

# Independent Evaluation Report of the Nottingham Sickle Cell and Thalassaemia Service 2009 - 2010



**I believe I can fly**

**The power of patient experience**







An Independent Evaluation of the  
Nottingham Sickle Cell and Thalassaemia Service  
the Nottingham Sickle cell and Thalassaemi

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Written by Lisa Robinson

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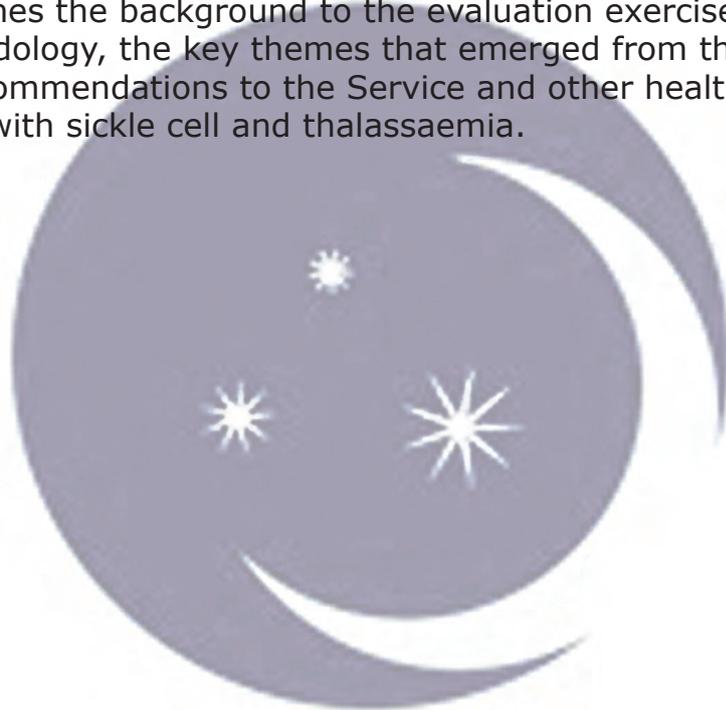
The Nottingham Sickle Cell and Thalassaemia Service hosted by CitiHealth NHS Nottingham commissioned Bright Ideas Nottingham to undertake the independent evaluation.



# Introduction

Bright Ideas Nottingham was commissioned by the Nottingham Sickle Cell and Thalassaemia Service to complete an independent evaluation of the service. Bright Ideas proposed to design an evaluation process that centred on the experiences of people who use the service; this proposal was accepted and an approach called the Mythical Journey was adopted.

This report outlines the background to the evaluation exercise, the evaluation aims and methodology, the key themes that emerged from the analysis, and the findings and recommendations to the Service and other health services that are used by people with sickle cell and thalassaemia.



# Background

The drive to set up sickle cell services in Nottingham was led by individuals in the community associated with the charity OSCAR (Organisation for Sickle Cell Research). In 1988 the Nottingham Sickle Cell and Thalassaemia Service was launched. It was the first to be set up in the East Midlands, ahead of Leicester and Derby. At that time the service was based at Victoria Health Centre in the city centre. The aims of the service were to:

- provide screening and counselling;
- provide advice, support and education to those with sickle cell disorders;
- raise awareness in the community;
- train health professionals.

The Sickle Cell and Thalassaemia Service is now hosted by CitiHealth NHS Nottingham and is based in the Mary Potter Centre in the midst of a vibrant inner city area of Nottingham, Hyson Green. It is very accessible and has good transport links to other parts of the city. The service caters for local people with sickle cell and thalassaemia disorders and their families/carers. It offers patient-centred care, focusing on case management, genetic counselling, health promotion, training and education. It is an integrated service, with service users coming from all age groups from newborn babies to older adults.

The Sickle Cell Thalassaemia Service strives to provide a culturally competent service, and invests in staff training and development opportunities that ensure that the service meets the needs of those who use it. Staff members take care to learn about the diverse needs of the families they work with. The service is fortunate in that it is reflective of the client group it serves in terms of ethnicity and languages spoken.

The Service has experienced some major changes in recent years. Following the national implementation of the universal newborn screening programme for sickle cell disorders in 2004, the service developed a proactive approach to following up people who were carriers of the gene and who were identified from the programme. It also has a very structured approach to ensuring that parents are informed of their newborn child's results within 12 weeks. Those who have babies born with a sickle cell disorder are informed within 6 weeks of birth.

In 2007 the Service significantly improved its awareness-raising activities by working in partnership with Kemet Radio, a local community station. In June 2008 the Service moved from Newbrook House (a business complex) to the newly built Mary Potter Centre, which accommodates a number of NHS, City Council and Nottingham City Homes services. This has raised the profile of the Service within health and social care.

It has also enabled better partnership arrangements with services such as adult care and the Independent Living team. The Sickle Cell and Thalassaemia Service is confident that these arrangements ensure a more holistic approach to meeting the needs of the people who use it. In 2008 the Service received additional funding to recruit 2 full-time specialist nurses. This has enabled the Service to provide

much-needed regular and consistent one-to-one care and support, as well as introduce a weekly drop-in clinic. 133 people with sickle cell or thalassaemia are formally registered with the Service; 82 per cent of those registered are affected by sickle cell and 6 per cent are affected by beta thalassaemia. The remaining 12 per cent are affected by other conditions which affect the blood but do not significantly affect their health and wellbeing.

There are a number of key drivers which influence the development and delivery of services offered by the Sickle Cell and Thalassaemia Service. There are several key policy documents which are relevant to the evaluation exercise and which drive service improvement. These include documents which set standards:

- Standards for the Linked Antenatal and Newborn Screening Programme, 2006
- Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK, 2008
- Standards for the Care and Management of Children & Adults with Thalassaemia, 2008

Other significant documents include the Department of Health's White Paper *Our health, our care, our say* (2006). In the introduction of this paper it was emphasised that changes in the way healthcare services are provided and developed need to be informed by the findings of the Citizens' Summit. These findings were published in the spring of 2007 and can be summarised as follows:

- People will be helped in their desire to remain healthy and independent.
- People will have real choices and greater access to both health and social care.
- Far more services will be delivered, safely and effectively, in the community or at home.
- Services will be integrated, built around the needs of individuals and not service providers, promoting independence and choice.
- Long-standing inequalities in access and care will be tackled.

# Aims of the Evaluation

The first aim of the service evaluation was to provide a number of recommendations for improving the quality of and access to Nottingham's Sickle Cell and Thalassaemia Service as a result of gathering feedback from people who use and need the Service. Through their feedback about their experiences of current and past service provision they would contribute to the improvement of local services and help the Service to identify how they can best work together as partners in their care and treatment. The second aim of the evaluation was to inform the script for a children's book which will be published for use in schools and educational settings. The book would be used to promote educational, inspirational and anti-stigma messages about living with sickle cell. (The book will be published at the same time as this report.)

An evaluation protocol was developed for the evaluation exercise. This was reviewed by a member of the Research and Governance Team at NHS Nottingham County. At the end of June 2009, all adults who use the Service, including parents/carers of children with sickle cell or thalassaemia, were sent information about the evaluation from the Sickle Cell and Thalassaemia Service. Staff also telephoned people who used the service regularly or told them about the opportunity to participate at visits and clinics. At a patient involvement day in July 2009 all those attending were given information on the study as an opportunity to influence changes to the service and tell their story. All potential interviewees were provided with enough information to be able to make an informed choice about taking part in the service evaluation. It was made clear that participation in the study was voluntary. Consent forms were signed by those wishing to take part in the interviews, giving permission for contact details to be passed to Bright Ideas' independent research and evaluation team.

An approach called 'The Mythical Journey' was adopted. This approach takes interviewees through an exploration of their personal journey whilst enabling them to recognise and reflect on significant 'events' (in the widest sense of the word) in their lives. Finally the approach allows each participant to identify the beneficial contributions the Sickle Cell and Thalassaemia Service has made to their life journey, as well as other areas which could have improved the experience for that individual and/or their family. The evaluation exercise, therefore, created a number of case-studies or personal stories of people who use the service.

