NEW Sickle Cell Disorder patient reported experience measure (PREM) under development - to give patients the care they want and deserve

Few people know this but Sickle Cell is the UK's biggest genetic blood disorder, affecting more people than other conditions like Cystic Fibrosis, for example. With this in mind you would think that general awareness would be wide spread and patient services not only exceptional but readily available, wouldn't you? Well, they aren't. In fact with **World Sickle Cell Awareness Day** next week (Thursday 19th June), awareness remains as much of an issue today, as it has ever been. One of the main reasons for this knowledge gap is an imbedded lack of understanding of the reality of Sickle Cell Disorder (SCD) patient, family & carer experience.

However **Picker Institute Europe**, a not-for-profit charity which uses people's experiences to improve the quality of health and social care for all, are currently developing a questionnaire that will allow healthcare services to collect feedback from SCD patients of all ages. They will then be able to use these insights to, over time, improve patients' overall care experience.

The Patient Reported Experience Measure (PREM) has been 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**. The Survey tool will focus directly on patient experience and include reference to patients' access to healthcare services, experience of seeing clinicians about their condition and key questions surrounding the stigma associated with sickle cell disease, such as physical and mental wellbeing and the state of public awareness. It will be used specifically to monitor the integrated care programme for improving management of SCD which is funded by CLAHRC NW London and will be implemented initially in NW London where many SCD patients reside.

Of the commissioned project **John James, Chief Executive of the Sickle Cell Society**; England's only charity dedicated to improving sickle cell awareness and patient services, said; *"We are 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 SCD patients do get good, even exceptional care, but more get the reverse and that needs to change."*

One of the key reasons behind these care discrepancies? Lack of awareness; *"There are still people who are not aware of what SCD actually is, and a common misconception is that sickle cell is a cancer or like HIV, which of course it is not – it's a chronic, genetic, blood disorder."*

Instead of being round like regular red blood cells, those afflicted with the disorder have red blood cells that develop into crescent or sickle shapes, restricting blood flow, clogging up blood vessels and most importantly, stopping oxygen from reaching all of the body's organs in the way it should. These blockages lead to episodes of excruciating pain, known as a sickle cell crisis, which can last for anything from a few minutes to several weeks. The disorder most commonly affects those from Black or Afro-Caribbean descent, a fact widely acknowledged to have fuelled the disorder's marginalisation; *"There is a definite level of ignorance causing marginalisation, around the disorder. This is one of the things that we are all trying to change."* Said Mr James.

Of the difference between the exceptional specialist care services available, and the often less than exceptional, localised ones, **Professor John Warner, Professor of Paediatrics and Hon. Consultant Paediatrician, Imperial College Healthcare NHS Trust London** said; *"One of the issues with SCD vs. 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 about it 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. It's been said before that there is a fracture line between specialised and general services, but there isn't, there is a huge gap! A gap that is currently full of neglected patients, we need to ask ourselves why that is, so that we can deliver the care that is needed, across all services."*

Picker Institute Europe are known for their progressive, evidence based approach to patient experience analysis and healthcare quality. Based on extensive cognitive testing and focus group analysis, the new survey tool will ask patients the right, robust questions, that are needed to provide insight into exactly what care SCD patients are getting, the care they want and more importantly, the impact that this or the lack there of, has on their quality of life.

Of this impact Warner said; *"Distress is a key word in patient treatment, it occurs when people are fighting to get the care they need, it is far too common in SCD patients and we want to lessen this wherever possible."* For this to be achieved it is crucial that clinicians work with families and patients, who have these problems – not against them. *"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. Alongside the Picker Institute we have run focus groups and set up resources to help support these patients, and introduce them to the services available to them, to better engage them in their care."*

Currently in the early stages of testing, the final questionnaire will be available for Sickle Cell patients' from September, with result analysis to be shared in early 2015.

In John James' own words; *"Sickle Cell Disorder is unpredictable, agonising and most importantly there is no cure so it's a life-long battle that has a massive impact on an individual's quality of life."* Look at the picture like that and it's not just important to improve SCD awareness and understanding, it's essential.

Notes to editors:

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