulty in managing unpredictability

The unpredictable nature of sickle cell attacks makes it challenging to effectively manage the condition.



Impact on all aspects of life

Sickle cell affects all aspects of patients' lives, including their relationships, social life and career.



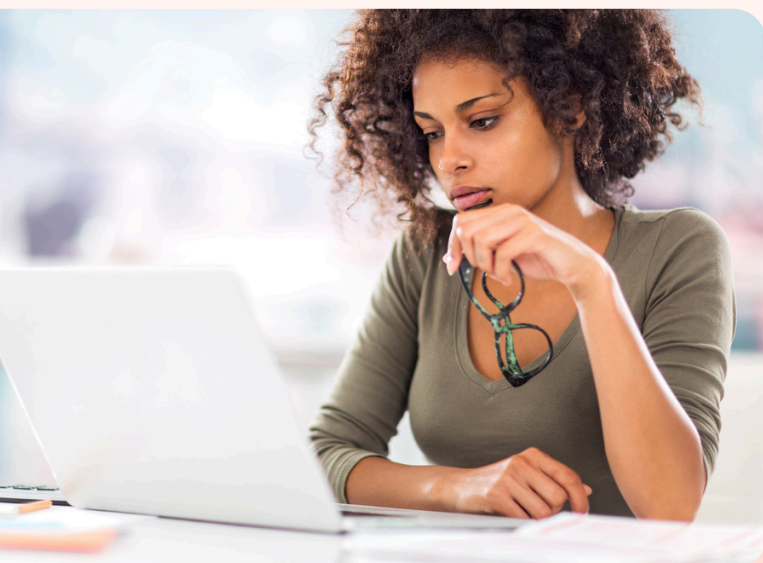
Mental health challenges

The ongoing management of sickle cell, the awareness of it being a lifelong condition and the potential tragic consequences of a crisis have a significant impact on the mental health of patients and carers.



Access to reliable information

All participants agreed that easy access to reliable information about sickle cell is one of the most important aspects of effectively managing this condition.



"Reliable information is very important because you hear a lot of things that might not be true. A lot of the time I read information and I'm wondering if this is actually true."

Research Participant



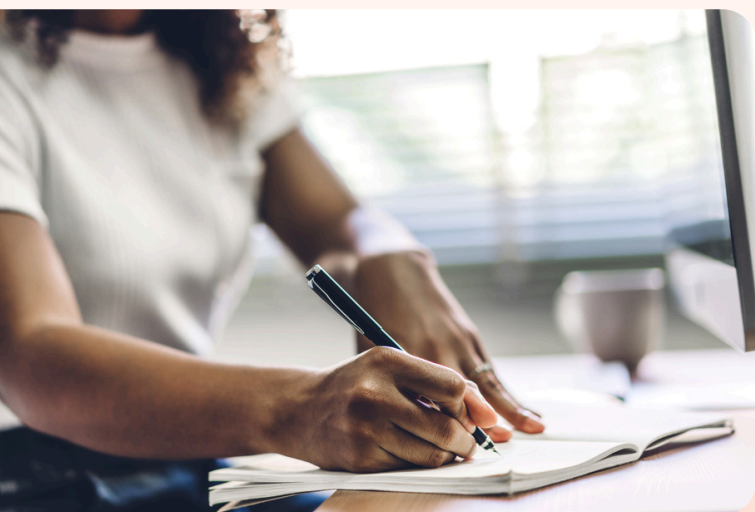
Lack of understanding and poor healthcare services:

Sickle cell patients often face a lack of understanding regarding their condition, leading to difficulties in accessing essential services like care and education. This lack of awareness and associated stigma have contributed to the provision of substandard healthcare services for these patients.



Lack of joined-up care:

There is a notable lack of effective joined-up care for sickle cell patients. Communication failures between different hospital departments impact care, and patient care plans are often ignored.



“When my son was diagnosed the nurse just rang to let me know and that’s it, no further information.”

Research Participant



“Sometimes at the hospital they look for hours to find someone who understands sickle cell. Even in a bigger hospital they might have a specialist but they might not be on duty.”