All participants were from African, African-Caribbean or Asian backgrounds and living within Nottingham City. Parents of children affected by sickle cell as well as children, young people and adults with sickle cell were interviewed. The Service works with a small number of people with thalassaemia but none of these came forward for an interview.

All potential participants were asked for their consent to take part in the study and were invited to choose a name to protect their identity. Where individuals insisted on using their own names they were asked to sign a separate consent form.

A semi-structured interview schedule with open questions was used. This allowed participants to highlight issues that were important to them. Participants' responses were very much influenced by aspects of their culture, heritage, religion and patterns of migration. The information was gathered between July and December 2009 and was used to build case-studies. These powerful stories enable the reader to gain an insight into the lived experience of sickle cell and how services might be sustained or improved to meet evidenced needs. Capturing personal stories from each participant, rather than simply a range of issues and experiences, 'humanised' the evaluation approach.

A culturally competent team of researchers carried out the interviews between July and December 2009. The independent consultant provided training for the researchers as well as an interview brief. The researchers set up the interviews with the participants; every interview was carried out in a place chosen by the participant, e.g. home, the Mary Potter Centre or a community venue. The majority of interviews were carried out face-to-face, although one interview was conducted over the phone. The researchers took detailed notes during the interview and these were typed up soon afterwards. These notes were then compiled as individual case-studies. Each participant received a copy of their case-study to review it and make any changes. The researchers kept informal reflective diaries of their experiences and shared these in a research team meeting, capturing information that was not necessarily highlighted in the case studies.

An inductive qualitative approach was used to analyse the data. The detailed qualitative information gathered is indicative of the variety of perceptions and opinions of service users. A qualitative approach was appropriate given the size of the target group of interviewees, so the evaluation does not quantify the prevalence of particular views. The data provided important insights into the views, opinions and experiences of these participants. There were no preconceived ideas in the analysis; it was about what emerged from the data. The themes from the case-studies were identified and have been used as a basis for recommendations.

# Strengths, Limitations and Added Value

Initially the acceptance of the opportunity to take part in the evaluation exercise was slow. In order better to engage people who use the Service in the activities of the Service a patient involvement day was organised towards the end of July. This was approximately four weeks after people who use the service had received information in the post about the service evaluation. The study was introduced as a chance for people to tell their story so that services could be changed to meet their needs. This did have a positive impact on the recruitment of participants to the service evaluation.

The specialist nurses from the Sickle Cell and Thalassaemia Service were then involved in contacting potential participants to check that they had received the information and to give further explanation about the study. They also used other opportunities to discuss the study at home visits, clinics and drop-in services at the Mary Potter Centre where the Service is based.

The decision on where the interview would take place was given to individual participants. The researchers were very flexible and were able to interview participants during the day or evening and at weekends. It was clear that the participants really appreciated taking part in the study and expressed this to the researchers. The researchers were independent of the service, and the aim of service improvement was stressed, allowing participants to express their views and concerns and make suggestions.

The interviews were not recorded or written verbatim in full. Short verbatim statements and quotations have been included and highlighted in italics. It was thought in the development of the protocol that recording the interviews would be a barrier to participants and was therefore not suggested. Now that people who use the Service can see how the information will be used, in future evaluation activities the Service might suggest the use of a voice recorder and gain consent for this from individuals.

The participants came from a wide selection of people who use Nottingham Sickle Cell and Thalassaemia Service. They included parents of children with sickle cell as well as children, young people and older adults who have sickle cell. The intention was to recruit two participants with thalassaemia. Unfortunately the Service was unable to get consent from potential interviewees; therefore the study does not reflect the views and experiences of people with thalassaemia. However, the writers feel that if the recommendations from the study are acted on, this will improve services for people with thalassaemia as well as those with sickle cell.

The themes that emerged from the evaluation exercise have already been used to inform the script for a children's book which will be published for use in schools

and educational settings. It is hoped that this will lead to the development of a script for a play or even a short film which people who use the service can be involved in producing, directing and acting in.

The writers believe that the narratives will reassure people that they are not alone and that other people have had similar experiences. The readers will benefit from some of the encouraging and inspiring stories that individuals and families have shared. Many of the participants thanked the researchers, saying that their interview experience was positive and, for a significant number, even therapeutic. One of the interviewers is a cancer expert and was able to signpost and assist one of the interviewees to access appropriate information and support. The cancer information also proved to be of benefit to staff at the Nottingham Sickle Cell and Thalassaemia Service. The writers believe that providing such a good experience will improve the take-up of future involvement activities undertaken by the Sickle Cell and Thalassaemia Service.

The Head of the Sickle Cell and Thalassaemia Service (as well as those of a number of other services) said that the patient narratives brought the information from the evaluation alive for her, giving her a greater understanding and grasp of issues. Indeed the case-studies or personal stories resulting from the study will make excellent training and development tools for health care staff; patient narratives bring human interest to the topic of sickle cell and thalassaemia.

The researchers also thanked participants for the unexpected benefits that the interviews led to. Their experiences of the interviews were very powerful indeed. The interviews focused on service improvements and the team gained valuable insights into the challenges of living with sickle cell. Participants' personal experiences were moving, inspirational and uplifting and their stories have left the team wanting to champion work relating to sickle cell and thalassaemia. Indeed Bright Ideas has, since, voluntarily worked on a conference paper with the manager of the Service, Joanne Bloomfield, who delivered the well-received paper at an international conference on sickle cell. Bright Ideas is also planning to offer people who use the service the opportunity of learning film-making skills so they can make a film about sickle cell that can be used for both health promotion and campaigning purposes. We will also be sending volunteers to help out at the next engagement event in July 2010.

A welcome benefit of the service evaluation was that Bright Ideas was able to identify people with sickle cell who do not proactively use the Sickle Cell and Thalassaemia Service. For example, Ash had never visited the Mary Potter Centre, but, after having done an interview, made an appointment to see the staff. Bright Ideas will continue to direct people to the Service.

# Key Themes and Implications for the Service

A number of key themes emerged from the data analysis, namely:

1. the impact of sickle cell on emotional health and well-being and the coping strategies used to manage this impact
2. the impact of sickle cell on the family and relationships
3. the importance of religion and faith
4. experiences and views about stigma and misinformation
5. the importance of and need for more awareness-raising activities
6. the need for the Sickle Cell and Thalassaemia Service
7. improvements to health and wellbeing services for people with sickle cell and their families
8. access to services for people living outside the geographical boundaries defined for the Service.

These themes are discussed in more detail below. We illustrate them with examples from the stories we collected. A brief profile of each of the participants is provided. This may give a useful reference point when reading the snapshots provided below.

- i. Coral is aged 20 and her mother, Demi, who is African-Caribbean, had an amniocentesis when pregnant with her. The results showed that Coral had sickle cell.
- ii. Marcey is African-Caribbean, a working single mother; her child, Prince, aged 11, has sickle cell and was diagnosed at the age of 9 months when they still lived in Jamaica.
- iii. Bakari and Aziza are Nigerian parents of a 2-year-old daughter, Binty. Binty was diagnosed with sickle cell at the age of six weeks.
- iv. Junior has a wife and five children. A UK-born African-Caribbean man in his 30s, he went undiagnosed until he moved to Nottingham at the age of 11.
- v. Angel is a UK-born African-Caribbean woman in her 30s who was diagnosed with sickle cell as an adult.
- vi. Veb is an African-Caribbean woman in her 30s who was born in the UK. She is a single mother with two sons. She was diagnosed with sickle cell soon after birth.
- vii. Peaches is a single parent with a daughter, Gem, who was diagnosed with sickle cell at the age of 8 weeks. Peaches is African-Caribbean and was born in the UK.
- viii. Born in the UK, Jada was diagnosed with sickle cell as a baby. She is in her early 40s, an African-Caribbean mother of three children.
- ix. Sonia is aged 60 and was diagnosed at the age of 18 when living in Jamaica where she was born. She came to England in the 60s. Sonia did marry and have children but later divorced.

