CAHN
Caribbean & African Health Network

Greater Manchester – A Sickle Cell Report

Community Listening Exercise July 2021

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Acknowledgement and Thanks

CAHN would like to extend a big thank you to everyone who attended the event. Special thanks to our healthcare professionals and the Sickle cell patients from the community who spoke about their experience of sickle cell care in Greater Manchester.

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Greater Manchester Listening exercise

This report presents the feedback from a listening exercise that took place in July 2021 with people diagnosed with sickle cell and for those who have a role in caring or advocating for those with sickle cell conditions. The listening exercise began with the premise that we ought to start with what people need and how people experience the services so that we can really understand how we can improve the services. This opportunity to listen was also particularly welcomed as a way to strengthen some of the relationships so that there was some assurance that what was being initiated, developed and implemented reflected the needs of those using the services, their carers and the wider community.

The listening event occurred via Zoom and included commissioners and service user voices which was a great success. We had many attendees joining Zoom and social media to share their lived experiences of sickle cell and about how our healthcare services administer sickle care support for the community.

During the listening event we had number of guest speakers that were introduced by Charles Kwaku-Odoi, Chief Officer, CAHN. Speakers included Katy Calvin Thomas, CEO, Manchester and Trafford Local Care Organisation; Stuart Moore, Director of Strategy for Manchester Royal Infirmary and Rev Anthony Mason, CEO, Sickle Cell Care Manchester. We then heard some patient stories before going into break out rooms to discuss experiences and what our community would like to see improved to enhance the experience of those living with sickle cell in Greater Manchester.

CONTEXTUAL BACKGROUND

In the United Kingdom, there are around 15,000 people living with Sickle Cell Disease (SCD)[i]. SCD is the most common inherited genetic blood disorder in England. It is a genetic disease that predominantly (but not exclusively) affects people from Black Caribbean and African backgrounds. In the UK, 300 babies are born each year with sickle cell disease [ii], a group of inherited blood disorders that can cause a wide variety of different health complications and chronic conditions.

The first specialist Sickle Cell and Thalassemia centre in the United Kingdom was founded in Greater Manchester by Dame Elizabeth Anionwu in 1979. Dame Elizabeth was a student nurse during this time and frustrated at the lack of information provided during nurse training about the condition. Prior to that, Sickle Cell and Thalassemia was largely ignored as a condition and those suffering with the condition were treated without specialist knowledge and input. Dame Elizabeth continues to raise awareness and support a large population with the condition in the UK.

Over the past decades, there have been some developments that have extended the lives of those with sickle cell. Technology screening in newborn babies to detect sickle cell, an increase in knowledge about how to adapt lifestyle to reduce sickle cell crises and improvement in treatments/medications have now increased the lifes of those with sickle cell. The disease that was a childhood life limiting condition is now a condition where as many as 50% of those with sickle now live into their 50's and beyond.

NORTH WEST PROVISION OF SICKLE CELL SERVICES

Sickle cell services do not fall under the arrangements for devolved local decision making around health and is therefore not listed as one of the priority health areas for Greater Manchester. Instead, sickle cell services, thalassaemia and other haemoglobinopathies are procured under The North West England Sickle Cell and Thalassaemia Network (NWESTN) via NHS England Specialised Commissioning North West of England.

NWESTN collaborative consists of healthcare professionals from Specialist haemoglobinopathy services at two hospitals under Manchester Foundation Trust (Manchester Royal Infirmary, the Royal Manchester Children's Hospital), the Royal Liverpool University Hospital and Alder Hey Children's Hospital.

Community Care for Sickle cell service users and carers is provided by Manchester Local Care Organisation (MCLO) commissioned from NHS Manchester Clinical Commissioning Group. The MCLO is a community-based holistic service that operates out of the Sickle Cell and Thalassemia Centre and is in close proximity to Central Manchester University hospital Oxford Road.

