Addressing the long recognised failings in sickle cell care

November 2026

NHS RACE & HEALTH OBSERVATORY

We're Listening

Building a Personalised Digital Sickle Cell Care Plan with Patients and Clinicians



SickleCell SOCIETY

Foreword

This review of the Digital Sickle Cell Care Plan programme is an important step in understanding how best to address long-recognised failings in sickle cell care. In focusing on patients' and clinicians' views, it seeks to ensure that the Digital Care Plan is rooted in the needs of patients and what works for clinicians, providing a blueprint for patient-centred, practical innovation.

We have long understood the issues with sickle cell care, as articulated in *No One's Listening*, the 2021 report produced by the All-Party Parliamentary Group on Sickle Cell and Thalassaemia and the Sickle Cell Society. It highlighted the low awareness of sickle cell among healthcare professionals which often results in patients having to explain their needs while in the midst of excruciating sickle cell crises. This lack of awareness – sometimes accompanied by prejudicial attitudes – can lead to analgesia being delayed or denied.

In response, the NHS Race and Health Observatory, in partnership with University Hospitals Bristol and Weston NHS Foundation Trust, conducted discovery work on the benefits of a Digital Sickle Cell Care Plan – a personalised digital record of a sickle cell patient's care needs. The intention of the Digital Care Plan is to tackle these care failings by helping healthcare professionals to quickly understand the severity of sickle cell and the needs of patients, thereby eliminating the need for patients to explain their condition or justify their need for pain relief. It is also intended to be highly personalised, thereby reducing the risk of complications relating to hidden or underlying factors.

This independent, expert-led review constitutes a crucial step in the Digital Care Plan programme, and the NHS Race and Health Observatory is committed to moving from discovery and design into delivery: confirming a delivery partner, securing further funding, and piloting the Digital Care Plan in a real NHS setting so that its impact can be tested and the model refined in practice.

We are incredibly grateful to everyone who participated in this review – the patients, carers and clinicians. Their experience and insights will help to ensure that the programme delivers the greatest possible change for patients with sickle cell.

We are also grateful that NHS England, alongside London's Integrated Care Boards and Haemoglobinopathy Coordinating Centres, laid the foundations for digital innovation in sickle cell care with the integration of sickle cell information into Universal Care Plans. However, the NHS is in a period of substantial change, with accountability for commissioning specialist care having shifted and the future of centralised initiatives to improve areas like sickle cell remaining unclear. This makes it all the more important that all care providers who are able to implement innovative and patient-centred initiatives such as these do so, and the NHS Race and Health Observatory and the Sickle Cell Society look forward to working with partners to deliver them.

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Acknowledgements

This report was led and authored by Zainab Garba-Sani, with contributions from Dr Carl Reynolds and Professor Habib Naqvi (NHS Race and Health Observatory) and John James, Zac Barnett and Aidan Rylatt (Sickle Cell Society). Cristiana Vagnoni provided operational support. Funding was provided through a grant from Vertex Pharmaceuticals. Vertex had no role in its design, content or delivery.

About the Reviewer



Zainab Garba-Sani is a Stanford and Imperial-affiliated Research Scholar and UK Commonwealth Fund Senior Harkness Fellow (2022–23), working at the intersection of health policy, innovation and community-centred practice. Her work focuses on how emerging fields such as artificial intelligence, genomics and regenerative medicine can be translated responsibly into real-world health impact – particularly for underserved populations and people living with chronic and rare conditions. She is the founder of ACCESS AI, an international initiative advancing equitable and inclusive approaches to health AI, and she holds senior advisory roles across gene and cell therapies, health equity and rare diseases. As one of the first adults in the UK to receive a curative stem cell transplant for sickle cell, she brings both professional expertise and personal experience to this review. She is Interim Chair of the Sickle Cell Society, was previously Founding Chair of NHS England's Sickle Cell Transformation Patient Advisory Group and Co-Chair of Genomics England's Diverse Data Advisory Board.



1. Executive Summary

This report presents the findings of an independent expert review and user insight gathering exercise conducted on behalf of the NHS Race and Health Observatory (NHS RHO)'s Digital Sickle Cell Care Plan programme. The review comprised two components: (i) an expert assessment of the programme's concept, priorities, approach and governance model, and (ii) seven structured focus groups gathering feedback on the prototype from patients, carers and clinicians.

A total of 38 participants took part: 28 patients and carers and 10 clinicians (paramedics, haematology and emergency department (ED) doctors, and red cell clinical nurse specialists), drawn predominantly from London with representation from Birmingham, Bristol, Hertfordshire, Kent, Leeds, Leicester, Manchester, Nottingham, Oxford, Southampton and Wakefield.

There was clear support across all groups for the underlying ambition of the Digital Care Plan: a personalised, portable, accountable digital record that reduces the time taken to administer adequate analgesia, eliminates the need for a patient to repeat their medical history/needs, and gives patients a stronger voice in their own emergency care. In particular, both patients and clinicians responded positively to specific prototype features such as the access/audit log, the plan's simplicity and readability relative to the existing Universal Care Plan (UCP), and the inclusion of patient preferences, escalation plans and feedback mechanisms.

However, support remains conditional. The plan's relationship to the existing UCP dominated the discussions. Participants were consistent in warning against a parallel, competing system and in asking for clarity on integration, data-pull automation and a single source of truth. A second consistent thread concerned how individual care plans would be governed, primarily: who may change what, how changes are validated, how the quality and trustworthiness of each plan is maintained, and what accountability exists when things go wrong. Clinicians were particularly cautious about patient-editable clinical fields (especially medication) while patients were concerned about clinicians overriding their input without consent. Some participants, particularly those without current UCP access, explicitly welcomed the initiative as a way of addressing a long-standing gap, whereas others suggested alignment and integration with the existing UCP.

The recommendations in Section 5 aim to address the risks participants raised while retaining the strengths that have been highlighted.