- x. Challis is a 30-year-old African-Caribbean student. Born in the UK, she was 5 years old and living in Bristol when she was diagnosed with sickle cell.
- xi. Mr Igbinosa is married with two daughters. The younger child was diagnosed with sickle cell at the age of 1 after moving to the UK from Nigeria.
- xii. Howard is the father of David, aged 5. David was diagnosed with sickle cell in 2006. Howard and his wife Una are Nigerian.
- xiii. Mary is 28 years old and was diagnosed with sickle cell as a baby living in Gambia. She married in the UK but is now a single parent with two small children.
- xiv. Yemisi is the mother of 5-year-old Patience, who was diagnosed with sickle cell at the age of 2 after moving from Nigeria to the UK.
- xv. Kevin, aged 3, was born to African-born parents Comfort and John. Kevin was diagnosed with sickle cell as a baby.
- xvi. Eddie, an African man in his late 20s, is the father of Cara, aged 5. Cara was diagnosed with sickle cell at birth. Her mother is not currently living in the UK, leaving Eddie as the lone parent.
- xvii. Marcia is a black British-born (Caribbean) woman in her thirties who was diagnosed with sickle cell at the age of 19.
- xviii. Ash is an Indian man in his 30s and was diagnosed with sickle cell at primary school age.
- xix. Leon, in his 40s, was diagnosed with sickle cell in Jamaica at the age of 10 or 11.
- xx. Stella is a Nigerian woman in her 30s. She and her husband left Nigeria to live in England when her twin daughters, Gladys and Vivian, were born. They were diagnosed with sickle cell at 11 months old.
- xxi. Barbara is of mixed (white and black Caribbean) heritage and is the mother of Kascia, aged 15. Kascia has sickle cell and was diagnosed when she was almost a year old.
- xxii. Josephine was born in England to parents of Nigerian origin and was first diagnosed with sickle cell when she was a year old.
- xxiii. Niomi was born in the UK and is of African-Caribbean parentage and first became aware that she had sickle cell around the age of 11.
- xxiv. Marcus is a young African-Caribbean man in his late 20s who was born in the UK. He was diagnosed with sickle cell as an older child.
- xxv. Salome is of mixed parentage (white British and black Caribbean) and in her 30s. She is married with two daughters and an 8-year-old adopted son, Matthew. Salome first became aware that Matthew had sickle cell when he was 18 months old.

## **1. Impact on emotional health and wellbeing and coping strategies**

Many people who now use the Sickle Cell and Thalassaemia Service were diagnosed late in life because of a lack of appropriate services at the time. The impact of late diagnosis is illustrated by Sonia, who recollects her early years as a young girl growing up in Kingston, Jamaica, and her parents sending her off to the country where she would have a better quality of life. Sonia was aware that she had an illness but had no knowledge of what this was. It was in 1964 at the age of 18 that she was diagnosed with sickle cell. Being diagnosed was a relief and helped her to see her life more positively, regardless of the pain. People could now believe that she had an illness and it had a name. Other participants, like Junior, shared this same sense of relief at being diagnosed.

In the past, before the days of sickle cell and thalassaemia services, people with sickle cell went through life with symptoms, but, because they were not tested, they were not appropriately treated. Others who were given a diagnosis were not given any information about the condition and care/treatment. For example, Marcia was told over the phone that she had sickle cell disease. There was no explanation given. She remembers being shocked as she knew nothing about sickle cell anaemia.

Howard and Una discovered their four-year-old child had sickle cell after an admission to a Nottingham hospital in 2006. They were both tested in Nigeria before they came to the UK and were given a negative result. They felt traumatised when they realised their son really did have the condition and were so shocked that they had to ask for the test to be repeated. This experience of having been given a negative result was common amongst the Nigerian interviewees.

An important role for the Sickle Cell and Thalassaemia Service is ensuring that people have access to antenatal screening and that staff are trained to explain the meaning of being a carrier. Where people have come to the UK from abroad, the NHS ensures that people are tested and does not rely on any previous results. Comfort and John's experience illustrates the necessity of retesting here in the UK. For them the news was a shock to the family as Comfort was aware that she was a carrier of the sickle cell gene but her husband John had tested negative in Nigeria. They had both been tested in Nigeria prior to their marriage and therefore as far as they were concerned there was no risk of having a child with sickle cell.

Since the introduction of universal newborn screening for sickle cell disorders in England in 2004, parents of all newborn babies who are diagnosed with sickle cell disorder are informed within 6 weeks of their child's birth. There should now be fewer late diagnoses in children born in the UK. However, Howard and Una's story illustrates the need for children, young people and adults who were born

abroad to be tested for sickle cell anaemia. The Sickle Cell and Thalassaemia Service has recently become aware that there are 70 children under the age of one in Nottingham who have not yet been screened for sickle cell; most of them were born abroad. Plans are in place to offer screening to all these children.

Anionwu and Atkin (2001) cite a number of examples of literature which focus on the "key factors that facilitate successful coping" in families where someone has a long-term medical condition. "Early diagnosis and appropriate information, the availability of material and social support, and family dynamics are all implicated in successful coping."

It was clear from all the participants in this study that sickle cell affected them throughout their lives. It has been shown in some of the case-studies that when individuals are diagnosed at a later age, especially after a previous misdiagnosis, it can be more difficult to accept the diagnosis. Parents do experience shock and disbelief when they are given the initial diagnosis, but it is felt that, where a child is diagnosed early, the family can access better support and information. This inevitably leads to better care and treatment in the long term and a child that is better equipped to manage the condition as they get older.

Several parents, such as Marcey, talked about feelings of guilt, blaming themselves for their child's condition. Within the first 8 weeks after her child's diagnosis, Peaches found herself continually asking herself the questions "Why me?" "Why *my* daughter?" She explained that she became bitter and depressed and found it hard to cope. She clearly blamed herself for her daughter having sickle cell. However, she decided to change her attitude and was able to be more positive once she started visiting the clinic regularly and asking more questions about her daughter's condition. She eventually gathered the confidence and strength to do as much research about sickle cell herself as she could. This gave her a greater understanding of the condition, and helped her to face her in-laws to explain what their grand-daughter's condition was.

Anionwu and Atkin (2001) explain that self-blame is common in parents of a child with a genetic condition, indicating that Peaches' reaction was predictable. Affected individuals develop more successful coping strategies as they get older. Peaches said that she began to recognise the importance of working with the illness rather than against it. She was one of several participants who told us how they did not allow their feelings to stop them taking positive steps towards becoming more informed and more able to manage the condition.

The Sickle Cell and Thalassaemia Service can look at ways to improve support for families with coping strategies. This might take the form of a course or an 'expert patient' type of approach as well as more informal support. Offering

one-to-one and group work approaches and alternative therapies could also offer opportunities for families to strengthen their coping mechanisms.

## **2. Impact on family and relationships**

The impact of the diagnosis of a long-term medical condition can never be underestimated. Peaches spoke about the moment when she and her partner discovered that their child had sickle cell. They were shocked, but Peaches' natural instinct was to try to come to terms with the situation. She explained that at first they did not mention anything to either of their families. She went on to share the effects on the family, expressing that it was a very difficult time for her because she lost contact with her parents and consequently lost their support too. She also noticed her partner was distancing himself from his supporting role and the family unit. Within three months of her daughter's birth Peaches was left all alone to care for her child. The number of adults who had sickle cell or who had a child with sickle cell and who were also single parents was significant.

For many people it is difficult to tell others they have sickle cell anaemia for fear of being rejected. Mary, who is now divorced, feels strongly that her "sickness" influenced her husband's decision to leave. She said that he would probably never have married her if he had known that she had sickle cell anaemia. She also believes that her husband's abandonment was influenced by what his friends were saying to him about having a sick wife. Mary's experience brings up the question of how and when someone discloses that they have a condition. Other stories highlighted that disclosure of being a carrier can also be difficult. Veb, Sonia and Angel said that they do not talk about sickle cell very often. Peaches felt that talking with her friends about the impact of the condition put a strain on her friendships with them.