[i] [ii] Sickle Cell Society. About Sickle Cell Disease. Available from https://www.sicklecellsociety.org/about-sickle-cell/ [Accessed 24th November 2021]

Patients are encouraged to attend the centre however there has been a significant lack of investment in relation to resourcing the centre including staff. To the best of our knowledge there are gaps in reviewing service specification and Care Quality Commission Inspection. Previous case studies from users and those who have sadly passed on identified a real lack of community support and education for staff who are meant to be caring for them in a holistic and joined up way. There have been recent discussions to move the centre to another location which is a few miles away from the Central Manchester hospitals and this has been contested by CAHN with support from other community organisations and service users. There has now been acknowledgment from the MCLO of the need to remain in the building and invest in refurbishment of the premises. CAHN has presented a case to look at and support fundraising due to the lack of capital allocation in the MLCO current budget for refurbishment. CAHN in their engagement with commissioners have emphasised the statutory obligation of the NHS to invest in the services and building to ensure that the needs of those living with sickle cell are met.

At the Greater Manchester, CAHN raised concerns over 3 years ago about specialised commissioning decisions that takes place at North West level. Such regional decisions do not always serve the best interest of the Black Caribbean and African Community locally.

This report describes services provided by Manchester Foundation Trust and the Manchester Sickle Cell and Thalassaemia Centre commissioned by Manchester Clinical Commissioning group. It hears the voices from our commissioners, community organisations and user case studies who shared their hopes for the future of sickle cell services in Greater Manchester.

INTRODUCTION TO THE LISTENING EXERCISE

Charles Kwaku-Odoi DL – Chief Officer, CAHN

Charles welcomed everyone to the listening event and to the Caribbean African Health Network (CAHN). He spoke about one of the ambitions of CAHN to work with various other organisations across Greater Manchester and beyond. Charles provided an overview of what to expect from the evening event and introduced some of the speakers who were there to present the current sickle cell services, to listen to the community and to reaffirm their commitment to improvement.

Charles declared that he is one of the nominated governors at Manchester Foundation Trust. He went onto say that he hoped the conversation, the commitments and the genuineness heard during the listening event will be carried through. Charles shared that the challenges for sickle cell patients, their carers and families were raised by him at Council of Governors meeting as well and that there was real support. Charles spoke about the number of previous conversations, but felt now that they were on a new path, a new journey…
he asked that we watch this space.

Dr Faye Bruce DL – Chair, CAHN

Faye thanked everyone for joining the meeting on such an incredibly hot day which she stated demonstrated their commitment to sharing their experiences of sickle cell services. Faye highlighted that given what we know about the statistics in terms of the numbers of people that are affected by sickle cell within our communities that it was only right that we had sickle cell as one of our priority areas for improvement in Greater Manchester (GM). Faye spoke about the importance of listening and how this skill is deemed one of the most important roles we need to do to bring about the change we need to see. Faye highlighted the importance of good and high-quality sickle cell care for people pre-pregnancy, during pregnancy and the aftercare once people had given birth. She spoke about the terrible statistics of those women that suffer due to lack of health professional's knowledge of the condition. So Faye reiterated the importance of listening to people to inform how we move forward in terms of services that people need, and people will want to use. Faye highlighted that if services are provided in a non coproductive way, and people do not want to use them, it makes no economic sense for the NHS or public purse to provide them. She stated her passion to address health inequalities and highlighted that the community needs to be at a place where we hold statutory partners to account when decisions are made without us that lead to health inequalities. Faye reiterated that CAHN would not stop in its mission to fight for fairness, justice and equity and would use all the tools at its disposal to root out what creates worse outcomes for our community. Faye saw the event as a really good opportunity to listen to people with those lived experiences and to help us to shape some of the services that have not received equitable investment for decades. Faye thanked all for attending.

The facilitated discussion in 4 breakout groups were guided by 4 questions around key areas to address the aims of the consultation.