Summary of Recommendations

Phase 1:
Before Further Development

1. **Adopt integration with the existing UCP as the programme's model, rather than developing a standalone competing system.** *[Owner: Platform Delivery Team, working jointly with the UCP team]*
2. **Commission a workforce capacity and technical infrastructure assessment before further development.** *[Owner: NHS RHO Programme Team, with input from piloting Integrated Care Boards/trusts]*

Phase 2:
Before Pilot Deployment

3. **Develop a joint patient-clinician creation and sign-off model.** [Owner: Platform Delivery Team]
4. **Finalise content, set mandatory minimum data fields to guarantee a baseline standard of completeness and define a required review/update cadence.** *[Owner: Platform Delivery Team]*
5. **Establish clear data protection measures covering access, privacy and consent.** *[Owner: Platform Delivery Team, with Data Protection Officer input]*
6. **Design and communicate a clear, owned feedback and accountability pathway.** *[Owner: Platform Delivery Team]*

Phase 3:
During Pilot Testing, Training and Rollout

7. **Educate patients and clinicians about the Digital Care Plan and implement required testing and training.** *[Owner: Platform Delivery Team, with pilot trusts, system partners and advocacy leaders]*
8. **Undertake an equality impact assessment (including digital exclusion) and co-develop a mitigation plan with patients.** *[Owner: Platform Delivery Team]*

Phase 4:
Following Initial Pilot (Enhancing Functionality)

9. **Build functionality for real-time handovers.** *[Owner: Platform Delivery Team]*

2. Background and Methodology

The NHS RHO commissioned this programme following its research with University Hospitals Bristol and Weston NHS Foundation Trust in 2022-23 into acute sickle cell crisis care. It builds on the foundations of the *No One's Listening* report, a landmark inquiry in 2021 led by the All-Party Parliamentary Group on Sickle Cell and Thalassaemia and the Sickle Cell Society that exposed severe care failings, stigmatisation and systemic racism faced by UK sickle cell patients in secondary care settings.

The NHS RHO *Sickle Cell Digital Discovery* project found that a personalised digital care plan could improve healthcare access, experience and accountability for people with sickle cell. In particular, a good care plan has the potential to: enable faster, personalised analgesia; reduce the need for a patient to recount their medical history; improve accountability; minimise errors; facilitate care continuity and coordination between care providers and services; and help to address inconsistent or biased emergency care. The prototype under review is being developed as an open-source, patient- and clinician-facing service, distinct from the existing NHS UCP.

2.1 Review Scope

This review was led by Zainab Garba-Sani (see 'About the Reviewer') and comprised two elements:

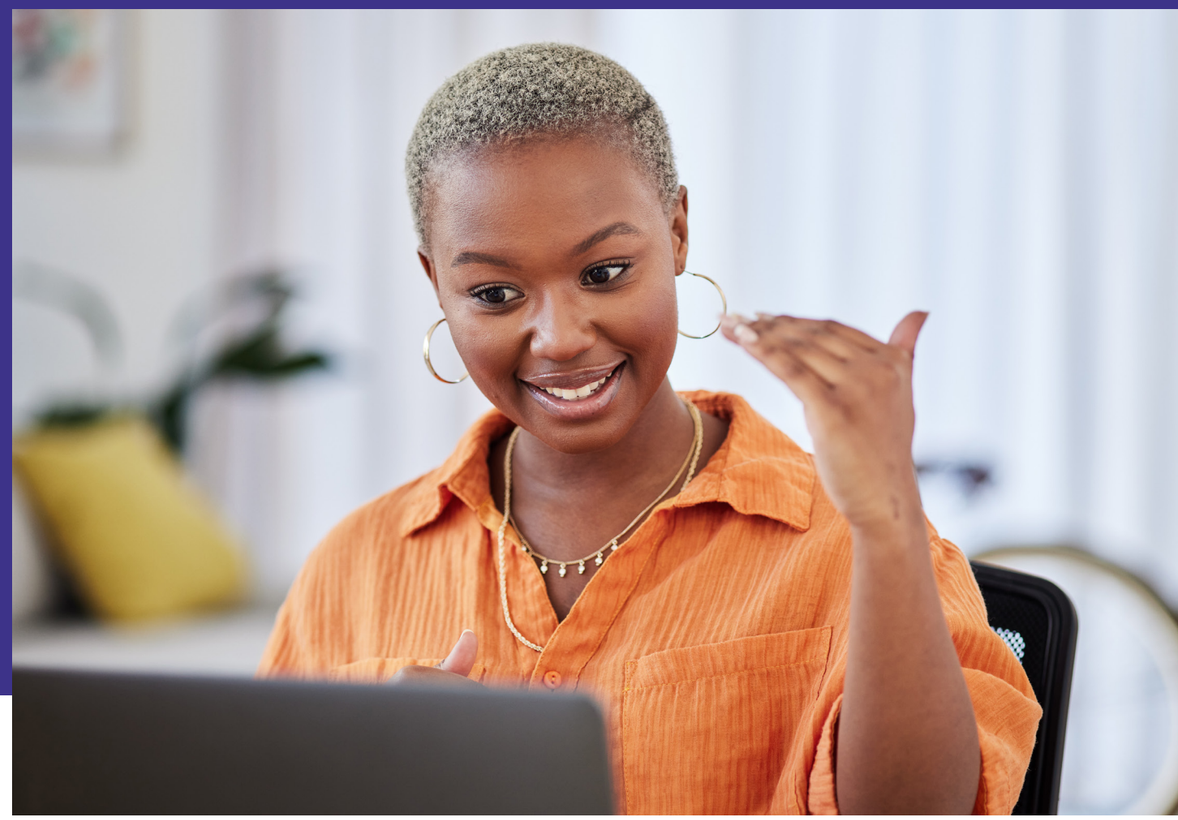
- An independent expert analysis of the programme's concept, priorities, approach and governance, drawing on health policy, digital health and sickle cell expertise alongside lived experience of the condition.
- Facilitation of seven one-hour focus groups to gather structured feedback on the prototype from patients, carers and clinicians.

