SICKLE CELL SOCIETY

Sickle Cell Service Review

Findings from the Sickle Cell Society's Engagement Activities

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September 2018

Introduction

Between June and August 2018 The Sickle Cell Society carried out engagement activities with sickle cell patients, carers and supporters to gather feedback on NHS England's planned changes to sickle cell services. The changes cover short and long stay hospital admissions for people with Sickle Cell Disease (SCD). Details of the planned changes can be found here. Our engagement methods consisted of an online survey, a Facebook Live session and two workshops delivered in Birmingham and London.

Summary of insights from engagements

Summary of survey insights

- We have 86 responses
- Answers are varied, some of which are directly relevant to the planned changes and others not
- Many patients and families do not fully understand what the proposed changes mean for them and the care they will receive
- There is some confusion about the Haemoglobinopathy Coordinating Centre (HCC) model, with a common perception that they will directly deliver services.

Summary of AGM consultation insights

- We have feedback from approximately 140 people
- More than one third of participants find the information jargon-heavy or otherwise too complicated
- Many emphasise the importance of ongoing patient involvement, prior to and after, any changes have been made.

Summary of Birmingham consultation insights

- 22 people participated
- The small workshop format helps people to talk in depth about the possible impact of each change
- Many raised issues for attention that sit outside the remit of the current changes.

Summary of Facebook Live insights

- We have 189 comments and questions
- The majority of these are not related to the planned changes
- Of those that are, queries focus on the availability of psychological services; how the changes will address the 'postcode lottery' of care; details of the Haemoglobinopathy Coordinating Centres (HCC) and their possible impact on clinicians' knowledge of SCD, and how HCC will help improve pain management for patients.

Key themes from engagement

Clarity of information and plans

Respondents felt that the information provided was primarily structural - focusing more on how care would be delivered, than on what difference would be made to quality of care.

A quote that stood out was: *"I don't understand how this will affect my care,"* illustrating the emphasis on structural changes as opposed to patient benefit.

- The materials need to be simplified. Participants stated that the language used was too directed towards clinicians and 'people in the know'. Some suggested that infographics would be better than bullet points
- The benefits need to be more clear - e.g. *'we are changing the way patients access services to improve the quality of care'*
- Should the presentations on the planned changes be simplified by NHS England or a neutral body? They need to be as accessible as possible, including using larger fonts and plain language.

The Sickle Cell Society believes that a deeper understanding of the proposed changes could have been achieved if NHS England had held a formal, three month consultation

on their review. This may have also facilitated increased feedback from patients and families by providing a longer timescale and a more structured process through which to respond.

Scope of the review

Respondents felt that the review did not really address the key issues they face; their overriding concerns are not the care settings addressed by the review.

A quote that stood out was: *"The quality of my care hasn't improved in 50 years - how are you going to address that?"*

The most common areas of concern are:

- Receiving appropriate, informed care during A&E admissions
- GPs' knowledge of SCD
- The urgency for new treatments to be more widely available
- Awareness of SCD, within clinical environments, but also in and beyond affected communities
- Consistency of community support.

Transitions consistently arose as a fundamental issue that is not being addressed:

- Between paediatric and adult care
- Across care settings and geographical areas.

As did the need for psychological services, that:

- Provide individualised support for children and adults.

Prescription charges were mentioned consistently in all of our engagement activities, specifically:

- The perceived inequity where people with SCD pay for prescriptions while others with chronic conditions do not.

Furthermore, we note that while geographical variability in the quality of SCD treatment is high, the proposed changes do not set out clearly enough how they will end the 'postcode lottery' that affects significant numbers of people. How will changes to this be

measured? Which tests or audit procedures will be used to demonstrate clear and sustainable improvement?

Lastly, The Society observes that while the proposed changes will 'mandate staff training', via the structures of the HCC, there are no specific plans mentioned to address the shortage of SCD specialist nurses and psychologists. It is a fact within this field that a number of consultants are soon to retire, leaving a huge skills and knowledge gap; historically these expert clinical staff have not been routinely replaced with substantive appointments.