Aim of the listening exercise

- To bring together service users and commissioners together to understand the experiences of those living or caring people with sickle cell
- To articulate what good looks like for those experiencing sickle cell or those caring for people with sickle
- To inform commissioners about ways to enhance their experience of living with sickle in Greater Manchester

Questions

Q1. What is working well for individuals living with or caring for those with sickle?

Q2. What is not working well for those living with or caring for those with sickle?

Q3. How accessible are services and do they respond timely to meet needs of individuals with sickle?

Q4. What needs to change to enable a good service for those living with or caring for those with sickle across hospital and community services

INTRODUCTORY CASE STUDY

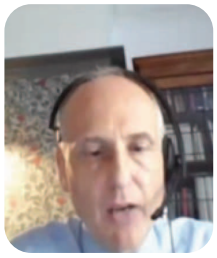
The session commenced with a presentation of a lived experience case study of a patient with sickle cell using services in GM.

- **Case Study**

Service User who we will call Angela had sickle cell from around the age of 12. Angela experienced a crisis a few weeks ago and went to accident and emergency. Accompanied by her sister, security at accident and emergency did not view her situation as urgent and she was asked to take a seat in the waiting area. Despite her sister saying she's having a crisis, the security guard insisted it wasn't urgent, and reinforced that Angela should take a seat in the reception area. Fortunately, one of the reception staff overheard the conversation and recognised that it was a sickle cell crisis, and she jumped into action.

Had the receptionist not been aware of the condition and the need to get immediate action and necessary treatment, the outcome could have been much worse. This experience led those involved to raise questions about Power and where service users turn when they are not being listened to or taken seriously. Should there have been a helpline or a telephone number to call. The other aspect of learning from this case includes the education of hospital, staff around sickle cell, not just for clinicians but for all staff including security staff.

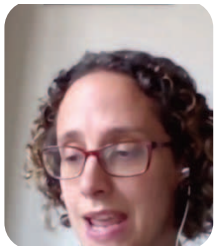
SPEAKERS AND PRESENTERS



Stuart Moore Director of Strategy for Manchester Royal Infirmary

We were delighted to be joined by Stuart who spoke about his involvement in hematology and the hemoglobinopathy coordinating centre (HCC) bid he contributed to for the HCC 2 years ago. Stuart spoke about other key members of the team Mary Aziz, network manager for the HCC and Dr. John Granger consultant pediatric hematologists who will be the new clinical lead for sickle cell across MRI and the children hospital.

The community welcomed the possibilities of a single point of contact hospital clinical lead that would work with the community and provide the opportunity to hear if people are experiencing issues. Stuart also highlighted the support from Peter Blythin who would work with the community to identify from the conversations how they can provide the right service for people across the hospital and the community. There was also an emphasis on relationships and what good looks like to those coming into contact with and accessing sickle care services.



