FIRST NATIONWIDE SICKLE CELL SURVEY IDENTIFIES AWARENESS AS KEY TO HEALTHCARE IMPROVEMENT

Results published from the first patient experience survey of people living with Sickle Cell Disease (SCD) across England with adults, children and parents /carers of young SCD patients

Key findings include

- Clinical awareness and knowledge of the condition are lacking – particularly in emergency care
- Participants reported that their friends, family and co-workers did not know or understand enough about their condition
- Healthcare staff do not provide enough information externally (for example to schools and workplaces.)
- Specialist-led (planned) care is viewed more positively than care in urgent settings such as A&E departments
- Londoners have more confidence in the care they receive than people receiving treatment outside of the region
- More negative survey responses from adolescents and young adults (aged 16-20) than other age groups – this is the age that children are likely to be transferring to adult services

The results of a newly developed survey of people living with Sickle Cell Disease (SCD) in England have revealed that information provision and lack of public awareness of the condition are some of the biggest issues affecting their experiences, and in turn, the care they receive.

The results highlighted specific concerns about urgent care provision, with many people reporting less positive experiences of A&E attendance versus planned tertiary care. Whilst over three quarters (76%) of respondents felt that planned care staff knew enough about SCD, under half (46%) felt the same way about emergency care staff. Respondents felt that urgent care staff were not only less knowledgeable, but also less sympathetic and understanding of their needs, than their tertiary care colleagues.

Adults with sickle cell disease in particular had less confidence in the knowledge of emergency care staff, preferring to self-manage as much as they could at home and seeing emergency treatment as a very last resort. This comes despite the fact that one in three (38% of respondents) did not receive enough information about coping with pain and self-care. By contrast, for the majority of children and parents of children with the condition, A&E was the first route that they took.

The survey was a Patient Reported Experience Measure (PREM) which ran for a total of six months, from March to October 2015. It was available in three separate versions, suitable for both paediatric and adult patients, and parents/ carers of young SCD patients. The first of its kind, the tool was intended specifically to monitor the integrated care programme for improving the management of sickle cell services. Developed by the Picker Institute; the charity dedicated to healthcare improvement, the research was commissioned by researchers from the NIHR CLAHRC Northwest London based at Imperial College London and Chelsea & Westminster Hospital, in partnership with the Sickle Cell Society.

Speaking on the reality of these findings John James, Chief Executive of the Sickle Cell Society; *"Though not surprising to those in the SCD community, these results should represent alarm bells to us all. Not only is SCD the UK's biggest genetic blood disorder, affecting more people than other conditions such as Cystic Fibrosis, but the condition is known for its invisible nature and defined by bouts of "crisis". Where often outwardly people look well (despite the fact they are literally in agony). Awareness could potentially be the difference between life and death and these results signal an urgent need for improvement. It has massive impact on the quality of life people with the condition are able to have, but is so easily rectified, better education for healthcare staff and the general public, and more investment in information resources about pain management. Self-care is key for long term condition management, and relieving our overstretched emergency care services in general."*

View a breakdown of the key pilot findings in our infographic

-Ends-

For further information contact Lanisha Butterfield, Senior Communications Manager, Picker Institute Europe on 01865 208166 or Lanisha.butterfield@pickereurope.ac.uk

Further findings of note were as follows:

Information Provision

Information provision was a key area highlighted as needing improvement. One in five respondents stated that they are not given enough information about different treatment options - though they would like this. Pain management was a particular concern, with just three fifths of people feeling they have enough information about coping with pain. Since emergency treatment for long term care accounts for a significant amount of A&E attendance, addressing this issue could result in fewer A&E admissions.

Participants also highlighted a need to educate the general public about the reality of the condition. While the majority of respondents felt that they had enough information themselves, they indicated that healthcare staff could give more resources and share knowledge with others on a wider scale (schools, colleges and places of work for example). Many participants (86%) felt that their friends, family and co-workers did not know or understand enough about their condition. More than any other age group, this was a specific concern for patients aged 16-20 years old. This age group also responded more negatively on survey questions about coping with pain, and the age-appropriateness of hospital wards. Therefore there may be a need to improve care provided to young people around the time that their care is transferred to adult services.

Interestingly, though perhaps not surprising, given the high sickle cell prevalence and subsequent specialist services in the region, the results also suggest that those living with sickle cell in London are more satisfied with the care and treatment they receive, than those living outside of the area.

For all groups (children, parents and adults), access to support networks and groups for people living with SCD were found to be essential but lacking, with only a third of respondents reporting that they have enough information about support groups and the opportunity to meet others with sickle cell to share experiences. Since the majority of respondents would welcome this support, it is evident that

such services would be well received, as would psychological services. Half of all adult and parent respondents felt that a counsellor or access to some form of psychological service would be beneficial to both them and their child.

Children and Young People's Experiences

In general, most Children and Young People (CYP) were more positive about their care and treatment than their adult counterparts.

The majority of CYP and parents of children with SCD positioned A&E as their first choice of treatment, suggesting that adults have a better understanding of managing their condition than younger patients and parents of CYP. The finding also sheds further light on the need to provide enough appropriate information about coping with pain, which may well improve this group's ability to self-manage at home, therefore reducing their likelihood of attendance at A&E.

CYP felt less involved in decisions about their condition and treatment than parents/ carers, suggesting that care perhaps needs to be more tailored to young patients directly rather than focussing only on those who care for them.

Notes to editors

- The full report "Piloting a new Patient Reported Experience Measure for Sickle Cell Disease: A report on the findings" is available to download here
- View a breakdown of the key pilot findings in our infographic here
- The data was gathered from a total of 722 respondents: 280 adults aged 16 and over, 220 parents of a child with SCD aged 0-15 years, 222 children aged 8-15 years
- Picker Institute Europe are a leading charity, dedicated to health and social care improvement and more specifically, to measuring, understanding and using people's experiences effectively, as a tool to support care quality and patient experience improvement. For further information about Picker Institute Europe visit http://www.pickereurope.org/
- The Sickle Cell Society is Britain's only national charity for sickle cell disorders, an inherited haemoglobin disorder. The Sickle Cell Society was founded in 1979 by a group of patients, parents and health professionals who shared concerns about the lack of understanding of sickle cell disorders and the inadequacies of treatment. The Society raises awareness of sickle cell disorders, pushes for improvements to treatment and provides advice, information and support to the sickle cell community. For further information about the Sickle Cell Society, visit www.sicklecellsociety.org
- The National Institute for Health Research (NIHR) is funded by the Department of Health to improve the health and wealth of the nation through research. Since its establishment in April 2006, the NIHR has transformed research in the NHS. It has increased the volume of applied health research for the benefit of patients and the public, driven faster translation of basic science discoveries into tangible benefits for patients and the economy, and developed and supported the people who conduct and contribute to applied health research. The NIHR plays a key role in the Government's strategy for economic growth, attracting investment by the life-sciences industries through its world-class infrastructure for health research. Together, the NIHR people, programmes, centres of excellence and systems represent the most integrated health research system in the world. For further information, visit the NIHR website www.nihr.ac.uk
- The National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Northwest London (NWL) undertake high quality applied health research focused on the needs of patients and service users, and support the translation of research evidence into practice in the NHS and social care. Bringing together the knowledge and insights needed to make lasting improvements to healthcare. For further information about the organisation contact c.njoku@imperial.ac.uk