The Sickle Cell and Thalassaemia Service needs to explore how it can work with people to help them with approaches to disclosure. This might be addressed through the transition programme when young people are transferred to adult services. Otherwise it could be included as part of a broader offer of psychological support services. The impact of the condition on the family and the relationships of the person with the condition emphasises the need for the Sickle Cell and Thalassaemia Service to work with whole families rather than simply the person with the condition.

### 3. Religion and faith

Many participants spoke about the importance of their faith and beliefs in keeping them optimistic and thankful for the support and services they were receiving. A significant number of participants, including Veb, Mary, Comfort, Jade and Mr Igbiosa, talked about the importance of prayer and spirituality. Ellie's parents explained that the first person they told about Ellie's diagnosis was their pastor, followed by close friends. The pastor and their friends were very supportive and prayer was greatly appreciated. The family felt spiritually strengthened and encouraged.

Faith commonly plays an important part in African and African-Caribbean communities. It often forms a foundation for health beliefs and experiences. A study on the health belief system of African-Americans (Fields, 2001) recognises the importance of religion and spirituality in the way that people cope with illness. Religion provides a world view, which is acted out in narrative (story), doctrine, symbols, rites, rituals, sacraments, a moral code, and gatherings; and in the promotion of values and ties of mutual obligation. It creates a framework within which people seek to understand and interpret, and make sense of themselves, their lives and daily experiences.

In recognising a person's religion and/or spirituality the Sickle Cell and Thalassaemia Service is addressing one of the most vital aspects of care. People who use the Service increasingly want services to view them holistically, and spirituality and faith are vital elements in that. Veb was admitted into intensive care for two weeks due to the severity of the crisis. "Only God has brought me back!" she said. "The doctors were surprised I pulled through. It was simply through prayers!"

A study of African-Caribbean patients with type 2 diabetes (Brown et al., 2007) briefly discusses the role of religion and faith in health beliefs of people with a long-term condition. In their study several of the participants had a strong Christian faith. This faith was often accompanied by a feeling that the outcome of their illness was in "the hands of a higher power". Another study on the other side of the Atlantic indicates that there can be a comfortable relationship between a person's faith and belief and their experiences of health care services. "Eighty seven percent of our sample reported that they felt comfortable with the care they received at the clinic, leading us to assume that African-Americans are not kept away by organised medicine by their belief in faith and prayer as healing tools" (Quaye, 2003).

The evaluation exercise indicated a high level of satisfaction with the Sickle Cell and Thalassaemia Service. The culturally competent approach of the service is partly responsible for the positive perception of the service. As with the study on people with type 2 diabetes, our evaluation found that, regardless of faith and



belief, people recognised the importance of taking responsibility around care and management of the condition. Faith, religion and belief do not create barriers to treatment. On the contrary, they are seen as part of the person's treatment. "I'll be fine," said Veb. "God will take care of everything."

In their work with other health and well-being services, the Sickle Cell and Thalassaemia Service needs to promote the acknowledgement of the importance of religion and belief in a culturally competent and holistic approach to the health and well-being of people with sickle cell and their families.

#### **4. Stigma and misinformation**

A significant number of participants said that at some point they had held the belief that they would die young as a result of having sickle cell. This view seemed to be held by people who were born abroad. For example Mary said that she was grateful for the help she has received in the UK and believed she would be dead without it. She was never expected to live beyond the age of 25. Another participant, Leon, was told by his doctor in Jamaica that he would not live beyond 20.

Some participants spoke of the circulation of inaccurate or misleading information which reinforces false myths and stereotypes about sickle cell and thalassaemia. It can also lead to the use of negative language and labeling relating to the condition and people who are affected by it. Marcus's story illustrates the dangers of misinformation. For example Marcus has never thought it necessary to use the Sickle Cell and Thalassaemia Service and before the interview could not see the benefits. In his interview he used the term 'sufferer' several times. He also used terms such as 'trait' and 'full-blown sickle cell disease'. His lack of understanding of how he has inherited sickle cell anaemia is clearly shown by his belief that he was diagnosed with the 'sickle cell trait'. He is sure that this later "turned into full-blown sickle cell disease".

Following are examples of the language used by the participants. We have also included suggestions for alternative terminology. Interestingly, during the process of the literature review we found many examples of negative labeling in academic reviews and books. This seems to be particularly the case in articles and literature from America, where much of the work and research around sickle cell anaemia has been published.

Language used by participants in the evaluation and alternative choices:

*sufferer/sickler - person with sickle cell anaemia*

*full blown sickle cell - sickle cell anaemia*

*sickle cell trait - carrier of the sickle cell gene*

*illness/disease - condition*

*crippled in pain - severe pain*

Marcus was not the only participant to refer to sickle cell anaemia as being the 'full-blown' version of the condition. Marcey and others also use this language. Marcey's first son was tested for sickle cell at the age of 9 months in Jamaica. The doctors told her that her son had "the full-blown sickle cell anaemia". Clearly the language used by some participants has negative connotations which lead to misinformation and stigma. The terms 'full-blown' and 'disease' would give the impression of sickle cell being something that can be caught, and the term 'full-blown' is often used (again unfortunately) in connection with HIV and AIDS.

It is Jada's belief that there is a stigma attached to sickle cell. "People wrongly believe it is a 'disease' which you can catch." Likewise, describing people with sickle cell as 'sufferers' or 'sicklers' gives the impression that they are victims, are constantly ill and are defined by the condition. Again, even referring to sickle cell as an 'illness' would suggest that people with the condition are constantly unwell. On the contrary, many of the participants were positive about their lives, managed the condition well and were rarely ill because of preventative care.

In countries like Nigeria where sickle cell is very common there may be less stigma because it is a condition that communities are familiar with. In Mr Igbinosa's view sickle cell is not stigmatised in Nigeria. It is accepted as a "normal sickness". He thought that there was more of a stigma here in the UK because it is not as common. He felt that the stigma was not coming from community members but was present amongst health services that lacked awareness and treated his child as if sickle cell was unique or abnormal. Howard echoed much of what Mr Igbinosa said and felt that there was little or no stigma.

On the other hand, Stella and Comfort, who are also from Nigeria, provided an alternative viewpoint. They individually felt that there is a lot of stigma attached to having sickle cell among everybody, including their community. Stella stated that she does not think much can be done regarding the stigma and that "it's just in my culture and the way it is seen within it".



Salome spoke in detail about the association of sickle cell with disability. Whilst she then went on to describe it as an 'illness', she emphasised that her son, Matthew, does not see himself as a disabled person. Salome thinks that Matthew is now realising that sickle cell is viewed as negative by other people and he doesn't like to refer to it as a disability. She gave an example where the word 'disability' came up in a conversation overheard by her son, and concluded: "*He doesn't see himself as disabled and he realises this has negative connotations*".

There was a strong theme around stigma and pain relief requirements during hospital admission. Participants felt that health staff displayed prejudice, believing that the only reason that they had come into hospital was to obtain drugs. One participant said that she was made to feel like someone who takes drugs illegally. Some also believed that this was not just as a result of the stigma associated with having sickle cell, but was also about race/ethnicity.

Participants spoke of encountering stigma or were worried about encountering stigma from health services, schools, employers and the wider community. Marcey and Josephine said that people often think that sickle cell is contagious. Niomi experienced some stigma whilst at school in the dinner hall. A girl said to one of her friends "Don't drink from that glass because she's got a disease." She was teased by boys because her physical development was delayed when compared to other girls in her year group. Niomi believes that this stigma could be reduced if awareness of sickle cell was introduced in schools at an early age. Unfortunately some participants spoke about having to hide the fact that they had sickle cell from their employers. Angel has not told her employer for fear of pity. Comfort hasn't told her employer about her child having sickle cell for fear of prejudice in relation to having to take time off as a carer. It took Jada five years to tell her employer about having sickle cell because she did not want to be labelled.

It is clear that ignorance and stigma can come from anywhere and any community. However, those participants that took time to educate individuals with a direct role in their lives were less likely to have these negative experiences. The Sickle Cell and Thalassaemia Service proactively seeks opportunities to raise awareness about sickle cell. It does this through talks in schools and community settings, through events in the community and through interviews on community radio. It also provides professional development opportunities for health staff. The Service could incorporate issues around stigma and the impact of it on people and their families. The Service is already using the case-studies collected for the evaluation to illustrate people's personal experiences of stigma and how it affects them and their families. Participants such as Ash felt that it was this crucial work around awareness-raising that was successfully reducing the ignorance about sickle cell in services and communities.