Research Participant

CO-DESIGNING THE PROTOTYPE

The workshops identified what a digital service for sickle cell anaemia should provide.



Access to reliable information:

Many people struggled to find trusted information about the condition and treatments, so had to do their own research. Putting trusted information in one place would provide an immediate benefit to families.



Better support during initial diagnosis:

The emotional shock during the initial diagnosis makes it challenging for patients and carers to absorb the information provided at that time. There is a lack of consistency in the way information is conveyed or available to patients at home. This issue could be addressed by utilising digital technology to offer information tailored to individual needs and age groups.



Peer support:

Participants found peer support to be the most useful source of information, allowing them to learn from individuals who have experienced similar situations. Peer support provided both medical and emotional advice and should be easy to access.



Pain tracking:

People would benefit from the ability to track and share their pain experiences with clinicians at appointments and during emergency department admissions. An easy to use digital tool is preferable to paper diaries for many.

**Trigger recording:**

People should be able to learn about, and track triggers to better manage their condition and get alerts for things such as weather changes.

**Appointment reminders and access to blood test results:**

Participants want convenient access to other health services within the app.

**User profile:**

A section where app users can save basic information about themselves and their condition for emergency situations.

**Well-being content and reminders:**

The inclusion of general well-being and mental health advice specific to sickle cell patients alongside gentle prompts and reminders to complete tasks.

**Additional languages:**

Content in multiple languages would help overcome language barriers for some patients.

**Information sharing for carers:**

Tools that facilitate information sharing among caregivers, including spouses, were also desired.



Digital care plans: There was some scepticism regarding the effectiveness of care plans. Participants reported negative experiences when presenting documents from their haematology specialists, as these were often not adhered to by the admitting doctors. While they liked the content and structure of a Care Plan, they expressed doubts about its effectiveness in real-life situations. Incorporating a digital care plan as part of a wider set of support, resources may offer more value than if used alone.

Digital care plans are a priority for NHS England and implementation is advanced in London with the Universal Care Plan (UCP). As part of this project, the Digital Health Passport team created a blueprint for 3rd party integration with the UCP and demonstrated interoperability with OpenEHR systems.



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“Hearing the personal experiences of people living with sickle cell anaemia was humbling, powerful and enlightening. The impact the condition has on people and on families looking after frightened children in extreme pain cannot easily be put into words and we’re extremely grateful to all the participants who took the time to share their stories. The knowledge that healthcare services fall short for these patients is not new, so it was motivating to understand how exactly we could make small but impactful changes.”

Dr Greg Burch

CARE PLANS

Demonstrating interoperability with London's Universal Care Plan

Our research demonstrates that a care plan provides limited value to patients in isolation. We recommend that care plans should be available to trusted 3rd party applications that offer value beyond the features of the NHS app. The Digital Health Passport team has demonstrated interoperability with OpenEHR systems that underpin the Universal Care Plan for London and is positioned well to offer a fully featured integrated service designed to meet the needs of people with sickle cell anaemia.

The Universal Care Plan service provided by the NHS allows every resident of London to have their care and support preferences digitally shared with healthcare professionals throughout the City. From March 2024, the Universal Care Plan (UCP) for London has been extended to support people with sickle cell disease, helping to ensure they get the right care wherever they are in the Capital.

Universal Care Plans in London are now available to patients via the NHS app.

The DHP technical team has worked with OpenEHR consultants and demonstrated the following technical steps to pull down a sickle cell care plan and return information to the 'About Me' section.

- 0 Initialisation
- 1 Retrieve the patient EHR object
- 2 Identify Care plan Composition ID
- 3 Read a Care plan
- 4 Update the "About Me" Section

This means that the Digital Health Passport can provide access to care plans created in London and support patients with the features they have told us they need.

