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NEW tool to understand and improve care for patients with sickle cell disorder launched nationwide

A new feedback tool which allows healthcare services to obtain feedback from Sickle Cell Disorder (SCD) patients of all ages, and channel these insights into long-term care improvements, has launched nationwide. The survey is now live and available for completion from March 2015 until late summer.

Picker Institute Europe, the not-for-profit charity which uses people's experiences to improve the quality of health and social care for all, led the development of the questionnaire, which was commissioned by researchers from the **National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care Northwest London (NIHR CLAHRC NWL)** based at Imperial College London and Chelsea & Westminster Hospital, in partnership with the **Sickle Cell Society**.

Intended specifically to monitor the integrated care programme for improving management of SCD services, the questionnaire was developed and tested in London. It is now being conducted nationally across England to gain feedback on sickle cell care, with versions suitable for both paediatric and adult patients, and parents/carers of young SCD patients.

Focusing directly on patient experience, the survey asks about patients' views on a number of care considerations across inpatient, outpatient and emergency care settings. Question areas include access to healthcare services, experience of seeing clinicians, information, support and management of the condition.

The tool has been created to provide equal care to people with SCD regardless of their geographical location. **John Warner, Professor of Paediatrics and Hon. Consultant Paediatrician, Imperial College Healthcare NHS Trust London** said; *"One of the key issues with SCD versus other long term conditions is that outwardly you look well, but if you have a crisis you are literally in agony. Unless you scream & shout, people just would not know. Patients need to know that there is that understanding, that if they are in pain- even if they "don't look ill", they can get the care they need quickly and effectively, not just at a specialist centre but in their own communities."*

Findings from the qualitative research stage of the project have already informed the development of a community support worker for SCD in Northwest London (an area with a high population of people living with SCD), and led to a successful NIHR research grant to study SCD transition from paediatrics to adults.

Discussing the tool's development, **John James, Chief Executive of the Sickle Cell Society**; England's only charity dedicated to improving sickle cell awareness and patient services, observed: *"Sickle Cell Disorder is unpredictable, agonising and, without a cure, so a life-long battle, that has a massive impact on an individual's quality of life. We are therefore pleased to support the Picker Institute's quality research. Good quality patient feedback can really help clinicians to understand the impact of the care they give. Don't get me wrong, some patients do get good, even exceptional care, but more get the reverse and that needs to change."*

***"There are still people who think is SCD is a cancer or like HIV, which of course it is not – it's a chronic, genetic, blood disorder."* – John James, Chief Executive of the Sickle Cell Society**

To provide effective person centred care for SCD patients, it's crucial that clinicians work with the families and patients who are living with the condition. Which, in Professor Warner's opinion, is where the newly launched tool comes in: *"We can't be paternalistic, we need to understand that patients and their families know their care experience issues better than anyone else - because they are happening to them."*

Why it works

Like all Picker Institute led research, the survey's content is based upon focus group findings and has been extensively cognitively tested. These processes ensure that any new survey asks patients relevant questions about aspects of care that matter most to them, and that the questions can be understood across all age groups.

To obtain a balanced view of the national reality of sickle cell care, the data will be collected and reported on an overall level. The questionnaire will then be made available for individual clinics to use to collate feedback and inform service and care quality changes locally.

Since condition-specific survey findings can be used to inform the delivery, design and commissioning of services, Picker Institute Europe feels strongly that such tools should be developed for those living with all chronic health conditions. **Amy Tallett, Associate Director of Health Experiences explained**; *"When feedback tools are specifically tailored to the healthcare needs of particular patient groups, they can be used to effectively capture and improve the care experiences that are most important to them. I look forward to seeing the results from the national SCD survey, and to promoting use of the tool within specific SCD clinics to drive improvement locally."*

Notes to editors:

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If you would like further information about the questionnaire, or if you can help with asking sickle cell patients to complete a survey between March and August 2015, please email Amy or Harriet at the Picker Institute: scdsurvey@pickereurope.ac.uk

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