Katy Calvin Thomas CEO, Manchester and Trafford Local Care Organisation

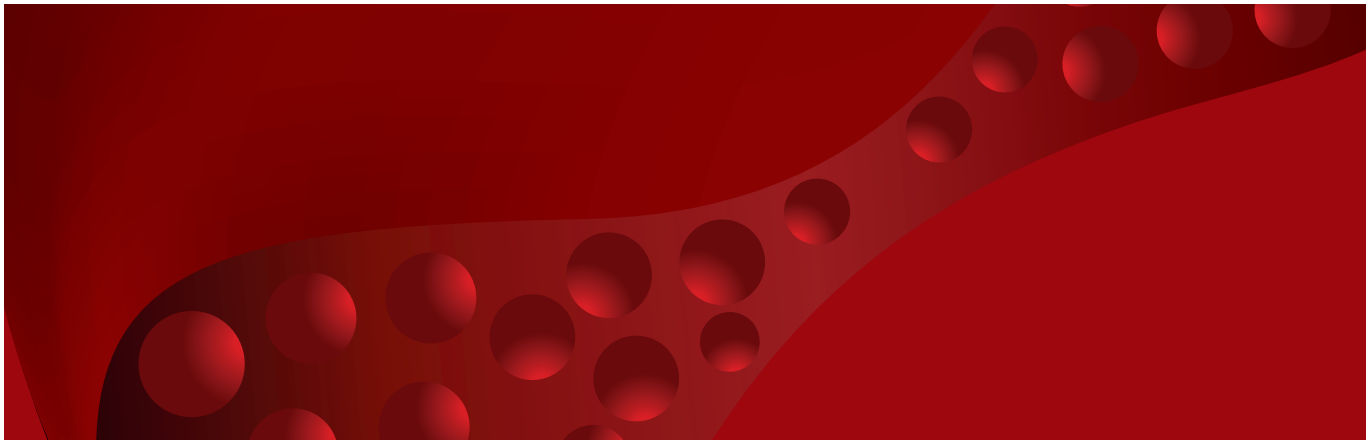
Katy commenced her presentation with a thank you for the case study shared. From there, Katy made a commitment to feed back the experiences and feedback gathered from this event into the hospital through Vanessa Gardner, the chief executive at the Manchester hospital. Katie shared the last few years of her work at the Manchester Local Care Organization that runs community services. The presentation highlighted a meeting between Charles Kwaku-Odoi (Chief Officer, CAHN), Ngozi Edi-Osagi (Medical Director, Neonatologist, MFT, and Volunteer Medical lead, CAHN) Peter Blythin (Group director, MFT), about some early exploratory discussions with staff regarding movement of some of the community services out of Sickle Cell and Thalassemia centre on Denmark road into different premises. During the conversation, Katy recognized that this was a very real accommodation concern that was going to impact those using the services at the Centre. Katy stated how through listening, it was quickly realized that this issue, raised by CAHN via the community, was not soley about accommodation or clinic space but also about the sense and the feeling that from the perspective of Black people, their families and the community that decision makers did not take fully into account the needs of service users using this facility. Katy highlighted how there was a real and pressing need to give due care and attention to the voice and needs the community and users in improving sickle cell services and to work together to increase investment from the system into sickle cell community services.

Katy ended her presentation by emphasising the need to work with the community by listening and to start to build some improvements. Katy told the meeting attendees that she had met with Peter Blythin and Stuart Moore (present at the meeting representing Vanessa Gardner) to address these issues raised especially around her main focus which is community and social care.

Rev Anthony Mason CEO, Sickle Cell Care Manchester

Charles introduced Reverend Anthony as one of the co founders for CAHN, and highlighted how sickle cell has always featured as one of our priorities.

Anthony began his presentation by thanking CAHN for the platform to speak about the concerns with Sickle Cell services in Greater Manchester. Anthony the Co-founder and CEO of Sickle Cell Care Manchester was setup in 2011 and became a registered charity in 2015. Anthony spoke of his previous role as regional care advisor for Sickle Cell Society between 2004 – 2009 where he worked at the Sickle Cell Analysis Centre which focused on the community working relationship and building some level of community assets. Anthony shared that he is a person living with the condition approaching the age of 52 and that he has currently outlived the life expectancy of 40 years for males with sickle cell condition. Anthony spoke of the case study shared earlier on in the evening and the disappointment in relation to the experiences that Angela had been faced with at the Manchester Royal Infirmary. He highlighted a concern raised from the case study for a community liaison officer that would be working in the community whilst also having access within the statutory system. He highlighted the work he was involved in to write world recognized adult standards (undertaken as part of the Sickle Cell Society) These standards highlighted the need to put into place appropriately targeted pain relief within 30 minutes of a sickle cell patient arriving in hospital which were written over a decade ago. Anthony highlighted the lack of adherence to this guidance and from his earlier experiences and those of people using hospital services currently provides examples of patients in crisis being placed in hospital side rooms and their immediate concerns unaddressed. Anthony in his presentation also highlighted an issue already raised about the lack of appropriate training of nurses and doctors who do not actually understand sickle cell or how to treat and care for people with the condition. Cases were shared of nurses, medical staff and others on the frontline asking patients in crisis irrelevant questions rather than addressing the emergency in front of them, namely a patient in crisis. Anthony concluded his presentation by stating that the public health system and its care for people with sickle cell needs to be addressed not only for the sake of the patient and their family but also for the NHS that ends up spending more from inappropriate care and therefore admittance to hospital and for a longer period of time.