Responses to planned changes

Where the changes were fully understood, some respondents expressed cautious support for their potential to minimise variations in care *(Haemoglobinopathy Coordinating Centres)****; make best use of resources*** *(National Haemoglobinopathy Panel)* ***and monitor individual health and group trends*** *(National Haemoglobinopathy Register)****. However, respondents were overwhelmingly concerned with how NHS England will ensure quality and equity of services, and how they will involve patients at every level of change.***

A representative quote that stood out was: " *Please ensure full co-production is taken at every step of the process. The involvement of the patient stakeholder is important."*

- More information is needed about how HCC's will be procured and governed
- It is vital that The Sickle Cell Society and patients are involved in the HCC procurement process and contribute to designing the pass and fail criteria for potential Centres
- Guidelines for the NHP need to be developed with patients so the criteria for referral is clear
- Patients' distrust and fears about signing up to the NHR, including community concerns about the misuse of their data, need to be fully understood and allayed to make the best use of this system
- Patients' views and experiences need to be *"at the heart"* of any new changes.

Reflections on engagement approach

- Participants requested that information be sent in advance (e.g. of the AGM). Sending information via post may not be practical. Information was made available through the website though this relied upon participants finding it. Links to supporting information could be made more explicitly available in the booking confirmation when participants sign up to future engagement opportunities online.
- Participants are requested to complete a lot of surveys - is this the best form of engagement?
    - In Birmingham we facilitated and took notes from a dialogue with the group, allowing a detailed discussion and opportunities to share personal experiences
    - Through Facebook Live we collected and responded to comments posted online, enabling us to reach across geographical boundaries, involve our biggest audience - more than 1800 people have viewed the broadcast - and return the most diverse range of responses to the proposed changes.
    - During the Sickle Cell Society AGM we asked people to complete surveys and to engage in discussion in groups, and capture their conversations to feed back. The relatively large volume of information we asked people to digest and reflect on was difficult for some people to manage. Future similar initiatives may benefit from 'opt in' workshops with smaller groups and more dedicated time.
    - Whilst we made the survey available online to reduce unnecessary processing, we found that participants at the AGM had a broad preference for completing information on paper.

- **Engagement challenges to consider and address**

  Challenges with GDPR legislation mean that the Sickle Cell Society is limited to making proactive contact with only those who have 'opted in' to be contacted. We believe that due to the significance of the planned changes many people who have not actively opted in still want to be kept informed and/ or participate in planned working groups on this subject. Some have told us this, and others have complained about not having received information. It's imperative that we address this quickly and consider using our database to send out a specific request to take part in this work. We note the associated resource cost.

Next steps for engagement

October

Clarification and communication

- Secure a clarified definition of proposed changes, with an increased focus on patient impact
- Present engagement findings to NHS England, noting the requests for changes and improvements not addressed in the review and recurrent areas needing clarity
- Update stakeholders, including support groups, on findings and future plans, via social media and a follow up Facebook Live session.

October - December

Formulation of working groups of patients, carers and supporters to input on:

- How Haemoglobinopathy Coordinating Centres are procured
- How the National Haemoglobinopathy Panel will ensure fairness, securing of access and effectiveness of treatments
- How changes in the National Haemoglobinopathy Register will be enabled *(subject to NHSE timescales for developing the Register)*
- How patients will be directly involved in improving services, and, to
- Define success indicators for each new area of work.

The Society will explore collaborative funding opportunities to enable support groups to deliver regional working groups on the changes.

Summary recommendations

Following the findings from our engagement activities, The Sickle Cell Society strongly recommends:

- The creation of a clear, infographic document explaining the proposed changes and how they will benefit patients

- For NHSE to respond to:
  - The specific patient priorities and needs as raised through this engagement exercise - there are significant gaps in what people have told us they want versus what the current review covers, and,

  - The Sickle Cell Society's commentary on key omissions

- The development of structured and ongoing patient involvement throughout the planning and implementation of all proposed changes.