2.2 Participants

A total of 38 participants took part, providing feedback between 27 July and 7 August 2026 across seven sessions held on Microsoft Teams.

Recruitment: Participants were recruited primarily through the reviewer's existing patient and clinician networks, supplemented by contacts suggested by the NHS RHO team. Given the aim of capturing a diverse range of perspectives and experiences, the reviewer used purposive sampling, deliberately inviting and asking contacts to recommend individuals meeting specific criteria (e.g. an ED clinician, a young person with sickle cell) to ensure coverage across clinical roles, age groups, geographies and levels of health service use. All participants were required to have direct experience of sickle cell emergency care, either personally, through caring for a loved one, or through treating patients with the condition. Participants were invited via social media, WhatsApp or email.

Participant Breakdown: The 28 patient and carer participants (24 patients, 4 carers) spanned a wide demographic, service usage and clinical range: from teenagers to retirees, employed and non-employed, male and female, high and low-frequency users of emergency services, and a range of genotypes and disease severity. The 10 clinician participants included 1 ED registrar, 2 paramedics, 3 red cell clinical nurse specialists and 4 haematology consultants.



Across all participants, geographic spread was predominantly London-based, reflecting where sickle cell prevalence is highest: 18 of 28 patients/carers and 8 of 10 clinicians were London-based, with the remainder (10 patients/carers and 2 clinicians) drawn from Birmingham, Bristol, Hertfordshire, Kent, Leeds, Leicester, Manchester, Nottingham, Oxford, Southampton and Wakefield.

Consent: As this exercise was conducted as an expert review and stakeholder engagement activity rather than formal research, no written consent form was used. Participation was opt-in throughout: individuals were invited to take part and were free to decline, with no obligation to participate. Prior to each session, participants were given background information, including a link to the programme website and the prototype, to allow them to familiarise themselves ahead of the discussion. At the start of each session, the reviewer explained the purpose and background of the exercise, confirmed that feedback would be written up in a report for the NHS RHO to inform the programme's next steps, and sought permission to record the session, making clear that recordings would be used solely for note-taking purposes and would not be shared. The reviewer also took written notes during each session as an additional record. All feedback has been anonymised and kept to a level of detail that prevents attribution to any specific individual.

2.3 User Insight Gathering Approach

Each session followed a consistent one-hour structure: welcome and introductions; background to the programme; discussion of the biggest challenges sickle cell patients face in emergency settings; a live demonstration of the prototype; open feedback discussion; and close.

2.4 Reporting Approach

Participant feedback has been summarised, thematically aggregated, and reflected upon through the reviewer's independent expert lens, resulting in recommendations to support the programme team's ongoing development and governance decisions. In 'Section 3: Thematic Findings', the reviewer has noted where a perspective was specifically that of patients, clinicians or the reviewer's own.

3. Thematic Findings

The following themes are presented sequentially, first addressing strategic questions, then structural and design considerations, and finally matters of delivery and wider context.

3.1 Relationship to Existing UCP

The theme most often raised by patients and clinicians alike, and arguably the most pressing strategic question for the programme, was how the proposed Digital Care Plan would relate to the existing UCP.

- **Risk to Existing Investment:** There was strong, repeated caution against introducing a system that duplicates or competes with the UCP, which many patients have advocated hard for, clinicians have already invested significant time in populating, and numerous advocates and health leaders have fed insight and feedback into. Furthermore, London clinicians expressed concern about fatigue from a succession of systems – "first the London Care Record, then the UCP, and now this proposed plan".

- **Workforce Capacity:** Clinicians explicitly reported that there was "zero appetite to re-enter data manually a second time" and asked whether a new plan could instead pull data automatically from the UCP and other clinical systems rather than requiring duplicate entry. This was especially the case for centres with large patient numbers, where the responsibility falls to a small number of staff on top of their existing clinical workload. (One clinician shared how a handful of staff members have already manually inputted over a thousand patients for two systems simultaneously).

- **Unmet Need in Areas Without UCP:** Regions where the UCP has not yet been implemented were particularly enthusiastic about the prospect of a personalised digital care plan of this kind.

- **Case for Expanding/Enhancing the UCP Instead:** Set against this, several participants asked directly why the programme did not simply improve or expand the UCP rather than build something new, noting that in some localities the UCP is already integrated into the NHS App and that the London Ambulance Service uses it widely for pre-hospital care.

- **Opportunity for Transformation:** Many participants nonetheless welcomed a fresh, patient-led, purpose-built system – both as a way of extending digital care plans to those currently without UCP access and, for those with UCP experience, as a chance to address its existing limitations (e.g. its palliative-care origins, limited patient visibility and input, complexity and difficulty to find/use for clinicians, and variable quality). Participants saw this as an opportunity to build trust and drive transformation through a genuinely community-led design and development process.

- **Logistical Implications:** Across both those in favour of and those cautious about the proposed programme, the consistent ask was for the team to define and clearly communicate, before wider rollout, the relationship between the two systems, including whether adoption will be opt-in or opt-out, how the two care plans will interoperate, what happens when a patient has an existing UCP and the two sources differ, and which plan should take priority in that scenario. One clinician suggested drawing lessons from child protection plans. *[Reviewer Note: Child protection plans are linked to a central database of electronic care records so that when a vulnerable child presents to an ED or unfamiliar care setting, a system flag automatically notifies treating clinicians to follow specific protocols.]*

"... the most pressing strategic question for the programme, was how the proposed Digital Care Plan would relate to the existing UCP."

3.2 Care Plan Editing Rights, Validation and Accountability

Both patient and clinician groups raised detailed and largely convergent concerns about who should be able to create or amend which fields, and how those changes should be validated.

- **Creation Model:** There was broad support for a joint creation model whereby the Digital Care Plan is populated collaboratively by the patient and specialist consultant (and/or nurse) in the same session, with both parties formally agreeing before the plan is saved.