A Sickle Cell Patient Story

- **Case Study**

Elizabeth a staff member of MFT trust, Oxford Road spoke of the benefits of working at MFT and being close to the centre in terms of access and treatment. Elizabeth shared both good and bad experiences going into hospital during the COVID pandemic. Last year when I went into the hospital, the security guards were there. I was waiting for an ambulance, but the ambulance was taking too long so I called a taxi. The driver asked me, "why are you here? and I said sickle so he could see my eyes. I was crying because I was so much in pain. So then he went inside, and someone came. They took me to a different corridor, and a different ward and told me they would look after me. However they said to me, that this is the only space to treat people (……bay with other patients) then I told them, I'm shielding, I let them know, I'm shielding. I need to be protected. I asked them to put me in a sideroom or something because I cannot be among other patients because I don't know if they had COVID or not. So I asked for all these things and I was in pain. When the pain was a little bit manageable, I was able to demand for these things……. Since living with sickle cell as a child, my parents they told me at a very early age what was happening to me. Well, they put me on the side room and then after I was better, they discharged me and I came home.

SERVICE USERS AND CARERS FEEDBACK

Discussion points raised from presentations

- **Lack of knowledge of sickle cell**

> "In all of the groups, participants spoke about the lack of insight from professionals including doctors, nurses, paramedic care, physiotherapist and others involved in the care journey that sickle cell patients make. Participants spoke about how this lack of knowledge impacted the care they received and that it was not received in a timely manner. There were stories about how people had to wait endlessly whilst staff would need to 'find' someone that could help to explain what was going on with the patient".

> "There is a huge issue in terms of sick individuals having the care plan, so that whichever hospital they go into, or whichever doctor they end up having to see, they would have an idea of what it is that they need to do, in order to kind of alleviate the stresses and the pain the individual came into hospital with".

> "Where is all of the NHS money, we are tax payers but yet we are not getting our fair share this is not equity. As a community we need to expose these injustices and hold decision makers to account for this unfair allocation and misuse of public money".

"There is not a consistent routine or pattern in terms of advising to do one thing, and then another nurse would come along and advise to do another thing, you need consistency across the board".

"Sickle cell just apparently isn't a priority, there is a lack of education, from some nursing staff and we almost have to take on board caring for ourselves which is very difficult to do when you're going in with sickle crisis".

"There should be an opportunity to explain what we need, even if you know, we need to put down our own care plan and say, Look, this is what I need to happen, and hand that over when you go in. I don't know if that's a possibility for us to do".

"The transitioning from child to an adult, there are differences between being a child and being looked after and being an adult and being looked after".

"We are fed up of being treated as second class citizens, why hasn't there been investment in the service, why cant I get care at home when I need it".

"Healthcare professionals need to know who and what they are treating, it is simply the sort of knowledge needed to do a job properly and with care, health care staff do not know much about haemoglobinopathies".

"There needs to be peer reviewed information that is made public, and that should be actual resources available for people to look at on their website".

"Sickle cell is a complex illness and it's not just the illness, people have got multiple multitude of challenges whilst they're dealing with the illness".

"The condition affects predominantly, the black community, we have to take the elephant (racism) out of the room, if we're going to make any progress and address the institutional barriers".

"We have lost so many people in our community from sickle, many of these have been new mums and died from negligence in the system. It's shocking how they treat us".

