

Hospital/Study	Short description of the study	Start date of the studies	End dates of the studies	Website address for further details
<b>Leeds Adults</b>				
Improving Black Health Outcomes (IBHO) BioResource	Research initiative is dedicated to studying health conditions affecting people from Black communities in the UK. The IBHO BioResource invites individuals from Black ethnic backgrounds to participate in research aimed at improving our understanding of how these conditions might develop and specifically affect those from Black communities.			<a href="https://bioresource.nihr.ac.uk/centres-programmes/improving-black-health-outcomes-ibho-bioresource/">https://bioresource.nihr.ac.uk/centres-programmes/improving-black-health-outcomes-ibho-bioresource/</a>
HALO	Enhance understanding of the outcomes of life-threatening haematological conditions diagnosed in young people by documenting the burden of treatment on survivors' long-term health and social outcomes. Identify the social determinants of optimal quality of life in these cohorts. Define risk factors for poor outcomes including factors such as treatments received, age at treatment, ethnicity and deprivation. Identify the most vulnerable survivors who are disproportionately affected by a leukaemia, beta thalassaemia or sickle cell disease diagnosis. Facilitate development of risk stratification tools and flagging systems within clinical follow-up services which will ensure resources are targeted appropriately at those with the greatest need. Inform the development of local, regional and national health care delivery programmes. Enhance understanding of quality of survival, including relationships and reproductive health outcomes	not opened yet, in set up	not opened yet, in set up	<a href="https://choralresearch.org.uk/sub-projects/haematology-lived-experience-and-outcomes-halo/">https://choralresearch.org.uk/sub-projects/haematology-lived-experience-and-outcomes-halo/</a>
The Sickle I project	The Sickle I project: Prevalence of sight loss associated with sickle cell retinopathy and maculopathy and the impact on vision-related quality of life  Research question What is the prevalence of visual impairment due to sickle cell retinopathy and maculopathy in the UK?	Sep-23	Sep-25	<a href="https://fundingawards.nihr.ac.uk/award/NIHR204961">https://fundingawards.nihr.ac.uk/award/NIHR204961</a>
REVAL in process	Evaluation of pilot hyperacute units to deliver acute sickle cell care as part of a wider programme of quality improvement (SCD) In response to recognition of avoidable deaths and failures of care for people with sickle cell, NHS England is funding a transformation programme to respond to areas of identified need and clinical risk for people affected by the condition.  As part of this programme, hyperacute units are being set up for people with sickle cell to attend when they are in vaso-occlusive crisis. The aim of these units is to deliver optimal care more quickly via contact with specialist health professionals who can ensure the correct treatment is administered and prevent further escalation.	17.10.24	01.05.25	<a href="https://sites.manchester.ac.uk/reval/current-evaluations/evaluation-of-pilot-hyperacute-units-to-deliver-acute-sickle-cell-care-as-part-of-a-wider-programme-of-quality-improvement-scd/">https://sites.manchester.ac.uk/reval/current-evaluations/evaluation-of-pilot-hyperacute-units-to-deliver-acute-sickle-cell-care-as-part-of-a-wider-programme-of-quality-improvement-scd/</a>
<b>Leeds Children's</b>				
HALO	As above			
INSCHOOL	The INSCHOOL project is a 5 year National Institute for Health and Care Research (NIHR) funded research programme looking at the school lives of young people (11-18) living with long-term physical health conditions.			<a href="https://choralresearch.org.uk/sub-projects/the-inschool-project/">https://choralresearch.org.uk/sub-projects/the-inschool-project/</a>
<b>Newcastle Adults</b>				
Bioresource IBHO	As above			
HALO	As above			
The Sickle I project	As above			
<b>Sheffield: Adults</b>				

REDRESS:	The purpose of this trial is to determine whether stem cell transplant using haplo-identical related donors is safe, effective, and cost worthy in treating people with sickle cell disorder compared with the standard of care treatment.  Stem cell transplant from a haplo-identical donor is not currently available on the NHS and can only be accessed through this research study.	25.09.23	30.06.27	<a href="https://www.redresstrial.co.uk/about">https://www.redresstrial.co.uk/about</a>
HIBISCUS:	Exploring the use of a new drug in patients with sickle cell disease. The HIBISCUS study started at the King's College Hospital Denmark Hill campus in June 2022 with patients attending the King's Clinical Trials Facility for their treatment. This includes a monthly medical review, examination, blood tests and to collect a further supply of the medication. The medication is pre-prescribed and collected by the trial nurses to avoid waiting for a prolonged period.	12.07.22	31.05.2028	<a href="https://www.maudsleybrc.nihr.ac.uk/posts/2024/october/hibiscus-study-exploring-the-use-of-a-new-drug-in-patients-with-sickle-cell-disease/">https://www.maudsleybrc.nihr.ac.uk/posts/2024/october/hibiscus-study-exploring-the-use-of-a-new-drug-in-patients-with-sickle-cell-disease/</a>
NIHR: BioBank (IBHO)		24.10.23	14.10.27	
HALO	As above			
REVAL	As above			
Sheffield Childrens				