- **Confidence and Trust in the Plan:** There was consistent concern about patients independently editing clinical fields, particularly medication details (e.g. drug, baseline and maximum dose, and route). Both patients and clinicians shared anecdotes and concerns regarding medication errors (involving under- or over-stating doses), citing risks associated with patients who lack clinical training, misuse of the system by individuals fraudulently claiming a sickle cell diagnosis, and the particular vulnerability of patients with opioid dependency. Clinicians highlighted that, although this applies to less than 1% of their patients, for these individuals, "giving them the authority to indicate what drug and dose they want will be problematic", especially given "how often they use the system". One clinician also recalled individuals "pretending" to have a sickle cell diagnosis in order to access opioids in their ED. While clinicians were clear that the overwhelming majority of patients presenting to emergency services are unwell and deserve trust and excellent, compassionate care, this small minority (rather than the patient population as a whole) was what drove their caution. *[Reviewer Note: Despite being rare, these incidents amplify stigma and mistrust from clinicians and subsequently emphasise the need for a system that can be trusted so that patients can get the care they need, when they need it. This is an important consideration for the wider design of the Digital Care Plan, as any innovation of this kind needs to safeguard the wider population.]*

- **Ownership and Approval Model:** Clinicians felt strongly that ownership of clinical information in care plans should lie with them since they have ultimate responsibility for patient safety. However, in line with good practice, they felt patients should contribute to a shared decision-making process. Some patients agreed, especially those concerned about the risk of a small number of individuals who may misuse the system, or about inadvertently disadvantaging themselves by recording too low a dose. Clinicians also worried that, if other treating staff could not easily and quickly distinguish between patient- and clinician-authored entries, it could undermine trust in the plan and unintentionally introduce further bias or discrimination. Several participants noted that existing care plans are already undermined by a lack of trust of this kind and are inconsistently followed as a result. *[Reviewer Note: The aim for the Digital Care Plan should be to avoid repeating this pattern.]* In response, patients proposed a "traffic light" model to signal approval status: red where neither patient nor (named) specialist has approved the plan, amber where one has, and green where both have, or a pending-approval status on clinical entries such as medication. Clinicians, however, were concerned that a visible amber or red status could undermine confidence in the plan during an emergency and instead felt that clinical fields (e.g. medication and escalation plans) should be editable by specialists only. Nevertheless, both patients and clinicians agreed that patient preference fields should remain editable by patients at any time, without requiring approval.

- **Patient-Provider Relationship:** Some patients worried about clinicians amending or overriding patient-entered information without consent and the damage this could do to trust in the relationship. They foresaw the risk of unresolved disagreement leading to each party repeatedly overriding the other's edits. There was a repeated request for a patient-approval step before any clinician-made change is published and for patients to be notified when changes are proposed.



- **Audit Trail:** The access-log/audit-trail approach was widely welcomed as a way of understanding what edits had been made to a plan and by whom. Some patients felt that this alone was sufficient to address concerns about distinguishing patient from clinician edits, whereas others believed additional safeguards (as discussed above) were necessary in busy clinical settings.

- **Feedback Mechanism:** Patients praised the feedback form's simplicity, noting it would be easier to use during a crisis. However, both patients and clinicians repeatedly requested a clear complaints and accountability pathway. They emphasised that audit logs are only useful if breaches or errors trigger a defined route for escalation and consequences. They also sought clarity on ownership – specifically, who receives and is responsible for acting on the feedback. This varied, with some clinicians believing the feedback should go to the specialist team. Regardless, the concern was ultimately underpinned by a recurring caution (drawn from experience of existing complaints and feedback channels) that collecting feedback does not automatically change practice. Several patients expressed frustration with a perceived lack of accountability and limited visible impact from previous feedback, and asked what mechanism would "drive action this time". Furthermore, both patients and clinicians warned that using the tool punitively, rather than developmentally, could spark clinician resistance and jeopardise implementation.

3.3 Access and Equity Implications

Reflecting well-evidenced disparities in sickle cell care outside specialist centres, participants placed strong emphasis on the Digital Care Plan's reach and portability.

- **Timely and Appropriate Emergency Care:** Patients frequently described ambulance crews defaulting to the nearest hospital rather than their preferred hospital, which would be familiar with their history and (often) possess specialist sickle cell expertise. Consequently, the prototype's preferred-hospital and named-consultant fields were welcomed as a direct response. Additionally, reflecting frustrations regarding ambulance and ED delays, patients requested functionality for paramedics to add real-time ambulance-to-hospital handover information (such as treatment already started) to give EDs visibility before the patient physically arrives.

- **Support in Unfamiliar Settings:** Some patients reported concerns that existing care plans are not reliably accessible across trusts or regions (e.g. a plan created in one trust being unavailable to ED staff elsewhere). This led to strong support for the Digital Care Plan being linked to an NHS number rather than a hospital-specific number. However, it also raised a practical question regarding how staff would access the plans: would clinicians need to register their own accounts before treating a patient? *[Reviewer Note: Where this presents a barrier, the programme must consider how to overcome the ongoing challenge whereby care plans shown directly to staff by patients are frequently mistrusted or ignored.]*

- **Improving Non-Specialist Care:** Patients emphasised poorer care from staff unfamiliar with sickle cell, including de-prioritisation from ambulance and ED staff. Clinicians confirmed marked variation in staff knowledge and confidence in treating sickle cell outside of London and major specialist centres, reinforcing the case for a nationally consistent, easily locatable plan. The NHS brand identity was seen as a strong credibility indicator in this respect, especially in minimising resistance to care plans from staff at other, unfamiliar hospitals.

- **Continuity Across the Care Pathway:** Numerous clinicians and patients asked for the Digital Care Plan to extend beyond the emergency setting and provide instruction across the full care pathway (ambulance, ED, ward (timely transfer/escalation) and discharge), especially for out-of-area hospitals and non-specialist services. This was a feature of the UCP that was well-regarded. A carer extended this further, suggesting access could also be given to schools and employers to support continuity of care outside clinical settings. *[Reviewer Note: Providing access to non-healthcare professionals raises further data security and privacy implications beyond those discussed in Section 3.4].*

- **Geographical Equity:** Clinicians and patients explicitly requested national rollout across the UK, not only London and Manchester where the UCP currently operates.