OPPORTUNITY TO LEVERAGE THIS DEVELOPMENT

The Digital Health Passport can provide access care plans in the context of a self-management app designed specifically to meet the needs of patients with sickle cell anaemia. This goes beyond the current functionality provided in the NHS app. Our user research demonstrates that this approach will be more effective than accessing a care plan in isolation. Patients tell us they want care plans alongside self management support. This should include educational resources, being able to track their symptoms and medication use, with easy to access peer support - these are not features currently on the NHS app roadmap, but could be available to patients within months.

Make self-management smarter by personalising and automating the care plan

- 1 Medications are not just listed – they can be reordered, reminders enabled and tracking is available.
- 2 Contingency parts of the plan can be activated based on symptom tracking.
- 3 Emergency sections of the plan are easily accessible.
- 4 The “About Me” sections are editable and updateable.

The TMA technical blueprint [available on request] outlines how the Digital Health Passport can connect to the Better openEHR Digital Health Platform underpinning UCP. From initialisation, fetching the patient EHR object, identifying the composition ID for the Sickle Cell Plan, Reading the Care Plan and updating the “About Me” section.



“We believe patients should be provided with access to Sickle Cell Plans via the Digital Health Passport as soon as they become available on the UCP. By doing so, we can provide added value beyond the functionality of the NHS app for a group with specific needs and a poor choice of digital support tools. Patients deserve the best co-designed digital tools. The features they need, such as access to reliable information, symptom tracking, medication tracking and easy access to peer support should be readily available without further years of delay.”

Dr Greg Burch



What is sickle cell anaemia?

Sickle cell anaemia is an inherited condition affecting haemoglobin in red blood cells, responsible for carrying oxygen and giving cells their red colour. It is inherited when both parents pass on the sickle cell gene. The disorder causes anaemia and painful episodes known as sickle cell crises, occurring when deoxygenated cells change shape and block blood vessels. Treatment focuses on managing pain, sometimes with strong painkillers like morphine, and preventing complications.

Complications include stroke, acute chest syndrome, blindness and priapism. Over time, it can lead to organ damage, including to the liver, kidneys, lungs, heart, and spleen, and can be fatal. Sickle cell is the most common genetic condition in the UK, named for the crescent moon shape of affected red blood cells. This shape causes rigidity and blood vessel blockages, leading to pain and potential organ damage.

There are over 1,000 types of abnormal haemoglobin, but the most common in the UK are haemoglobin S, C, D, and beta thalassemia. It's estimated that 1 in 7 adults of African and Caribbean descent in the UK carry the sickle cell gene, with over 15,000 individuals having the disorder and 250,000 carrying the trait.

Factors triggering sickling of red blood cells include dehydration, infection, excessive exercise, organ failure, stress, anxiety, and sudden temperature changes. Babies are tested for sickle cell in the UK using a heel-prick blood test within their first week of life.



What is already known?

The report 'No-One's listening' (2021) was triggered by the Coroner's report into the death of Evan Nathan Smith in North Middlesex hospital.

The enquiry demonstrated:

Sub-Standard Care and Variation: Sick cell patients often receive sub-standard care, with significant variations depending on staff and location.

Lack of Joined-Up Care: There is a notable lack of effective joined-up care for sickle cell patients. Communication failures between different hospital departments impact care, and patient care plans are often ignored.

Low Awareness and Training: There is a low level of awareness about sickle cell among healthcare professionals, often necessitating patients to educate them during times of pain and distress. This lack of awareness is attributed to inadequate training for trainee nurses and medics. As a result, patients are frequently treated with disrespect, not believed, or not treated as a priority, with evidence suggesting that racism plays a role in these negative attitudes.

Inadequate Investment: Sick cell care suffers from inadequate investment. Services are under-resourced and under-staffed, with a lack of investment in research and treatments over decades.

Non-Adherence to National Care Standards: There is a lack of adherence to national care standards in sickle cell care, causing frustration among patients and clinicians.

Fear and Avoidance of Hospitals: Many sickle cell patients, due to their experiences of sub-standard care, fear accessing secondary care or avoid hospitals altogether.

The Sick cell digital discovery report: 'Designing better acute painful sickle cell care (2022)' commissioned by the NHS Race and Health Observatory set out to understand the broad availability of digital products and services that currently exist.