## 5. Awareness raising

Awareness raising is one of the key activities of the Service and is acknowledged as one of the performance indicators in the service specification. Several participants expressed an interest in volunteering and supporting the Service to raise awareness of sickle cell. Some participants such as Howard already do so. Mr Igbinosa, amongst others, said that he felt more awareness was needed amongst health professionals and in the community. He also felt the Government could do more to raise awareness and there should be more sickle cell charities raising funds. Comfort was grateful to her GP for giving her the option to take Kevin, her son, to the emergency department at the hospital, as when she tried an NHS walk-in centre staff lacked awareness about sickle cell and sent her back to her GP, even though the surgery was closed. Salome emphasised the importance of the nurses coming to meetings and educating social services.

The Sickle Cell and Thalassaemia Service could broaden its audiences for awareness raising in relation to sickle cell and thalassaemia. For example, GPs, local authority frontline staff and housing departments would benefit from awareness-raising activities – as could a range of health care staff who do not currently access continuing professional development in relation to these conditions.

## 6. Need for the Sickle Cell and Thalassaemia Service

The relationship between the participants and the Sickle Cell and Thalassaemia Service was very important in shaping their experiences of living with sickle cell. All participants identified the benefits that they experienced as a result of using the service, or knowing that it existed.

The Sickle Cell and Thalassaemia Service is clearly valued by the vast majority of the participants. Aziza thinks that staff at the Sickle Cell and Thalassaemia Service are “doing a fantastic job” and is happy with the support she and her daughter Binty have received. The service provided has helped to make their lives “less stressful”. Stella hopes that the Sickle Cell and Thalassaemia Service will continue to contact parents from time to time to see how they are coping and cannot think of any ways in which it could improve. Mary has a good relationship with the health professionals that care for her now that she is settled in Nottingham. The sickle cell team at the hospital and at the Nottingham Sickle Cell and Thalassaemia Service are really appreciated. Eddie appreciates the support he and Cara have received from the team, saying that they have provided much-needed additional support in the community. This latter comment was reiterated in a significant number of the interviews. The nature of the community-based service makes it more accessible to people, with a feeling that the service belongs to them. The attitude of staff is community-friendly and welcoming.

Whilst the feedback was positive and constructive in nature, many participants spoke about the importance of and the need for more support for people with sickle cell, their carers and families. We have included their suggestions in the recommendations of this report.

## **7. Improvements to Services**

The participants were asked what improvements they would like to see within the Sickle Cell and Thalassaemia service. Their responses were varied and included comments about hospital care, primary care and access to services.

### **Sickle Cell and Thalassaemia Service**

Salome felt that a number of things could be improved for people with sickle cell and their families.

*"In the initial stages of diagnosis there is a real fear of what you are going to experience when a child goes into crisis. It would be good to talk to another mum with personal experience of having a child with sickle cell. Relating to other families with experience would help parents to cope better."*

Niomi was one of many who said that it would be good to organise more trips and social events so that people could meet each other. She remembers attending sickle cell parties when she was younger and believes these should be reinstated to celebrate the milestone of being another year older. Stella, like others, hopes that the Sickle Cell and Thalassaemia Service will continue to contact parents from time to time to see how they are coping and could not think of any ways in which it could improve.

Jada was one of several participants who wanted to see an improvement in the relationship between the Sickle Cell and Thalassaemia Service and OSCAR (a community sector provider of services to people affected by sickle cell). Participants talked about aspects of the service that they wanted to see enhanced or increased. They also spoke about additions to the service. These have been included in the recommendations.

### **Acute services**

There are two designated wards for adults in Nottingham City Hospital. The participants spoke about difficulties when admitted to hospital. For example, Angel remembered a nurse who implied that sickle cell wasn't real. Josephine felt that the NHS health professionals do not appear to have any idea about the excruciating pain experienced during a crisis. Even on the dedicated wards at the City Hospital the staff are not very aware of sickle cell anaemia and Josephine thinks awareness regarding care and treatment needs to be increased. Marcus

told us that when he has been hospitalised he has always been the youngest on the ward, with the other patients in their 50s, 60s, 70s and 80s. Marcus has never had the opportunity to meet anyone with sickle cell whilst there and feels that this would be helpful in terms of coping strategies whilst in hospital. Both Angel and Coral separately told the interviewers that their bad experiences mean that they avoid hospital admission at all costs. Coral said that the only way that anyone could get her into hospital was if she had to go into intensive care.

Participants' responses indicate that frequently the dedicated wards are full and patients are sent to other areas of the hospital where they felt that their care was not managed appropriately. There need to be alternative wards near to the designated wards or within the same directorate. This would allow for easy location of patients when they are admitted. Training for staff could be provided within that directorate so that staff would understand sickle cell and provide better pain management.

Stella felt that health professionals always assume that when they take their child for any kind of medical review it is related to sickle cell. On one occasion her child was given morphine for what transpired to be a urine infection. This highlights the need to consider that a patient who has sickle cell anaemia may be presenting with another illness or health issue which needs to be treated appropriately.

Marcey's experience with the hospital doctors and nurses has been generally good. However, she described a situation in which she saw a new doctor who did not know about sickle cell. The doctor discharged her son whilst he was still in pain. Being the determined mother she took him back into hospital. She said that the lack of understanding from doctors on the ward did not help at what was a sensitive and emotional time.

Stella has two girls with sickle cell, and is generally happy with the treatment they are given and appreciative of the fact that consultants listen to her and her husband. However she feels that the "registrars do not know how to manage the girls". In reality registrars change from time to time in order to get experience in different areas. There has been no change in consultant for the last eight years, and therefore the parents have developed a relationship and trust. Parents become experts in caring for their children and therefore it becomes even more important for professionals to listen to their concerns.

As already mentioned, participants often felt mistrusted in terms of their need for pain relief. Participants such as Challis felt that they were labelled as drug addicts. Challis said that there are so many nurses working in the hospital in Nottingham that it is difficult to have a relationship with any of them. This was not the case in another city where she lived previously. She also said that in the past she has



been in pain, has felt agitated and not listened to and has been kept waiting for treatment. She feels that sickle cell is perceived as a “black disease” and that patients sometimes do not get the care and attention they deserve. Jada echoed similar concerns around having to wait for treatment, saying “it would help if medical staff administered pain killers a lot quicker”.

Other participants felt that individual medical staff lacked empathy and stereotyped people with the condition. Some reported incidents where staff had been quite vocal about their beliefs that the patient was exaggerating the pain. Junior shared his frustrations and distress at not being believed. He said that some staff believe that the crisis is “not real” and that he is “making it up”.

*“Nurses are very ignorant to the patient’s needs when they come in with a crisis and their close family situation. What most patients need is their family there to comfort them to be a voice for them and to advocate on their behalf.”*

The evaluation team is aware that, since the study started, a hospital-based specialist nurse has been appointed. Her remit is to educate and support staff to improve the care patients receive. Systems need to be improved to ensure that pain management is administered effectively and efficiently. The specialist nurse is currently developing a training package on sickle cell and pain management.

### **Ambulance services**

Niomi believes that ambulance staff could benefit from training concerning sickle cell. Another participant said that it was frustrating having to inform ambulance staff about the condition each time they used the service. Jada said that a member of staff put on latex gloves before examining her. Whilst this was most likely an infection control measure, staff do need to be sensitive of patient’s perceptions and explain the need for precautions – especially with conditions like sickle cell where it is not uncommon to encounter misconceptions about it being ‘contagious’.

## 8. Access to Services

The Sickle Cell and Thalassaemia Service covers a defined geographical area. It is aware of two patients who live outside this area and who attend the clinic at the City Hospital. They do not have access to a dedicated service or a specialist nurse. One participant said *"It would be great if the service could be expanded geographically."*

A health needs assessment needs to be carried out to identify the location and the number of people living within the East Midlands region with sickle cell and thalassaemia who do not have access to specialist services. Services should be commissioned to ensure that their health needs are addressed and that they have access to appropriate services.