Appendix

Engagement Questions and Commentary

Facebook Live - 19th June 2018

Questions for NHS England related to changes

- How will you share the learning from the new changes with medical students?

- Are there any plans for the centres to support young people at university who may be many miles away from their usual hospital? I worry that my son's condition will be poorly understood. As the DWP hardly recognise the condition he may not be viewed as a vulnerable student by the university disability team.

- Where does the need for psychological support (for adults and children) sit within these changes?

- Will the changes improve pain management practices and attitudes? Patients report being 'disbelieved', 'made to wait' for long periods and being 'treated like criminals' when asking for pain relief.

- Is the training by the centres for health care professionals?

- What about local access to long term treatment such as red cell exchange? Will that be affected?

Comments on changes

-Networks are an excellent source for MDT's and it also facilitates teaching and allows for improvements to services.

- This is excellent! Transparency!

- Patient experiences help to change processes.

Questions for NHS England *not* related to proposed changes

New treatments

- Can you tell us when the NHS will introduce 'gene therapy' in the treatment of SCD and what will be the criteria for a patient to have their name on the list?

- What if people can raise half the money for new treatments, can the government potentially meet the patient halfway?

Free prescriptions

- Please provide a statement on why people with sickle cell are not provided with free prescriptions, although others with life long conditions are.

NHS, other statutory agencies and voluntary sector

- What role do you see local authorities and voluntary sector groups playing in supporting sickle cell patients in non acute settings to achieve better outcomes?

- Who reviews the care plan in schools? What are NHS England doing to ensure that the local authority take responsibility to ensure that sickle cell warriors are given suitable accommodation?

Specific treatment questions

- Any new recommendations about prevention of avascular necrosis in sickle patients?

- Do you have any idea about the benefit of thalidomide in transfusion dependent thalassemia?

- What research is going into the effects of sickle cell trait? (Mentioned several times by different contributors.)

- What about the use of L-glutamine?

- Is there a way of obtaining 35% food grade hydrogen peroxide through a GP this puts oxygen into the body (red blood cells)?

- My son used to have a sickle cell card which had his information that entitled him to emergency care, do these still exist? How do people get one?

Comments on poor clinical awareness

- When will all NHS staff be trained to know what it is? Doncaster hospital and ambulance service are one healthcare who don't monitor my son whose lowest oxygen level was 72%.

- Not many universities, hospitals etc. have an educational remit to include teaching on haemoglobinopathies. I've searched even the RCN website today, World Sickle Cell Day, not even a mention of awareness.

- Education and awareness is key for all health care professionals. If we are going to standardise care it needs to be invested in and imbedded in the education system. We should be given funding to have free study days. At the moment it’s based on getting

sponsorship.

- Our local GPs have little or no knowledge, we have to email our haematologist information and then give to our doctor, we have had a lot of battles there. Would be good training for local doctors plus nurses.

- I don't want my GP to have to 'ask someone' for advice.

- My son nearly died while paramedics are asking, 'What's sickle cell trait?'

- More awareness around mini-stroke and stroke surrounding sickle-cell disease.

- I have a 2 year old with sickle cell and the support in England (Peterborough) is not enough.

- Ambulances giving gas and air when that does not help.

- Some doctors and nurses don't know what sickle cell is or how to treat patients. Should they not add this into their learning?

- We need it desperately at Queen Elizabeth Hospital King's Lynn. Tired of having to educate, say what drugs etc. what to give and not to give. We need to trust the professionals.

- HIV/AIDS is understood by doctors etc. and has significant awareness - why should it be different for an inherited disease like sickle cell?

- Why doesn't sickle cell get the same attention as aids, cancer, STDs, high blood pressure etc.? Is it not considered life threatening? Why no NHS-sponsored TV / advertising campaigns about it?

- More research needed into the effect of fatigue.

- Most patients know what works for them, so when it's requested, sometimes the doctors feel like you are trying to undermine them, this is when disagreements come into play.

- The only support we have had is our haematologist in Addenbrooks but we have to travel 70 miles to get there.