- **Digital Exclusion:** A patient was concerned about other patients with limited access to digital infrastructure, whether due to data poverty or low digital literacy. *[Reviewer Note: Although joint creation (with a clinician populating the plan alongside the patient) may offer a partial mitigation in these circumstances, this does not fully resolve the question of access for other vulnerable populations who may lack a regular clinical touchpoint through which to create or maintain a plan. Special consideration is therefore needed in order to avoid worsening disparities.]*

3.4 Data Governance, Security and Consent

Participants were broadly supportive of the proposed data-sharing arrangements but consistently linked this support to clear safeguards as to who can see and act on their information.

- **Data Protection:** Concerns about data protection led patients to request tiered, role-based access to care plans rather than blanket clinician-wide access by default. *[Reviewer Note: This would mean identifying which roles should have access and at what level. For instance, specialist red cell doctors and nurses might hold editing rights, while ED doctors and nurses might hold viewing rights only, with other hospital specialities required to request access where appropriate.]* Patients were keen to know that the platform would be GDPR-compliant and secure while also raising concerns about the potential impact of a data leak on insurance, employment and privileges such as driving. *[Reviewer Note: Consequently, there is a need for the programme to publish clear, accessible guidance on data use and safeguards.]*

- **Delegated Access:** Patients, although welcoming the functionality, raised concerns about delegated/proxy access being granted to the wrong person in error and requested a confirmation step before access is shared.

- **Data Sharing Consent:** Patients wanted clarity around data ownership and more flexible (rather than one-size-fits-all) consent mechanisms for the research use of their data. Specifically, they requested that they be asked before data is shared for research purposes and to have greater choice over which research they consent to, what data is shared and how it is used.

- **International Access:** Whether access could be extended to non-NHS or international clinicians was raised as an open question, given some patients' experience of receiving care outside the UK.

3.5 Content Standards and Quality Assurance

Participants noted a tension between wanting sufficient personalised detail and avoiding a plan that is too long or complex to use reliably.

- **Minimum Quality Standard:** During the prototype demonstrations, both patients and clinicians commented on the clear disparity between two examples shown: one patient's detailed, well-populated plan and another that was sparsely populated. This led to multiple requests for mandatory minimum fields before a plan can be saved, to guarantee a baseline standard. This was noted as an existing limitation of the UCP, though it was acknowledged that staff capacity may be a barrier to developing in-depth personalised plans for large numbers of patients. *[Reviewer Note: Providing a way to automate and reduce this staff burden could significantly improve plan quality and help ensure plans are genuinely personalised rather than generic.]*

- **Comprehensiveness of Plans:** A number of participants across both stakeholder groups flagged that sickle cell emergencies are not always limited to pain and that plans must be comprehensive enough to capture other risk factors. Comorbidities (e.g. diabetes and heart disease) were repeatedly flagged as needing clearer, more prominent visibility, especially given the risk of a patient being unable to communicate this during a crisis. Similarly, where a patient has previously experienced other complications, such as aplastic crisis, acute chest syndrome, or severe infection, clinicians felt that this should be clearly communicated so that emergency staff are aware and can watch for signs of deterioration.

- **Simplicity:** Clinicians favoured keeping the plan to essential information only (e.g. baseline oxygen saturation and haemoglobin), citing capacity constraints around maintaining more detailed records at scale and time pressure in emergency settings. Some patients, conversely, valued the ability to record more personal detail (e.g. difficult venous access or personal, faith-based and cultural preferences). It was widely agreed that contact information for next-of-kin and the named consultant was a highly valuable inclusion.

- **Keeping Up to Date:** There was consistent uncertainty from both patients and clinicians about how plans will be kept current. Rather than relying on ad hoc updates that risk patients falling through the gaps, there was strong support for linking review and update points to in-person annual review appointments and each discharge, thus integrating plan maintenance into existing workflow to reduce clinician burden and encourage patient engagement.

3.6 Design and Usability

The prototype's interface and platform choices generated largely positive, practical feedback focused on usability in fast-paced emergency environments.

- **UCP Comparison:** The interface was consistently rated as clearer and quicker to navigate than the UCP, which several clinicians described as requiring extensive scrolling through less relevant (originally palliative-care-oriented) content.

- **Platform Type:** Several patients and clinicians asked how the service would be accessed, highlighting ease of access as an important feature. Some patients queried whether the Digital Care Plan could be delivered as a mobile app or integrated into the existing NHS App, while others were comfortable with a standalone website provided the sign-in process was straightforward. This was a particular point of discussion in one session, where patients noted that the current sign-in process (a separate registration via personal email rather than NHS App login) requires clearer user guidance to avoid confusion with the UCP. Clinicians similarly emphasised the importance of maintaining a simple, efficient sign-in process, noting that access barriers are a current limitation of the UCP.

- **Key Information:** Clinicians (especially paramedics and emergency doctors) displayed a strong preference for a concise, high-signal layout supporting rapid handover in emergency settings. They referenced structured rapid handover approaches such as SBAR (Situation, Background, Assessment, Recommendation) and asked for critical information (such as target time to analgesia (first 30 minutes and subsequent doses), oxygen requirement, escalation protocols and named consultant/ preferred hospital) to be bolded or otherwise highlighted to support this. Similarly, patients requested that key national guidance messaging (such as ACT NOW) be highlighted within the plan.

3.7 Implementation and Systemic Change

Participants consistently linked the plan's success to wider systemic factors beyond its design, including staff behaviour, workforce capacity and technological capabilities.

- **Poor Use of Care Plans:** Both patients and clinicians reported concerns that care plans (current and proposed) can be applied too rigidly, leaving little room for nuance and clinical judgement. It was noted that clinicians, especially those less familiar with sickle cell, may follow a plan without reference to a patient's actual presentation on the day or, equally, refuse to give medication not listed in a plan. Patients also shared how, conversely, care plans may be disregarded altogether in the same way verbal patient reports sometimes are. This was felt to be particularly pertinent to sickle cell patients (especially those "looking well" and/or presenting without carers/ advocates).