PROGRESS IN SICKLE CELL CARE

- Several meetings took place in the summer of 2019 with Louise Sinnott Head of Place Based Commissioning – Greater Manchester (Specialised Commissioning) following CAHN's proposal to undertake an Independent review of Sickle Cell Services in GM under the leadership of Dame Elizabeth Anionwu. Subsequently, there was a decision by Louise to scope sickle cell services with the view to develop the case for service improvement within Haemoglobinopathy support and care in GM. CAHN provided information to support this review and due to the pandemic, progression had been halted.
- Since issues had been raised in various meetings with CAHN and others since then, HCCs have recruited a sickle cell educator, to go across the Northwest region to train up individuals, because there was a need for a dedicated person to do that.
- There is a debate taking place in Parliament to mandate training on sickle cell disease within the curriculum of the nurses and the medics, this has already been mandated by National Institute for Care Excellence (NICE) for midwives under the Pegasus programme.

Good aspects of the GM Sickle Cell Centre

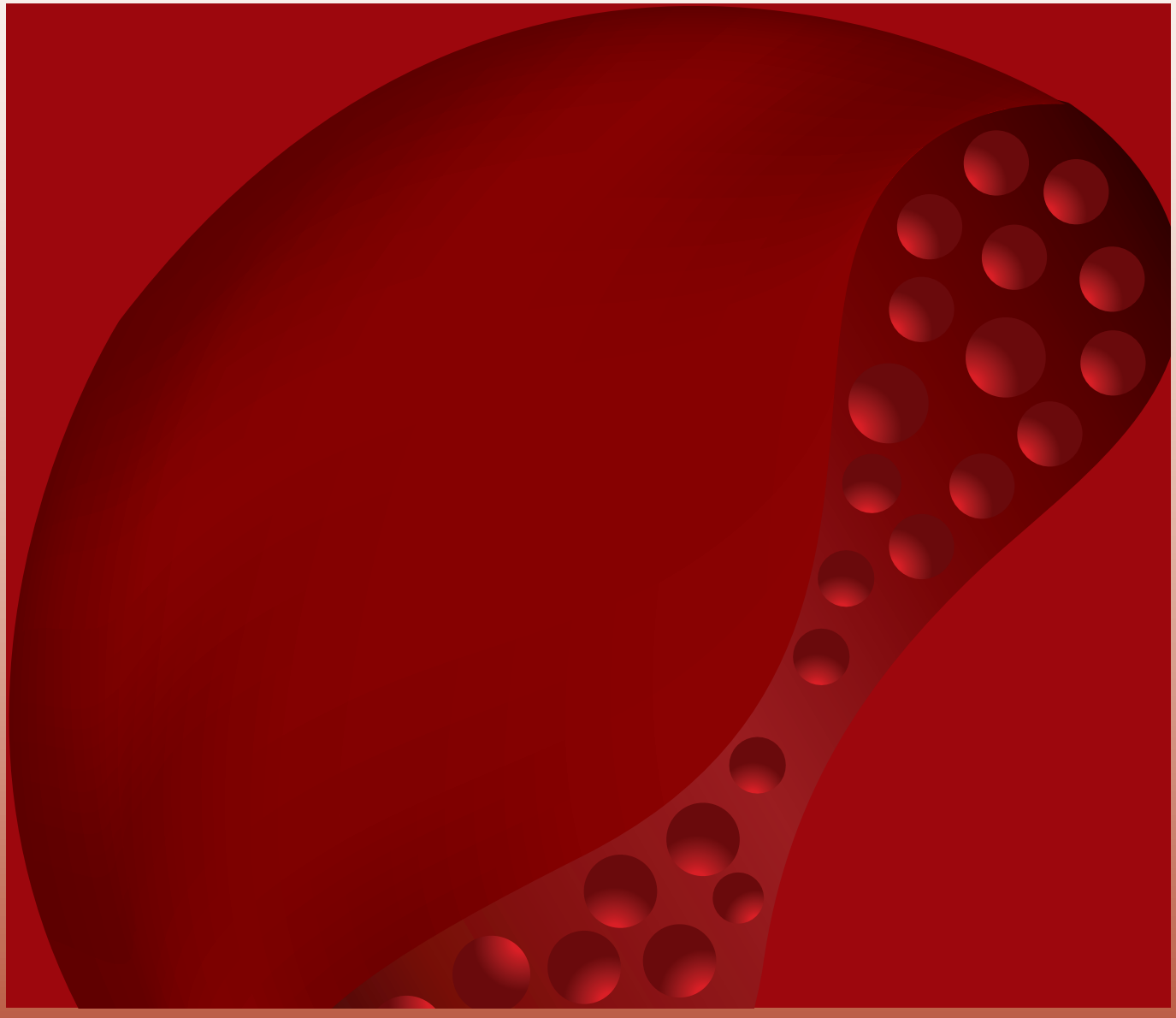
Accessible services

- The Sickle Cell Centre is very accessible, it has wheelchair access, because some of the patients have had a stroke and use for example wheelchairs to mobilise.
- The psychology appointment and engagement sessions take place at the centre
- The sickle cell clinic has access to social services

RECOMMENDATIONS AND NEXT STEPS

- Improved communication and partnership working between the Manchester Local Care Organisation (with responsibility for running the Sickle Cell and Thalassemia Centre), Manchester Royal Infirmary, and VCSE sector organisations working with people living with the condition.
- There should be a full thorough review of the current service provision including commissioning specifications, annual budget, and budget allocations to voluntary sector organisations that are addressing Sickle Cell needs and filling in gaps with tailored community initiatives.
- Discussions with key stakeholders including General Medical Council, Nursing and Midwifery Council, and Higher Education bodies to include Sickle Cell and Thalassemia in the medical and nursing curriculums.
- Ongoing engagement and consultation between statutory partners and key stakeholders including VCSE organisations on service delivery, changes and improvement. This includes patient engagement, Equality Impact Assessment and on-site facilities.
- Proactive patient engagement so that those with the lived experiences are involved in the coprodcution and codesign of services.