- We definitely need more knowledge and the nurses and doctors need more in-depth knowledge rather than just the surface knowledge.

- The need for individualised care.

- Watching from Kings Lynn, Norfolk. Husband has Sickle-cell Beta Thalassemia, G6pd deficiency, atopic dermatitis, pulmonary, dilated right side of heart. Just got over myocarditis which was very scary. We desperately need more help in knowledge in our hospitals.

- These centres are great if they will make a tangible difference to the lives of people living with this horrendous disease, but kids living with the disease every day with no financial help when kids are disabled from sickle cell is a real problem. Sickle cell is not officially classed as a disability and so many adults and kids are suffering. We are quickly discharged from hospital and the follow up appointments do not address these issues in a timely manner.

- As a long term illness the focus should be on proactive care (monitoring and follow up) rather than reactive care (A&E.)

Comments addressed to the Sickle Cell Society and community services

Working with HCCs

- Any idea on expanding support groups either by creating new where there are none or expanding the coverage of the existing ones and having the coordination centres collaborating with these for deeper knowledge of the reality of patients?

Awareness raising

- More awareness and community based support needed across UK.

- Need to raise awareness throughout society as well as the medical profession.

- An organisation making significant effort to raise awareness by visiting schools and in particular universities., worth supporting and checking out.
https://www.facebook.com/Sicklekan/

- I think there needs to be more awareness as there is hardly any within the women's prison services for women sufferers, they go with very little care as officers are ignorant.

- Need for benefit support and advice, information on self management and more psychological support for children and adults.

- Someone recently returned to my place of work and had suffered with pneumonia for the second time in her life. Not so sure that people understand how the condition affects the day to day experience of sufferers. Particularly the effects of cold weather, cold rooms and so on. Some work places even force people to go outside despite knowing the condition is worsened by the temperatures.

- Is it possible to get into schools to educate about them sickle cell?

- To campaign for prescription exemptions / can we please make the benefit department aware that sickle cell is a very serious illness and a lot of kids with sickle cell don’t get any benefit as it is not considered as a serious illness.

- Sickle cell should be recognised as a disability.

Viewing statistics

This graph shows at any one time how many people viewed the Facebook Live session.

- As of August 2018 the broadcast has had more than 1800 views
- Our peak number of people viewing at any one time was 38
- For a large portion of the live broadcast we had a consistent group of people watching which increased as the broadcast went on
- We also had 189 comments from 39 different people whilst live. It is clear from when they commented that many of these people were engaged throughout
- Our largest audience by far was in England and was also female between 45-54
- On the night we had a total of 445 views, however this figure does include people who watched for just a few seconds.

Engagement Questions and Commentary

Birmingham Consultation Event - 7th July 2018

The below summarises key questions raised by participants, including patients, carers and clinicians.

What is the rationale for the changes?

Response - the rationale includes:

- Inequity of care
- Fewer clinicians available
- Less resource available to maintain care to an appropriate standard.

What changes are proposed?

The changes include an overarching supervisory centre and Haemoglobinopathy Coordinating Centres (HCCs) which will sit on a national panel (NHP).

How will improvement be measured?

Through quality measures including standards; quality dashboard; draft specification.

How will this be funded?

- £5.8m - is that new money or recycled money?
- 9.2% more for sickle cell than non: preventing this from being subsumed into the system.

What is the current status of the National Haemoglobinopathies Register?

- The main functionality at present is a record of headcount.

What will the difference in centres be?

- The plan is to move from 23 self designated specialist centres to between 10 and 14 peer reviewed specialist centres.

Who will decide which of the 10-14 HCCs to establish? How will appropriate coverage be taken into account?

- Taking East Midlands as an example, there will be 1 HCC and 1 Specialist Centre
- We need to ensure we have the right expertise
- The decision will not be NHSE alone - has to be an inclusive decision making process e.g. in the development of service specification and in procurement.

Will the National Haemoglobinopathies Register (NHR) inform allocations?