- **Tackling Systemic Bias and Discrimination:** Many patients described experiences of not being believed about their pain severity and of care being influenced by stigma or assumptions of drug-seeking behaviour. Some even described having to "exaggerate" symptoms to be taken seriously. Some patients also expressed concern that clinicians recording notes about a patient's behaviour on a plan could reinforce bias in future encounters rather than reflecting an accurate or fair account of an individual crisis. Numerous patients described having a high threshold for deciding to seek emergency care in the first place, often shaped by past experiences of not being believed. Ultimately, both patients and clinicians expressed a clear need for the Digital Care Plan to be paired with staff training, investment in behavioural change interventions, and a marked cultural shift towards compassionate, consistent care rather than being positioned as a standalone technical fix. This need was felt to be especially pronounced outside London, where clinical knowledge, experience and attitudes towards sickle cell patients often decline. *[Reviewer Note: In 2024, NHS England's Behavioural Science Unit conducted research to understand clinical behaviour and attitudes towards sickle cell patients in EDs and its impact on administering timely and adequate pain relief.]*

- **Capacity and Infrastructure:** Beyond the duplication concerns raised in Section 3.1, clinicians were more broadly concerned about the time and workforce capacity required to populate and maintain plans to a high standard at scale, independent of whether this is a first or second system. Some clinicians did not foresee plans needing major changes after initial upload but nonetheless emphasised the significant upfront burden of initial population. *[Reviewer Note: This reinforces the case for automated data-pull from existing systems where possible, which would likely require investment in interoperable technical infrastructure.]*

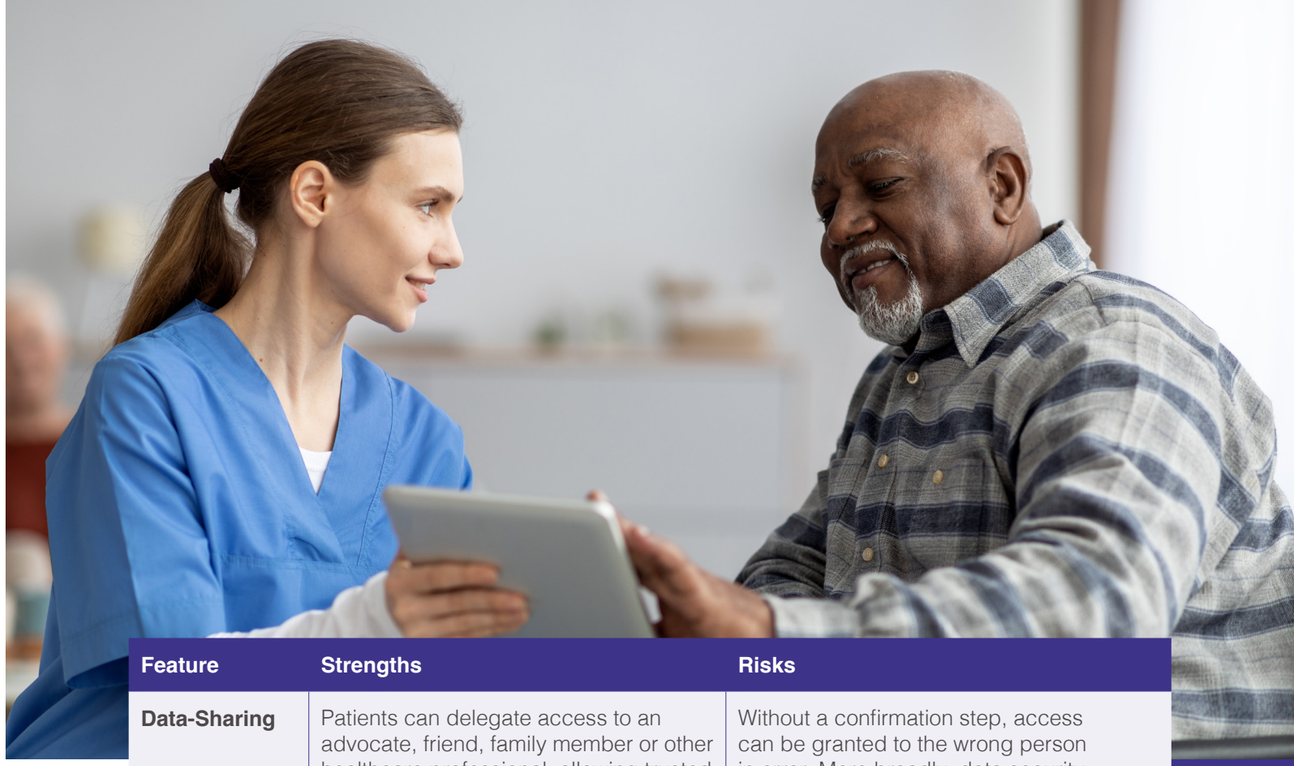
- **Operational Rollout:** Regarding implementation, participants supported the proposed phased approach, which focuses on piloting in a small number of hospital trusts before wider scaling. One clinician suggested testing the plan through simulation exercises with ED and ambulance teams before live deployment. Additionally, there was clear appetite for joint patient-clinician training sessions ahead of rollout, in which patients could support clinicians in understanding what a good care plan and approach look like from a patient's perspective. Both patients and clinicians also flagged that training should be coupled with communications to ensure people are aware that the Digital Care Plan exists – this was noted as an implementation limitation of the UCP.

- **Other Impactful Interventions:** Participants across both stakeholder groups highlighted the value of other transformation initiatives for improving crisis care, including ED bypasses, the UCP and local digital care plan variants, the London Ambulance Service's improvement work, and efforts to improve workforce training and culture (e.g. sickle cell e-learning modules). Patients and clinicians were clear that this programme should not be developed in isolation from this wider landscape of work.

