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SCORE - Sickle cell outreach, resources & engagement

Submission date
05/08/2025

Recruitment status
Not yet recruiting

Registration date
12/08/2025

Overall study status
Ongoing

Last Edited
12/08/2025

Condition category
Haematological Disorders

[X] Prospectively registered
[X] Protocol
[_] Statistical analysis plan
[_] Results
[_] Individual participant data
[X] Record updated in last year

Plain English summary of protocol

Background and study aims
Sickle cell disease (SCD) primarily affects ethnic minorities, so in addition to having a chronic health condition requiring lifelong medical care and frequent hospitalisations, patients experience stigma and poverty, with consequent marginalisation and disparities in healthcare.

The study research questions focus on exploring the functions, operation and locations of community SCD health and wellbeing hubs that bridge the community-health service interface. The questions have been articulated by our Liverpool sickle cell patients and their carers to reflect their need for more holistic, patient-centred care in their communities. These hubs could provide holistic and culturally appropriate support, thereby improving SCD patients' wellbeing and resilience. This would also benefit health services by reducing workload and helping patients navigate NHS access pathways more effectively.

This research responds to a highly critical UK government report highlighting the neglect of SCD and recommending improvements in community provision. In the UK, funding for SCD is disproportionately low compared to other chronic diseases and resources are concentrated in high-prevalence areas. There is very little evidence to guide the design and function of community SCD hubs that is transferable to the Liverpool area, where prevalence is low. Evidence from the USA, from non-SCD chronic conditions and from studies of social determinants of health indicates that community hubs can reduce hospital visits and improve quality of life, resilience and patient outcomes. Examples of potential SCD hubs' functions include health education, counselling and advice on screening and 'buddies' for hospital appointments.

Who can participate?
Adolescents aged 15+ living with SCD (with parental consent and their consent), adult carers of people with SCD, SCD healthcare providers, relevant stakeholders (e.g. from social services, Citizens Advice, councils, and academia), and individuals working with community or non-governmental organisations supporting those affected by SCD.

What does the study involve?
This 15-month project will collate and use evidence to co-design (with patients/carers)

community SCD hubs for Liverpool (i.e. an intervention) for trialling in a subsequent study, focusing on adult healthcare and the paediatric adult transition. The methodological framework is the Delphi process with three rounds of engagement with 8-10 diverse, representative participants to achieve a consensus recommendation about the intervention. Additional information from a scoping literature review, survey, focus group discussions and interviews will feed into the Delphi discussions. At the centre of all our activities are community research champions who will be trained and supported, drawing on the Research Delivery Networks (RDNs) successful model for engaging marginalised communities in research.

Our primary output is a 'test-ready' intervention to trial 4-5 SCD community hubs and to assess feasibility, acceptability and potential evaluation metrics. Secondary outputs include a literature review (month 5), a cohort of trained community research champions (start month 3), community engagement in research, a co-refined Theory of Change to underpin future testing of the intervention, and workshops (months 3,14) to gain multiple perspectives and share our findings with relevant local organisations.

Building on applicants' and collaborators' networks, the list of target organisations for knowledge sharing will be extended, and the timing and best modes (e.g. social media, face-to-face, publications) for reaching them will be determined. Ultimately, the impact will be to contribute to reducing health disparities for SCD patients in Liverpool and to relieving pressure on the NHS, simultaneously strengthening patients' research engagement and trust in health services to reduce their marginalisation.

What are the possible benefits and risks of participating?
There will be no direct benefits to study participants, but this study will help us to understand the key factors to improve the wellbeing and resilience of people living with sickle cell disease and how resource centres can help to realise this.

This is a very low-risk study, as it only asks participants to reflect on their experiences and how they feel community resource centres or hubs for sickle cell disease patients will be helpful. However, if participants have had some unpleasant experiences, this might be difficult for them to talk about. These experiences are not being asked about directly, but if at any point the questions are upsetting to participants, they can pause the survey or stop it altogether. Participants can decline to answer any questions they are not comfortable answering.

Where is the study run from?
Liverpool School of Tropical Medicine (LSTM), UK

When is the study starting and how long is it expected to run for?
May 2025 to August 2026

Who is funding the study?
National Institute for Health and Care Research (NIHR), UK

Who is the main contact?
Ms Susie Crossman, susie.crossman@lstmed.ac.uk

Contact information

Type(s)
Public, Scientific, Principal Investigator

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Additional identifiers

EudraCT/CTIS number
Nil known

IRAS number

ClinicalTrials.gov number
Nil known

Secondary identifying numbers
NIHR 207898

Study information

Scientific Title
Exploring the design and operation of community health and wellbeing sickle cell hubs ('sickle hubs') to relieve pressure on GPs and hospital services

Acronym
SCORE

Study objectives
Improve patients' and families' wellbeing and resilience, reduce NHS workload and help patients access NHS pathways more effectively.