# Findings and Recommendations

Participants' responses were very much influenced by aspects of their culture, heritage, religion and patterns of migration. The findings from the evaluation are detailed below and the recommendations take fully into consideration what participants said about service delivery, improvements and changes. Although the evaluation was about their experiences of the Sickle Cell and Thalassaemia Service, these findings also incorporate their experiences of acute services and primary care, as these are all part of their journey. It was noted that sometimes this journey can be relatively seamless and participants might not make a differentiation between primary and secondary care. We have also included recommendations for hospitals and other services around the country.

Analysis of the responses of the interviewees illustrates that services for people with sickle cell, awareness of the condition, quality of life and life expectancy have improved considerably over the decades. Nottingham's Sickle Cell and Thalassaemia Service is clearly providing a much-needed and valued specialist service. The team are able to provide a highly personalised service – and many interviewees spoke of both the present and former staff by name.

Again, there is good practice in the hospitals and amongst GPs and other health staff which is both recognised and appreciated by individuals benefitting from this. Nevertheless there are areas for improvement. The Sickle Cell and Thalassaemia Service welcomes challenge and these findings and recommendations will help them to improve an already excellent service. The research and evaluation team felt that the interviewees are all potential role models. They felt that an overarching recommendation is that people with sickle cell and their family members should be encouraged to tell their stories and inspire people regardless of whether they too have the condition.

## NHS Nottingham

**Finding:** Interviewees highly value the services provided by Nottingham's Sickle Cell and Thalassaemia Service. However, many expressed a desire to see the Service diversify and grow. Interviewees particularly wanted to see:

- community-based psychological support services
- increased access to safe alternative therapies and medications, e.g. massage and relaxation
- more individual and group support
- increased awareness-raising activity
- services for carers
- appropriate physical activity opportunities
- an 'out of hours' service for when people need support, advice or counselling
- a regular newsletter

Many participants were experiencing poverty because of the impact on earning potential (due to caring responsibilities, poor health or lack of qualifications). Financial support or assistance with accessing financial support is much needed. Given the nature of the suggestions and requests, the NHS might consider investing in new posts for family support workers to work with families to meet their varied needs. The evidence for the need for the development of a community-based psychological service for people with sickle cell and thalassaemia was overwhelming.

**Recommendation:** Additional resources should be invested into the service to meet needs. More funding is required to employ more staff and make the Nottingham Sickle Cell and Thalassaemia Service even more responsive to the needs of people who use or could potentially use the services.

**Finding:** Several participants talked about their reluctance to admit themselves into hospital because of their previous experiences or because they do not find the environment of the hospital conducive to well-being.

**Recommendation:** NHS Nottingham City could explore the possibility of setting up cost-effective day provision (outside hospitals) where people having a crisis can go.

## Nottingham's Sickle Cell and Thalassaemia Service

**Finding:** Interviewees (even those who do not approach the Service for help) appreciate the home and hospital visits and social calls provided by the Service.

**Recommendation:** The Service needs to continue to prioritise this highly valued part of the service. Recently the City Hospital has created a specialist post that will support patients in hospital and carry out discharge planning. A similar post for children has been created at the QMC.

**Finding:** Interviewees emphasised a need for more support options. It is not always easy for people to attend a support group due to school/work/childcare responsibilities. Many participants felt that their relationships with family members and friends were often strained, and that adequate alternative support systems would reduce this strain considerably.

**Recommendation:** It was suggested that emotional support could be provided via a website forum/blog and a telephone helpline. Ideally a community-based psychological support service should be set up and offered. The Service might explore a possible relationship with Health In Mind – a new psychological support service to which people can refer themselves. Bright Ideas' Champions of Change service could assist with this.

**Finding:** Faith, religion and belief were evidently essential to participants' coping strategies.

**Recommendation:** The Service needs to record information on religion and belief for each patient or person who uses the Service. Religion and belief should be taken into consideration in the care and support of patients. Staff may need some input on the importance of collecting and monitoring information around religion and belief.

**Finding:** Some interviewees spoke of inaccurate or misleading information about sickle cell. Some information reinforces false myths and stereotypes about sickle cell and thalassaemia.

**Recommendation:** The Service needs to remind existing service users and warn new service users about sourcing information on the Internet. It might recommend websites that are trustworthy. The Service should also continue its good practice in updating general information and educational materials for its users to disseminate to family members, community groups, schools and colleagues in the workplace. This information should include the signs and symptoms, care, treatment and management of both conditions.



**Finding:** Some interviewees were not aware that the Service carries out awareness-raising activities in schools, after-school clubs and other educational institutions and communities. This awareness raising includes educating staff about signs and symptoms, treatment and care management of pupils with sickle cell and thalassaemia. Those that did know about it praised the work. A significant number of interviewees emphasised the importance of and need for more awareness raising and some wanted to be involved in this.

**Recommendation:** The Sickle Cell and Thalassaemia Service should continue their good practice of raising awareness. They might consider broadening their audience to include ambulance staff, primary care staff, frontline local authority and housing association staff, employers in a range of workplaces, and leaders and workers in religious and community settings. The Service should ensure that all people who use the Service are aware of this important aspect of their work. There is the potential for a group of people who use the Service to work with Bright Ideas on making a short awareness-raising film. Discussions are now underway about this. The Sickle Cell and Thalassaemia Service might also consider approaching a local councillor and/or MP with a view to them becoming a champion for people with sickle cell. The Service needs to capitalise on the interest shown by potential volunteers. As well as raising awareness about the condition and its impact they should share good news stories about what people have achieved and do achieve – whether this is about having children, going into education, gaining employment or career advancement or simply enjoying leisure and social opportunities.

**Finding:** A number of interviewees talked about how the risk of a crisis often discouraged or prevented them or their child from enjoying certain types of physical activity. Examples given include swimming and outdoor sports.

**Recommendation:** The Service could hire hydrotherapy or teaching pools in leisure centres or hotels and provide swimming and sports sessions for clients. It would need to ensure temperature and other necessary conditions are monitored.



**Finding:** A significant number of interviewees highlighted the need for GPs and other health staff to be aware about sickle cell. It can be frustrating having to explain the same information to a number of different professionals.

**Recommendation:** A health professional handbook could be devised to be distributed to GP surgeries, hospitals and other medical institutions. (The Service has already started this. It includes an overview of sickle cell, diagnosis, roles and responsibilities, care management of patients with sickle cell in primary care, antenatal screening and key local contacts.) The Service could explore how it can empower patients to work with GPs and primary and secondary care staff so that they can influence their own care plans.

**Finding:** Those interviewees who take time to educate important people around them about the condition experience better levels of support and understanding than those who do not. Whilst interviewees spoke of encountering stigma or being worried about encountering stigma from health services and employers, it became clear in the analysis that ignorance and stigma can come from anywhere and any community. However, those interviewees that took time to educate individuals with a direct role in their lives were less likely to report negative experiences.

**Recommendation:** The Service needs to share this finding with service users – particularly those who keep the condition to themselves for fear of being pitied or stereotyped or stigmatised. It is hoped that the prospect of better understanding and support will encourage more people to speak openly about the condition.

**Finding:** Many interviewees spoke about the importance of and need for more support for people with sickle cell and their carers and families. Interviewees raised issues around the impact of the condition on mental health and emotional health. They spoke about feelings of blame, guilt, shame and stigmatisation. Some spoke about not feeling listened to, stress, coping mechanisms, lack of relationship support, financial worries and so forth.

**Recommendation:** Support networks and forums should be set up to empower people with sickle cell and thalassaemia and their families/carers. These forums would give them the opportunity to express their feelings and share experiences and information. They would also help to reduce stigma, false assumptions and ignorance surrounding the conditions. Examples of these support networks and forums can be achieved by:

- Internet website forums such as Facebook
- community self-help/support groups
- psychological support and counselling services.

(Since completing the evaluation activity the Service has set up a support group.)