4. Summary of Strengths and Risks

The table below summarises the participant-reported strengths and risks of various prototype features, alongside the reviewer's analysis.

Feature	Strengths	Risks
Accountability (Access/Audit Log)	The access/audit log clearly shows who accessed the plan, what action they took (e.g. view, edit, consent update) and exactly when. For clinicians, this fosters trust by identifying who authored the plan and its critical medical instructions. For patients, it promotes accountability and higher standards of care.	Audit logs must not be used to villainise individual staff. If perceived as punitive rather than developmental, they risk staff resistance and could undermine effective implementation. Framing the log as a route to identifying training needs and gaps (and not to assigning blame) will be essential. More broadly, any accountability or complaints pathway risks falling short without clear ownership of where feedback goes and who is responsible for acting on it.
Simplicity and Readability	Widely rated as clearer, less cluttered and easier to use than the existing UCP, which several clinicians described as "clunky" and requiring extensive scrolling or searching to locate a patient's plan. Patients also valued the simplicity of the feedback function.	A minimum amount of information is needed to ensure clinical utility. If too generic and overly standardised, it risks defeating the purpose of a personalised care plan, particularly for patients with more complex needs. Additionally, plans should be comprehensive enough to capture clinically important information such as comorbidities and other significant risk factors.
Patient Access and Voice	Patients can access and help to populate the plan, with dedicated fields for personal preferences, an advocate/ emergency contact section, and a feedback log to capture individual care episodes while still fresh in their memory.	Patient editing rights can undermine clinician trust in the plan, with particular concerns around rare instances of medication misuse or plans becoming inaccurate where patients lack the clinical knowledge to specify treatment correctly.
Escalation and Safety Information	Critical information (such as target time to analgesia, escalation protocols and named consultant/preferred hospital) is prominently displayed, supporting fast, high-signal handover in emergency settings.	If followed too rigidly, escalation protocols may be applied without reference to a patient's actual presentation on the day, echoing a concern also raised about the existing UCP.



Feature	Strengths	Risks
Data-Sharing	Patients can delegate access to an advocate, friend, family member or other healthcare professional, allowing trusted individuals to view or help manage the plan on their behalf.	Without a confirmation step, access can be granted to the wrong person in error. More broadly, data security, privacy, safeguarding and the associated governance arrangements must be prioritised. Clear role-based permissions and appropriate access controls will be required to ensure information is shared safely and appropriately (including with other clinical staff).
Design Credibility	The NHS-consistent visual style and colour scheme were cited by clinicians as increasing trust in the source and reliability of the information shown.	The UCP is already established and being integrated into the NHS App, which is widely known and recognised by both patients and staff. As a new, unfamiliar interface, this plan does not yet carry the same institutional trust and will need careful communications and sustained engagement to build an equivalent track record.
Portability (Cross-Trust Access)	The ambition for a single plan which is accessible across trusts and ambulance services was strongly welcomed, particularly by patients with experience of being treated outside their home trust. Some participants went further, requesting pathway-wide instructions spanning non-emergency services and even non-clinical settings.	Some trusts are already using the UCP. Where the two plans differ, it is unclear which should be followed and who is responsible for ensuring both are kept up to date and consistent with one another. This presents a significant challenge, particularly for sickle cell services with large patient numbers and an already stretched workforce. Adding non-emergency services and non-clinical settings also adds a layer of complexity and a risk to data security and privacy.

5. Recommendations

The following recommendations are drawn from the themes participants raised, the reviewer's expert judgement, and feedback from the Sickle Cell Society. Recommendations are organised by delivery phase and the body best placed to act on each. Given the shifting national landscape for sickle cell improvement work, including the expected transition of work from NHS England to the Department of Health and Social Care (DHSC) and Integrated Care Boards (ICBs), the ownership of recommendations may shift over time between national and regional bodies.

Key Stakeholders	Role Descriptor
NHS RHO Programme Team	Commissioning team responsible for strategic direction, commercial and programme delivery, tendering and the technical and legal infrastructure for a new service.
Platform Delivery Team	Joint operational team responsible for building and maintaining the Digital Care Plan. Will likely include the appointed delivery partners, UCP team representatives, and relevant NHS RHO staff, reflecting the recommended integrated approach.
NHS Trusts	The clinical settings responsible for operating and evaluating the pilot, with support from haematology, emergency services and IT.
Other Partners	
Sickle Cell Society	*Patient advocacy partner responsible for ensuring the programme reflects lived experience and community priorities and for providing ongoing feedback on programme direction.*
ICBs/NHS England/ DHSC	*Commissioning and system partners responsible for sickle cell transformation initiatives at regional and national level. ICBs are the anticipated local commissioning partners for regional rollout and coordination and are due to assume responsibilities currently held by NHS England as it transitions. NHS England and DHSC currently hold overall system responsibility for shaping health policy, funding priorities and improvement work relating to health inequalities and specialised services such as sickle cell care. As NHS England's functions transition, aspects of national oversight are expected to transfer to DHSC. Collectively, these bodies are key partners for coordination and collaboration across national and regional sickle cell transformation efforts.*

Phase 1:
Before Further Development

1 **[Owner: Platform Delivery Team, working jointly with the UCP team] Adopt integration with the existing UCP as the programme's model, rather than developing a standalone competing system.** This represents a change from the programme's current direction which seeks to deliver a standalone, workable digital service by 31 March 2027. Instead, the delivery team should work jointly with the UCP team to expand a combined system nationally, incorporating features and improvements highlighted through this review (e.g. simplified navigation, sickle cell-specific fields, patient preference and escalation content) into a single, universal plan rolled out consistently across all regions. This will require dedicated engagement with regional ambulance services, recognising that UCP access and ED bypass pathway arrangements vary by region. For instance, the London Ambulance Service's UCP access and its pathway with London's ED bypass units are not necessarily matched in other areas with a UCP and/or ED bypass pilot, such as Manchester and Sheffield/Leeds. Rollout should prioritise regions currently without UCP access.