Ethics approval required
Ethics approval required

Ethics approval(s)
Submitted 05/08/2025, Liverpool School of Tropical Medicine (LSTM) Research Ethics Committee (REC) (Pembroke Place, Liverpool, L3 5QA, United Kingdom; +44 (0)151 705 3100; lstmrec@lstmed.ac.uk), ref: 25-037

Study design
Observational - Delphi reflection cycles

Primary study design

Observational

Secondary study design
Delphi reflection cycles

Study setting(s)
Community

Study type(s)
Quality of life, Treatment

Participant information sheet
See study outputs table

Health condition(s) or problem(s) studied
Sickle cell disease

Interventions
Delphi reflection cycles on the feasibility of sickle cell community treatment hubs.

This is an exploratory study to explore potential functions, operation, feasibility, acceptability and potential measures of success of community resource centres or hubs for people living with sickle cell disease. The study will use the Delphi framework and will recruit participants for Delphi reflection rounds, surveys, focus group discussions and key informant interviews. There will also be community research champions who will co-facilitate the Delphi rounds, focus group discussions and key informant interviews.

The survey will be anonymous, conducted online, and participants are expected to spend no more than 30 minutes responding to survey questions. Participants for the Delphi rounds will be engaged 3-4 times throughout the study for 2 hours per round (total 6-8 hours). Participants for focus group discussions will take part in two roundtable discussions lasting 90 minutes each (total 3 hours), while participants for key informant interviews will be interviewed 2-3 times during the study, lasting 1 hour each (total 2-3 hours). Community research champions will undergo 4-5 training sessions totalling 24 hours, and will co-facilitate Delphi rounds totalling 6-8 hours, focus group discussions totalling 3 hours and key-informant interviews totalling 2-3 hours. Community research champions will be engaged for a total of approximately 35-38 hours.

Intervention Type
Mixed

Primary outcome measure
A 'test-ready' scalable intervention, in the form of community sickle cell disease hubs, with recommendations for potential locations and evaluation metrics ready to be trialled in a subsequent study. This will be developed from research outputs, including a scoping review [at month 5]; a cohort of trained and experienced community research champions with shareable training resources relevant for sickle cell disease [at month 6]; and a collaboratively refined theory of change [at month 14], to underpin future testing of the hubs developed from the Delphi framework.

Secondary outcome measures
There are no secondary outcome measures

Overall study start date
12/05/2025

Completion date
31/08/2026

Eligibility

Key inclusion criteria
1. All participants must willfully consent to participate.

2. Adolescents living with SCD
2.1. Aged 15 and older
2.2. Parent/caregiver has provided informed consent
2.3. Adolescent has given assent to participate

3. Carers of people living with SCD
3.1. Aged 18 and older
3.2. Caring for at least one person with SCD

4. SCD healthcare providers
4.1. Aged 18 and older
4.2. Playing a role in supporting clinical management of patients with SCD, including in hospital and GP practices

5. Stakeholders with potential to input to the functioning of hubs
5.1. Aged 18 and older
5.2. Representatives from social services, Citizens Advice and councils
5.3. Academics (including clinical educators)

6. Working with community-based or non-governmental organisations that support people living with SCD and their families

Participant type(s)
Patient, Health professional, Carer, Service user

Age group
Mixed

Lower age limit
15 Years

Upper age limit
100 Years

Sex
Both

Target number of participants
200

Key exclusion criteria
Not meeting the key inclusion criteria.

Date of first enrolment
01/10/2025

Date of final enrolment
31/08/2026

Locations

Countries of recruitment
England

United Kingdom

Study participating centre
Liverpool School of Tropical Medicine (LSTM)
Pembroke Place
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Sponsor information

Organisation
Liverpool School of Tropical Medicine

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Sponsor type
Research organisation

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https://www.lstmed.ac.uk/

ROR
https://ror.org/03svjbs84

Funder(s)

Funder type
Government

Funder Name
National Institute for Health and Care Research

Alternative Name(s)
National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Publication and dissemination plan
Knowledge sharing workshops

Intention to publish date
31/08/2026

Individual participant data (IPD) sharing plan
The datasets generated during and/or analysed during the current study will be published as a supplement to the results publication

IPD sharing plan summary
Published as a supplement to the results publication

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Participant information sheet	version 1	01/04/2025	11/08/2025	No	Yes
Protocol file	version 1	01/04/2025	11/08/2025	No	No