- Not currently
- As of September 2018 the voluntary register holds the details of 11,500 people living with sickle cell disease. *(A study published in December 2017 in Journal of Public Health estimates that around 14,000 people in the UK have sickle cell disease.)*
- Takes account of population metrics
- Recommendation - the changes present a significant opportunity to develop the usefulness of the NHR including its research potential.

How does access to the NHR Register take account of Data Protection?

- Access is not open
- Specific information is not made available
- Overall population level information is made publicly available

Where care is split across centres, there is frustration about the lack of ability to share records. Who takes ownership of a Sickle Cell Patient?

- Sickle Cell Centre is the primary contact
- GP is the conductor of general health
- Who to go to first? How do you know?
- How do you know what is causing a symptom e.g. is it sickle cell related or not?
- If in doubt, talk to a specialist
- “GP first”
- “GPs are scared”
- Collaboration and communication are key
- We need a point of contact behind the scenes who knows the whole picture

- Community nurse is the signposter?
- Expert patients - GPs & nurse accompanied.

How do we encourage / enforce consistent care and standards?

- Part of the issue is that non specialist clinicians do not know the referral routes
- This is an issue of lack of information sharing
- Are people appropriately trained? E.g. GPs?
- Simple triggers and flags
- Concerning my issue, I had to tell the GP what do do
- System for flags for patients to access HCC
- HCC responsibility to communicate to GP
- HCC training patients & clinicians
- HCCs need to enforce standards & the role of GPs.

Separation of paediatric and adult care is a major issue

- “Separation from paediatric and adult care really bothers me” - Christine
- “Paediatrics and adult care needs to work together as one network” - John.

Awareness is still a key issue

- Public awareness of Sickle Cell remains poor
- How are we incorporating wider feedback?
- Does the black community have enough awareness of sickle cell? Stigma and denial are issues. How do we tackle mythology?
- Focusing on areas of higher need
- Awareness in school for e.g. being able to wear e.g. extra layer of clothing / suitability of physical education
- Having a coalition and voice e.g. through online petitioning
- We should be making these arguments through the APPG
- A patient group produced 20 min documentary from Liverpool was referenced as an example to be shared.

Remaining questions to address

- A&E is a major issue and needs to be looked at as well “you need to wait your turn”
- Trickle down of information doesn’t get shared - we need better engagement of