Researchers were struck by the limited amount of technology, dedicated health sites and web or digital tools that currently exist to support patients at the point of crisis and for managing the condition at home. These included online medical care plans, apps, wearables and dedicated forum pages.

When apps for sickle cell anaemia were identified, these were considered to be highly variable in quality and subject to poor user interaction, not widely downloaded nor regularly updated.



What is the Digital Health Passport?

The Digital Health Passport (DHP) is an app to support self-management of long-term conditions that develop in childhood. It has been co-designed with young people, parents, carers and professionals. Starting with asthma and allergies, the digital service is now being expanded to support families and young people with epilepsy, sickle cell anaemia and other long-term conditions.

Everything in One Place

Simplifies self-management by consolidating all necessary tools, information, and support into a single, easily accessible location.

Personalised Care Plans

A digital hub for a personal action plan, making it easy to share emergency instructions with friends and family.

Medication Reminders

Supports adherence to medication regimes, thereby improving overall symptom control.

Symptom and Peak Flow Monitoring

Enables early detection of worsening symptoms, allowing for timely medical intervention.

Trigger Avoidance

Provides air quality, weather and pollen alerts, to assist users in avoiding environmental triggers and effectively manage their health.

Psychosocial Support

Connects users to peer support, charity helplines and NHS urgent care services, ensuring they get the right care at the right time.

Educational Materials

Offers educational content from trusted sources like NHS.uk, Asthma & Lung UK, Young Epilepsy and the Anaphylaxis Campaign, enhancing users' skills, knowledge, and confidence in self-managing their condition.

NHS login

In commissioned areas, patients can use NHS login to access their GP record, order repeat medications and book appointments (coming soon!).



Glossary of key terms

Anaemia	A condition that occurs when your blood has a lower than normal amount of red blood cells or haemoglobin.
CAHN	Caribbean And African Health Network.
Core20PLUS5	A national NHS England approach to support the reduction of health inequalities at both national and system level. It identifies '5' focus clinical areas requiring accelerated improvement.
Disorder	A functional impairment and a disruption to the normal function of the body.
DHP	Digital Health Passport is a personal health record assistant that enables young people aged 13-25 years old with long-term conditions to take control of their health.
DTAC	Digital Technology Assessment Criteria. An NHS owned assessment that checks if your digital health product, or health app, meets the requirements.
Heel-prick blood test	A test that screen babies for nine rare but serious conditions.
ICB	NHS Integrated Care Boards.
Interoperability blueprint	A set of recommendations and best practices to facilitate integration and data exchange.
ISO/IEC 27001	ISO/IEC 27001 is the leading international standard focused on information security.
NIHR	National Institute for Health and Care Research.
OpenEHR	An open standard and specification for creating clinical data repositories and electronic health record (EHR) systems.
ORCHA	Organisation for the Review of Care and Health Apps.



Glossary of key terms

PPIE	Patient and public involvement.
SCD	Sickle cell disease. A group of inherited red blood cell disorders.
Sickle cell crises	Occurs when the flow of blood is blocked to an area because the sickled cells have become stuck in the blood vessel.
TMA	Tiny Medical Apps.
UCP	Universal Care Plan. An NHS service that enables peoples who live in London to have their care and support wishes digitally shared with healthcare professionals across the capital.



Dr Greg Burch, clinical lead Digital Health Passport and co-founder Tiny Medical Apps

“Sickle Cell Anaemia presents a significant healthcare challenge that demands attention and tailored solutions. By developing a robust app that offers comprehensive support and reliable information, we aim to empower patients and carers, addressing key needs while also fostering a sense of community. Together with organisations like CAHN, we are committed to making a positive impact in the lives of sickle cell patients and working towards reducing the disparities and challenges they currently face.”

“I’d like to extend my personal thanks to all the participants who attended the workshops and interview sessions. I’d also like to thank the Caribbean & African Health Network, with special mention to Dr Gertrude Wafula, as well as the NIHR i4i FAST grant for funding this work.”



Get in touch



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In partnership with