[Reviewer Note: Participant views on the proposed plan's relationship with the UCP were genuinely mixed (Section 3.1), and the case for a fresh, purpose-built system (free of the UCP's palliative-care origins and limitations) was well made by several participants. However, Recommendation 1 is guided by the most strongly and consistently expressed concerns across the review, namely: the risk of undermining existing investment; limited workforce capacity and infrastructure; the practical challenge of maintaining two separate systems with potentially conflicting data; and the 'system fatigue' already reported by clinicians facing a succession of platforms. The UCP's existing integration with the NHS App and National Record Locator service means that several of the access and sign-in challenges raised about a new standalone system (Section 3.6) are already addressed within the UCP's infrastructure. On balance, integrating this review's recommended improvements into the UCP, rather than building a parallel system, offers a strong route to addressing the UCP's current limitations and widening access.]

2 **[Owner: NHS RHO Programme Team, with input from piloting ICBs/trusts] Commission a workforce capacity and technical infrastructure assessment before further development,** specifying what data-pull automation from existing clinical systems (e.g. Epic) is technically feasible and who is responsible for funding and delivering the staff time and interoperability work needed to populate and maintain plans at scale.



“Reflecting well-evidenced disparities in sickle cell care outside specialist centres, participants placed strong emphasis on the Digital Care Plan’s reach and portability.”

Phase 2: Before Pilot Deployment

3 **[Owner: Platform Delivery Team] Develop a joint patient-clinician creation and sign-off model**, with clinical fields (particularly medication) requiring clinical specialist validation and not being directly patient-editable, while preferences and contextual fields remain patient-editable without the need for specialist approval (only notification). Define the approval workflow for subsequent edits (e.g. patient-suggested changes to clinical fields triggering clinician review; clinician changes requiring patient acknowledgement) and confirm whether plans not jointly approved are published for use in an emergency.

4 **[Owner: Platform Delivery Team] Finalise content, set mandatory minimum data fields to guarantee a baseline standard of completeness and define a required review/update cadence** linked to existing clinical touchpoints (appointments, discharge, annual review), with named ownership for prompting and completing reviews. Patients should be invited to record suggested additions and amendments to their care plan in the weeks leading up to their annual review appointment to encourage attendance and increase efficiency. Furthermore, a distinct field should be introduced for comorbidities and significant prior complications (e.g. aplastic crisis, acute chest syndrome, stroke, transfusion reactions). The plan should also bold key details (such as escalation plans, patient preferences and other critical safety information) and include important awareness messaging from the ‘Can You Tell It’s Sickle Cell’ and ‘ACT NOW’ campaigns – e.g. marked in bold at the top of the plan: *Sickle cell is a medical emergency, and pain medication should be provided within 30 minutes…*

5 **[Owner: Platform Delivery Team, with Data Protection Officer input] Establish clear data protection measures covering access, privacy and consent.** This includes defining tiered, role-based access arrangements (rather than defaulting to blanket clinician-wide access); a confirmation step before delegated/proxy access is granted; published, accessible guidance on data use and GDPR compliance; and more granular, flexible consent options for research data sharing.

6 **[Owner: Platform Delivery Team] Design and communicate a clear, owned feedback and accountability pathway**, specifying who receives and acts on complaints, so audit logs and the Friends and Family Test translate into visible follow-up.

Phase 3: During Pilot Testing, Training and Rollout

7 **[Owner: Platform Delivery Team, with pilot trusts, system partners and advocacy leaders] Educate patients and clinicians about the Digital Care Plan and implement required testing and training.** Prior to rollout, run simulation-based testing with patients and ED, ambulance and specialist teams to plan and mitigate any implementation challenges, and confirm scope for discharge and ward-transfer plans. During live deployment, deliver mandatory clinician training (with patient input) and scale wider workforce education on sickle cell care so the tool is not positioned as a standalone fix for systemic bias and inconsistent care (Section 3.7) but rather builds upon existing transformation efforts. Training should include: (a) for specialists – what makes a good care plan and what additional information (e.g. documents) should be uploaded and (b) for emergency clinicians – essentials (including behaviour) for managing a sickle cell crisis.

8 **[Owner: Platform Delivery Team] Undertake an equality impact assessment (including digital exclusion) and co-develop a mitigation plan with patients**, particularly those unable to use a digital-only care plan.

Phase 4: Following Initial Pilot (Enhancing Functionality)

9 **[Owner: Platform Delivery Team] Build functionality for real-time handovers** which allows paramedics to share information such as treatment already administered so that EDs have visibility of a patient’s status before they physically arrive. The same functionality could extend to other transition points across the care pathway such as between ED and ward, or at discharge.

6. The NHS RHO's Next Steps

The NHS RHO has identified the following next steps, to enable them to achieve their immediate priority in moving from discovery and design into delivery.

1 Secure an NHS delivery partner

Identify and agree an NHS trust, working with the relevant ICB and clinical teams, to act as the principal pilot partner, and provide the clinical, operational and digital environment needed to implement and evaluate the Digital Care Plan.

2 Secure additional Vertex funding

Develop and submit a proposal for further Vertex support to fund the next phase of development and implementation, including the technical, clinical and evaluation resource required for the pilot.

3 Deliver the pilot

With a delivery partner and funding in place, focus programme activity on implementation: agree a minimum viable scope, resolve the key integration and governance requirements identified in this review, deploy the Digital Care Plan in a real NHS setting, and evaluate its impact. The emphasis for the next phase should be on delivery, learning from implementation, and iterating the model in practice.



"The prototype's interface and platform choices generated largely positive, practical feedback focused on usability in fast-paced emergency environments."

7. Bibliography and Further Reading

7.1 Programme Information

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7.2 Existing Sickle Cell Transformation Initiatives

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7.3 Sickle Cell Reports and Policy

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"Participants noted a tension between wanting sufficient personalised detail and avoiding a plan that is too long or complex to use reliably."



7.4 Peer-Reviewed Literature

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7.5 Commentary by the NHS RHO Programme Team

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