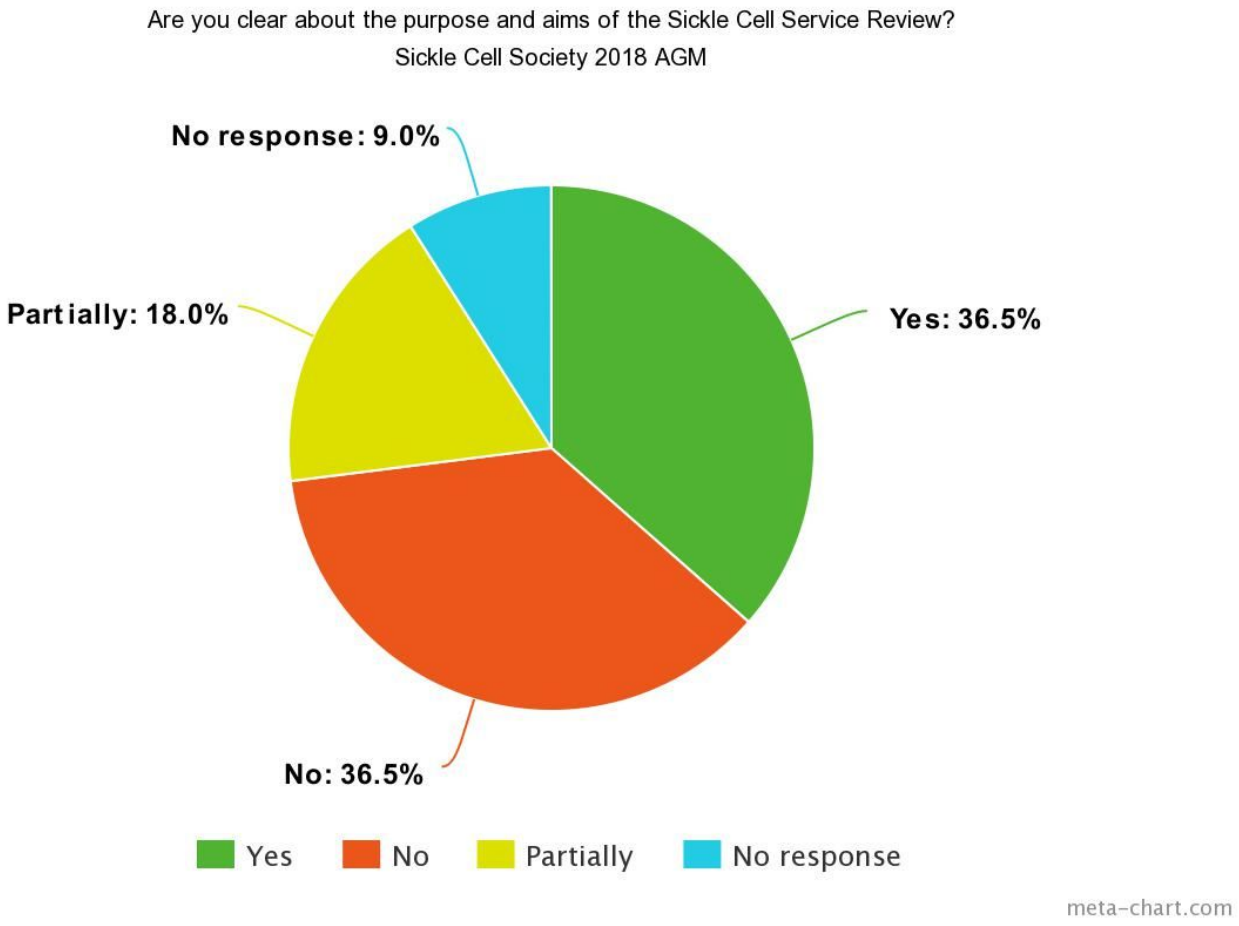
practitioners

- How will the District General Hospital network make connection with the main centres?
- Will the NHP deal with requests for exceptional or new therapies?
- There's a shortage of resources e.g. for hydrotherapy
- Some lack of clarity remains about extra funding and where that will go
- Will there be issues with regional bias?

Engagement Questions and Commentary

Sickle Cell AGM Engagement - 21st July 2018

The below is a summary of feedback gathered at our recent AGM following a presentation by Claire Forman of NHS England, and a brief workshop delivered by the Sickle Cell Society.



Comments

- No. It needs to be gone through more slowly for non professionals. Too much text on slides. Cannot make a decision or give an opinion with insufficient information. Need to go through and give some thought. Try giving out information beforehand for it to be understood and absorbed. Need smaller, more discrete discussion groups of knowledgeable patients.

- No. We need a diagram, more pictorial. On the website it seemed like too much

information. Not clear or easy to follow for an everyday person. The delivery of the information in the presentation was too rushed and needs to be more tailored to the everyday person who does not work in the NHS. More time needed to digest.

What, if any, additional information is needed?

- How will it differ from what is available now? How will they select the HCCs?

- Need to read more. Need user friendly format so pathways are clear. Define clearly what the HCC will produce/ purchase. Are local specialist nurses roles changing? Is Scotland represented?

- More publicity so people know why it's needed. Social media, Twitter. Snapchat. Young people and parents (need to be informed.)

- The terminology used is more geared towards health professionals and providers. Need simpler words and diagrams. No academic language. Need an example of a similar structural change that has worked.

- The centres should be listed so people know where to go when specialist treatment or information is needed.

How can we make sure the changes are a success for patients and carers?

- Patients need to engage right from the start. Role of Sickle Cell Society – working together sharing information. Community support needed.

- Share via haemoglobinopathy nurses and consultants.