- Improved patient and carers information packs that provides information of rights and support available for people living with Sickle Cell.
- Regularly updated information pack about management of the condition including healthy ethnic diet, physical exercise, and other relevant information that takes into account cultural and religious needs.
- Ceasing opportunities provided by devolution that builds on conversations between CAHN and the Greater Manchester Combined Authority under Mayor Andy Burnham. Considering the diverse population of Greater Manchester, Sickle Cell should be considered as a priority condition for the Greater Manchester Health & Social Care Partnership (and the Integrated Care Board when formed).
- Equity in terms of funding for Sickle Cell care provision which is the most common inherited genetic blood disorder in England disproportionately impact Caribbean and African people. For example, there is evidence of a stark difference in terms of the higher levels of funding for Cystic Fibrosis as opposed to Sickle Cell, yet, Sickle Cell patients in the UK far exceeds Cystic Fibrosis.



SUMMARY

Sickle cell is not being seen as a priority and many question whether this lack of investment is because it is a condition that predominantly affects Black people. There needs to be 360 degrees support when somebody is going through a crisis and when they go to hospital. There needs to be a more joined up approach to support not only the person going through the crisis, but also the family member that are with their loved one.

Charles thanked the community for their participation to speakers for listening and contributing to the discussions. He emphasized how much CAHN wanted to facilitate and to ensure that devolution was working for our community. Charles acknowledged the development of the Integrated Care Systems that will be in place in April 2022 and how CAHN with our partners and communities will be thinking through what opportunities that could present to us. He ended by saying that even as we work on local, regional, national level it was important to pick up the conversation around investment and specialised commissioning. In the spirit of activism, he spoke about the need to collectively build up the movement and bring in political leaders such as our GM Mayor Andy Burnham who committed in 2018, to make sickle cell a priority. Charles promised that CAHN will go back to the Mayor and knock on his door. He thanked Katy from MFT, and others for their support and also the community which he emphasizes should be in the lead collectively. CAHN wants the spotlight to be on Greater Manchester to do things differently.

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Caribbean & African Health Network

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