**Finding:** The practical support offered by the Sickle Cell and Thalassaemia Service is highly valued by people who use the service.

**Recommendation:** The Service should continue to support clients and carers to meet their basic needs such as completing benefit forms (e.g. Disability Living Allowance), and to provide advice and resources. They should also continue to direct people to relevant services – for example, services that can help with housework. The Service should also continue to ensure that service users are reminded of hospital appointments.

**Finding:** Interviewees spoke about financial issues, and some spoke about the costs of keeping their houses warm.

**Recommendation:** The Service can offer to put people who use the service in touch with a free project run by ACAF (African-Caribbean and Asian Forum) and Bright Ideas – the eNerGy squad. The squad is made up of local people (volunteers) who are trained to provide other local people with advice around energy efficiency and saving money. They can also direct people to other schemes such as Warm Front.

**Finding:** Some interviewees demonstrated a lack of awareness about national and local developments.

**Recommendation:** The Sickle Cell and Thalassaemia Service could do more to inform people who use the service about developments that affect them. The Service is thinking about producing a newsletter. However this would need resourcing. The Service needs to work with the communications department of the NHS in order to find a way to share information and developments with people who use the service.

**Findings:** The more information that a school has on sickle cell and thalassaemia, the better the support they are able to give the child.

**Recommendation:** One parent said that she makes it a point to give information to teachers at the start of every school year as their child moves up a class. The Sickle Cell and Thalassaemia Service could suggest this to all parents and carers.



**Finding:** Some people want to volunteer and be more involved in the Service. Several wanted to be involved in awareness-raising activities.

**Recommendation:** The Sickle Cell and Thalassaemia Service needs to tap into this valuable resource. Some patients may need to be supported with access issues – e.g. those with a disability or impairment. A regular newsletter from the Service would help people keep informed about how they can get involved and how others are making a difference.

**Finding:** Several female interviewees said that their partners or husbands had left them – directly because of her having sickle cell. These women don't have help from these estranged partners and have to cope as single parents.

**Recommendation:** Fathers can be involved in the lives of their children, regardless of whether they are still with their partner. More research is perhaps needed in order to explore the reasons why men leave and possible ways of enabling them to be more involved in the child's life. A research project exploring the impact of father deficit on families would be of interest. Martin Glynn, Sankofa Associates, is a recommended consultant and has delivered papers nationally and internationally on the subject of father deficit.

**Finding:** The difficulties of disclosure in relation to being a carrier of a gene and in relation to having sickle cell anaemia was a strong theme in the interviews.

**Recommendation:** A second recommended area for further research is in the issue of 'difficult dialogues'. How and when does someone disclose that they are a carrier for the sickle cell gene, or indeed that they have sickle cell or thalassaemia? How do they do so in the case of personal relationships, with employers or potential employers, and in other situations? Victoria Showunmi, Showunmi Associates, is a published writer and researcher on the subject of difficult dialogues.

**Finding:** Participants shared strong feelings of being overprotected by a parent or parents as children. They believed that this held them back in terms of development, socialisation or inclusion.

**Recommendation:** The Service could explore ways in which it can encourage parents to involve children in taking responsibility for their own care, treatment and management from an early age. The development and offer of family learning sessions using 'expert patient' methodologies and activities might help with this.

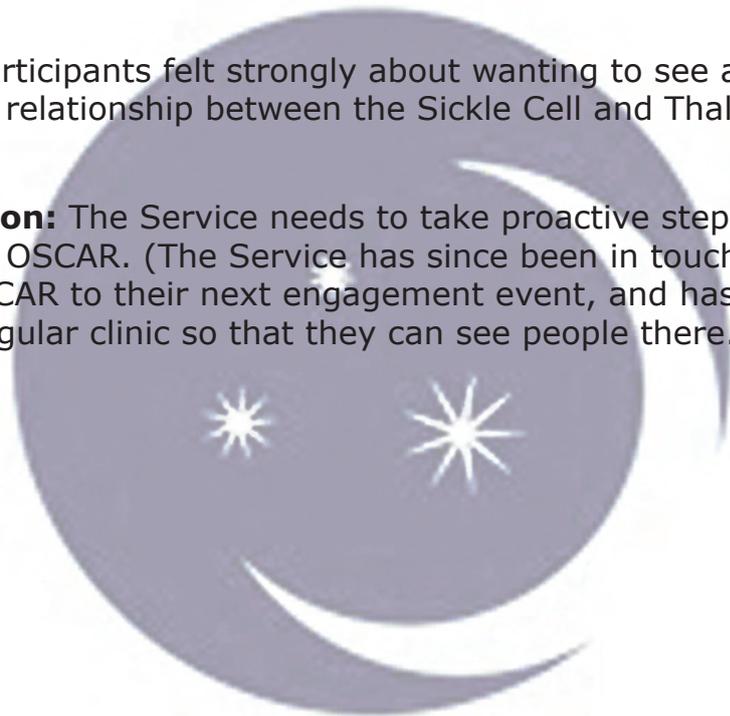


**Finding:** The evaluation exercise has produced a variety of rich and useful data which will inevitably lead to improved and therefore more cost-efficient and effective services.

**Recommendation:** It is recommended that the Service carry out a similar exercise every 3 to 5 years. We believe that once people who use the Service see the stories and the report it will be very easy to engage more of them in future evaluation activities.

**Finding:** Two participants felt strongly about wanting to see a closer and more positive working relationship between the Sickle Cell and Thalassaemia Service and OSCAR.

**Recommendation:** The Service needs to take proactive steps to work in partnership with OSCAR. (The Service has since been in touch to offer training and to invite OSCAR to their next engagement event, and has offered OSCAR staff space at their regular clinic so that they can see people there.)



## Hospitals

**Finding:** Sometimes when people are admitted into hospital with a crisis a bed is not available on a ward that has been designated for people with the condition. They are sent to wards where their care cannot be managed appropriately.

**Recommendation:** In the case of a designated ward being full, the hospital staff should be able to recommend an appropriate ward in the same directorate that is located in the vicinity of the designated ward. In other words there should be designated 'back-up' wards for patients with sickle cell and thalassaemia.

**Finding:** When new staff members get involved in a patient's case, they sometimes lack knowledge about the condition.

**Recommendation:** A smooth, effective handover is also required when new medical staff are appointed with responsibility for the patient's treatment and care. This applies to primary care teams and hospital staff on wards. Professionals need to heed the information provided by people with sickle cell and their parents and carers – they are often experts on the condition.

**Finding:** Interviewees are often mistrusted in terms of their need for pain relief. Some felt that they were labelled by some staff as drug addicts.

**Recommendation:** Hospitals need to educate staff on appropriate hospital wards to be aware of the pain relief needs of people in crisis. In hospital it may be beneficial to have a letter on the front of the patient's notes so that the new Senior House Officers know how much morphine needs to be administered. (The City Hospital has recently recruited a specialist nurse. Part of her role is to increase awareness around these issues.)

**Finding:** Some interviewees felt that individual medical staff could lack empathy and stereotype people with the condition. Some reported incidents where staff had been quite vocal about their feelings – for example, not believing a patient is in pain.

**Recommendation:** Hospitals need to ensure that staff listen to patients and ensure personalised care - every person with sickle cell is different. Hospitals and ambulance staff should ensure that infection control procedures are explained so as not to offend patients. (People commonly experience, from members of the general public, the stigma that sickle cell is 'catching', and staff need to be sensitive to this.)