- Ask the patients and support groups for feedback.

- Patients and carers (need to be) aware and involved in the planning and decision making.

- Patient involvement: share information and give views. (What about) pain management? Psycho social intervention (CBT)? More education in schools about SCD.

- Getting more awareness via support groups, haematology clinics. Service users should be involved in the planning of the changes for it to succeed. If they improve response times of LAS (London Ambulance Service) to take service users to A&E. Patients should be able to feedback their concerns about the service quite easily. If the changes include non-clinical care in the community. i.e. social care.

- When funding is being allocated to these centres of excellence it would be helpful to ensure that in each centre or hospital funds go into the appropriate specific area where there are gaps in each centre or institution as the gaps vary or are different from centre to centre. This would enable each centre to reach a benchmark level of excellence.

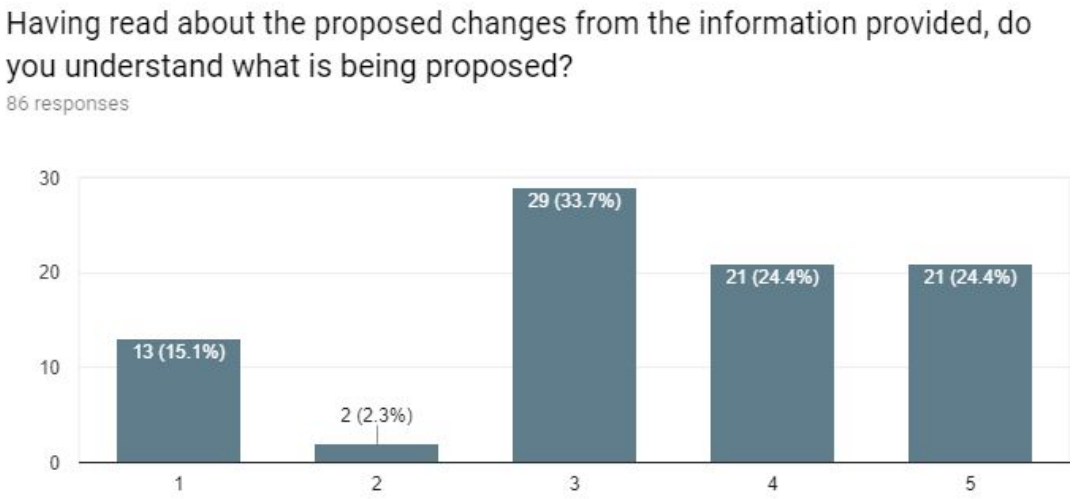
- By sending out emails, newsletters, text messages. By arranging workshops. One to one sessions with patients and their carers.

- Offering more support to carers making them aware of where they can get the help that they may need. In Leicester there is a small population and there does not seem to be much support. Yes, more information is needed about the changes.

- Ask patients their views about treatments. Show and monitor results as compared to other hospitals. Make sure more doctors know about SCD. For example SCS should establish links with medical schools so we can get students on board and they should attend the AGMs.

Survey Responses

Below is a summary of feedback from our online survey which collected responses up until 31st July 2018.



1 = Not at all clear / 5 = I understand clearly

Proposed changes

NHS England plan to introduce Haemoglobinopathy Coordinating Centres (HCC) in specific areas across England. They will be responsible for leadership, education and standards of care. How could a HCC improve care where you live?

Recurring points on how a HCC could improve care:

- By reducing variation of care
- By adhering to thorough and effective monitoring and quality assurance systems
- By offering out of hours services
- By overseeing transition care for young people
- By improving quality and collaboration across areas
- By training and educating clinicians, including those in emergency services
- By ensuring people receive appropriate pain management

- By exploring less medicalised ways of care, including psychological services and health promotion
- By raising clinical and community awareness of sickle cell disease
- By increasing access to new treatments.

Recurring concerns

- Will living far away from a HCC affect access to quality treatment?
- Will existing specialised centres close?
- How will centres be staffed?
- Will they be resourced adequately?
- How will communication be ensured between a HCC and the places they seek to influence? *"I see it as a positive but still a challenge - long term - for HCC's to influence other providers - this will (need) encouragement and exhortation."*

What priorities do you think Haemoglobinopathy Coordinating Centres should focus on?

Recurring priorities

- Raising awareness
- Overseeing transition programmes
  Health promotion activities
- Improving responses to pain relief
- Training and education
- Improving A&E care
- Funding for newer treatments to improve access
- Psychological support
- Research and clinical trials
- Blood transfusion.

NHS England plan to set up a National Haemoglobinopathy Panel (NHP) which will accept referrals about difficult clinical cases and consider which individuals would benefit most from new treatments. Please tell us why you think this is a

good idea or what, if any, concerns you have about this.

Recurring positives

- It will help in the rationalising of resources

Concerns

- How will fairness and transparency be assured?
- Will decision making be driven by the need to ration resources rather than the merit of individual cases?
- Will the panel be representative of the people affected by sickle cell disease?
- Will allocation of funds and treatment be affected by where a HCC is based?
- We need to define what is meant by 'difficult clinical cases'.

The National Haemoglobinopathy Register (NHR) keeps details of people with red blood cell disorders to monitor and learn from their treatments. How do you think the Register could be used to better manage care for people with Sickle Cell disease?

Recurring comments on better usage of the NHR

- It should hold a record of patients' care plans accessible throughout the NHS
- It should be used as a monitoring tool to manage individual care, e.g. trigger annual reviews, vaccinations etc.
- More accurate data should be gathered to ensure adequate financial and clinical resources are provided for where the patient populations are
- Anonymised data should be widely available to improve research and awareness raising.

Recurring concerns

- It needs to be a complete register to be effective
- We need to encourage people to sign up, understand why people decide to opt out and allay their concerns. Is the stigma attached to SCD part of the issue?
- People are suspicious about how their personal details will be used and shared
- The purpose of the register needs to be transparent and clear.

What else, if anything, would you like to see in the proposed NHS England plans?

- Free prescriptions
- A public health focus
- The inclusion of alternative therapies
- More focus on new treatments and cures
- More information about how SCD outcomes compare to that of other chronic conditions
  Clear cross reference to the Standards of Clinical Care for Sickle Cell
- The role of the voluntary sector in these changes
- Clearer about resource allocation
- More discussion about the psychological impact of SCD
- More information on research
  More acknowledgment of sickle cell trait and its effect on health.

Please add any further comments you would like to make

- I would like to see definitions of MDT broadened to include school liaison and support officers; employment advisors; benefits advisors and housing advisors: in other words some of what the sickle cell nurse counsellors used to do before being overwhelmed by screening work.

- NHS should conduct full statutory consultation. The findings will be germaine to identifying future work needed as it is conceivable it is not possible to provide the long term sustainable and resilient service that patients need in one go.

- Learning should be taken from HIV which has gone from a life threatening condition to completely curable with a wealth of political, business and social support in just 20 yrs. Haemoglobinopathies and HIV have a lot of parallels that the NHS should be learning from to operationalize as appropriate to address UN Resolution to do more for Sickle Cell around the world.

- How has the panel satisfied itself that they have consulted with as wide arrange of stakeholders for a sufficient period of time, to achieve its obligations on

consultation in a genuinely meaningful way?

- Please don't make this a tick box exercise and do proper investigations of Research already available via charities and CLAHRCs (soon to be ARCs) and build on work already started. Please ensure full co-production is taken at every step of the process.

- Where does the level of accountability lie, is it with the HCC, Commissioners, CRG, NHS? Who is going to be responsible for monitoring improvement for the patient?

- Perhaps this already exists but focus groups are a good way of gauging views. Professionals need to find out from patients what works best for them. There are obvious funding limitations but not every suggestion will have cost implications. I welcome this review and look forward to seeing how the changes work out in practice.

- How will needs of patients be put at the heart of the decision making process? Could you use a citizen jury process? To ensure patients and carers views are taken account of?