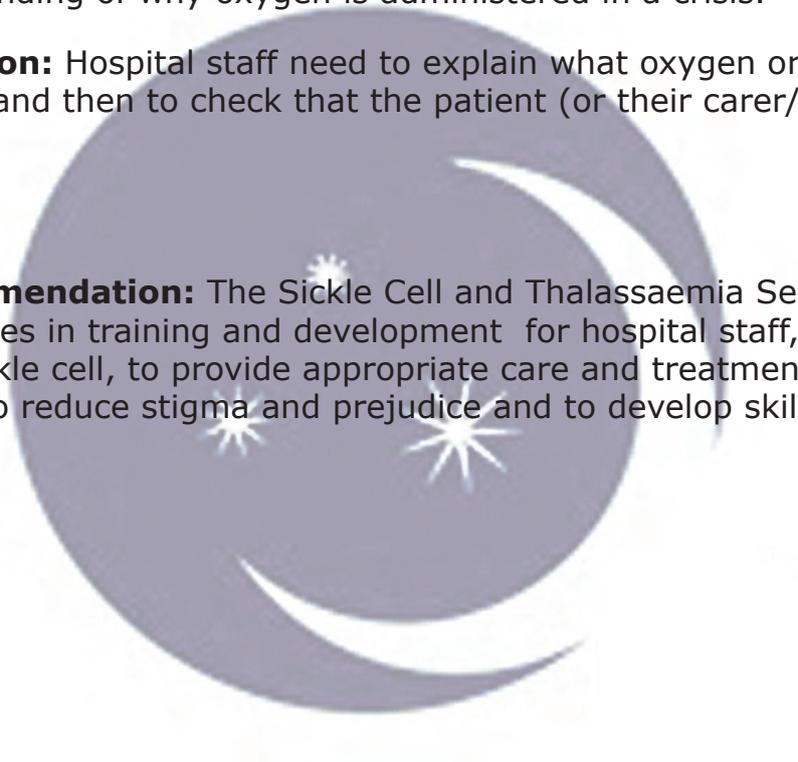
**Finding:** Several interviewees spoke about delays in receiving pain relief in hospitals.

**Recommendation:** Systems need to be improved to ensure that pain relief and effective care management are administered effectively and efficiently.

**Finding:** During interviews it became clear that some interviewees were mistaken in their understanding of why oxygen is administered in a crisis.

**Recommendation:** Hospital staff need to explain what oxygen or any other treatment is for and then to check that the patient (or their carer/parent) has understood.

**General recommendation:** The Sickle Cell and Thalassaemia Service could work with acute services in training and development for hospital staff, to raise awareness of sickle cell, to provide appropriate care and treatment (including pain management), to reduce stigma and prejudice and to develop skills in cultural competence.



## Health Care Services in General

**Finding:** The interviews provided numerous examples where health care staff (amongst others) had little or no knowledge about sickle cell anaemia.

**Recommendation:** Participants suggested that a number of different people who work in a variety of health care settings would benefit from training and development, both in sickle cell and thalassaemia and in cultural competence within health and social care.

**Finding:** Some of the language used in relation to sickle cell and people with the condition has negative connotations – for example leading to a picture of people with sickle cell having a contagious disease or being victims or constantly ill. Some interviewees used this language themselves. Many of the interviewees were positive about their life, managed the condition well and were rarely ill.

**Recommendation:** We need to change our language to ensure that it is less emotive and does not negatively stereotype or label people. (Examples of preferable terminology have been provided earlier in this report.)

**Finding:** Spirituality, religion and belief are essential to service users' coping mechanisms. Many interviewees spoke with feeling about the importance of their faith and beliefs in keeping them optimistic, thankful for the support and services they were receiving and in a positive frame of mind.

**Recommendation:** The Sickle Cell and Thalassaemia Service already acknowledges the importance of spirituality, religion and belief. Health staff should receive training in cultural competence that covers issues such as this. Services need to collect information about religion and belief and use the information appropriately in the care and treatment of patients.

**Finding:** The Sickle Cell and Thalassaemia Service currently sees some patients from outside its geographical area.

**Recommendation:** PCTs in these areas need to assess the needs of these patients and their families and commission services accordingly. It might be that they could buy in services from Nottingham Sickle Cell and Thalassaemia Service. The Regional Sickle Cell and Thalassaemia Service could help initiate this work with PCTs.



**Finding:** People with sickle cell often had other long-term health conditions. In addition, some interviewees spoke about having a short-term medical complaint that was not related to sickle cell. Health care staff had not investigated the complaint properly and assumed it was related to sickle cell.

**Recommendation:** As with anyone with a long-term condition, medical staff need to investigate health issues thoroughly rather than make assumptions.

**Finding:** Some participants could have clearly benefited from regular GP appointments.

**Recommendation:** Those providing primary care need to consider how they treat other people with long-term conditions - giving them regular check-ups. (The new patients' handbook being developed by the Sickle Cell and Thalassaemia Service should help with this.)

**Finding:** Some participants born abroad came to the UK with a misdiagnosis.

**Recommendation:** It is recommended that people who are newly registered with a GP are tested.

**General recommendation:** A story-telling approach is a culturally competent approach to the evaluation of a health service. Health professionals could consider how they might make patient narratives part of the service review. This ensures that people who use a service can have a say about any issues which affect their health experience, care and treatment. Involving them means that we can work together to achieve patient-centred solutions.

## Sickle Cell Services Across the UK

**Finding:** Some interviewees who were born outside the UK said that the diagnosis they had from testing in their country of birth was incorrect. They tested negative abroad, but tested positive in the UK.

**Recommendation:** Sickle cell and thalassaemia services should raise awareness about the need to retest people who enter the UK from abroad - especially those from African, Asian and Caribbean countries. NHS services and other health professionals should retest people who have come to live in the UK, particularly from countries where sickle cell is more common.



# Conclusion

Analysis of the responses of the interviewees illustrates that services for people with sickle cell, awareness of the condition, quality of life and life expectancy have improved considerably over the decades. Nottingham's Sickle Cell and Thalassaemia Service is clearly providing a much-needed and valued specialist service. The team is able to provide a highly personalised service – and many interviewees spoke of both the present and former staff by name. Again, there is good practice in the hospitals and amongst GPs and other health staff which is both recognised and appreciated by individuals benefitting from this. Nevertheless there are areas for improvement. The Sickle Cell and Thalassaemia Service welcomes challenge and these findings and recommendations will help them to improve an already excellent service.

Patient stories are a rich source of data for service improvement and planning. This service evaluation exercise demonstrates the importance of patient experience and will result in a shift in the Sickle Cell and Thalassaemia Service's perspective towards one that is even more open and patient-centred. The Service can demonstrate that it has meaningfully consulted, engaged and involved its users as well as some of its potential users. As well as leading to better, needs-led services, consultation and engagement comprise a statutory responsibility; therefore it is envisaged that other services in the UK will welcome the findings and involve service users in their future plans.

This report will be made available to all the people who use the Sickle Cell and Thalassaemia Service. It will also be made available to the Public and Patient Involvement team in Nottingham City NHS, with some discussion on how it can be disseminated appropriately in order to share good practice in engagement and involvement. A research paper has already been presented, in April 2010, at an international conference at De Montfort University - 'Sickle Cell: the next 100 years', proving the evaluation exercise to be a ground-breaking piece of work which has gained interest from health professionals both here and abroad.

The service evaluation proved to be a very dynamic and successful example of how the NHS can work in partnership, not only to engage public and patients but also to tap into the knowledge, advice and power of those who are experts by their very experience. The Service has already started to act on the findings and recommendations of the evaluation, using the patient narratives in community and professional presentations, setting up a support group, preparing a health professional handbook for primary care staff and proactively improving the relationship with community partner OSCAR. Accountable to the people who use it, the Service will keep stakeholders informed on the progress towards achieving the recommendations relating to this service evaluation.

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# About Bright Ideas

Bright Ideas is a vibrant community based business that is passionate about working with local people to effect change and improvement in their communities. We believe that the community voice should be heard and that it is the people from the community that can inspire and direct the most necessary and positive changes in the places where they live.

Bright Ideas seek to improve the quality and access to services for local people through cultural brokerage and community engagement and involvement. We specialise in research, training and development, devising campaigns and information materials, hosting vibrant events, training trainers and encouraging local people to be involved through volunteering.

Bright Ideas present and past clients and partners have included The Workers Educational Association, The African Caribbean and Asian Forum, One Nottingham, Nottingham CitiHealth, Nottingham Crime and Drugs Partnership, The Partnership Council, Lenton and Dunkirk Partnership, NHS Nottingham City, Nottingham City Council, Cambridge University and Nottingham University, amongst many others.

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