SCCM
Sickle Cell Care Manchester

Sickle Cell Care Manchester

# Sickle Cell Disease Patient Engagement Report

## A Qualitative Snapshot summarising the impact of Sickle Cell on the life of carriers, family and carers' living in Manchester

**15 March 2019**

Prepared by Anthony Mason

Manchester Health & Care Commissioning

## Acknowledgements

We would like to thank the following people for their contribution to the engagement report and preparation of this report:

Manchester Health and Care Commissioning

Sickle Cell Care Manchester staff, service users and trustees

# Contents

## Acronyms

| | |
|---|---|
| SCD | Sickle Cell Disease |
| SCCM | Sickle Cell Care Manchester |

# Executive Summary

## Background

At SCCM we believe services in Manchester should use the experience of people living with or affected by SCD to improve services. When we approached Manchester Health and Care Commissioning (MHCC) to discuss this, we were tasked with gathering the experiences and evidencing this through this brief report.

## Methodology

We conducted a focus group, an online survey and then analysed the data using the framework method. Emerging themes were cross-checked in a final survey.

## Key Findings

- SCD sufferers, their carers and families feel that staff should know more about SCD and the impact it has on them when in crisis.
- SCD has an impact on sufferers, their carers and families and it is agreed that counselling should be available to them.
- . There is a consensus in the engagement that prescriptions should be free for SCD sufferers

## Key Recommendations

- Further research should be conducted over a longer period and gathered through a variety of engagement methods.
- Conversations should be facilitated between MRI staff and SCD sufferers.
- Access to counselling for SCD sufferers, their families and carers should be explored.

# 1 Introduction

## 1.1 Background

1.2 Sickle Cell Care Manchester (SCCM) is a charity run by people whose lives have been affected by Sickle Cell Disease (SCD) to support people living with SCD and their families.

Our Focus is to raise awareness of the condition and help everyone affected by SCD to achieve their full potential and secure the care and support they need, until ultimately a cure is found. We do this through facilitating a support group and volunteer led support services. i.e. respite, hospital visits. Most people living with SCD spend 90%- 95% of their time living in the community. However, SCD can be a life threatening condition, so that stays in hospital and the intervention of medical professionals are also important in an affected person's life. At SCCM we believe services in Manchester should use the experience of people living with or affected by SCD to improve services and that more emphasis should be on community management, care and support structures can greatly help those affected and those that care for them. When we approached Manchester Health and Care Commissioning (MHCC) to discuss this, we were tasked with gathering the experiences and evidencing this through this brief report.

## Objectives

The objectives of this report are to:

- Help inform MHCC of the Health & Well-being needs of people living with SCD in Manchester
- Help identify what is working well
- Help identify what needs improving
- Give SCD sufferers on opportunity to be heard.

# 2 Methodology

## 2.1 Research Questions

The research questions to be answered by this report are:

1. What would improve quality of life for SCD sufferers, their carers and family living in Manchester?
2. What services are good at supporting SCD sufferers?
3. What services need improving for SCD sufferers?

## 2.2 Research Design

The report will use qualitative methods to answer the research questions. The following table summarises the methods used to answer each question:

**Table 1 Methods used to answer research questions**

| Research Method |
|---|
| SCD Survey |
| Focus Group |
| Cross Checking Survey |

## 2.3 Instruments

The first sample survey was a list of questions taken from a survey completed by Wolverhampton CCG in partnership with Wolverhampton Sickle Cell Care. The report helped to shape services and we felt this was the ideal pre-test. The questionnaire was developed on Survey Monkey and a link was sent out.

See Appendix 1 for the Survey Questions

The questions for the Focus Group, again were influenced by the partnership mentioned above and checked against our own objectives to make sure we would get the information needed. Responses were then recorded in a one-hour discussion.

See Appendix 2 for the Focus Group Questions

The questions for the Cross checking survey were based on themes that emerged from analysis of the focus group discussion and first survey. The questionnaire was designed on Survey Monkey and a link was sent out.

See Appendix 3 for the Cross checking survey questions.

## 2.4 Sample

SCCM has a database made up of individuals and families we have supported over the years. A convenience sample was purposefully chosen as we knew most of them have used services in Manchester. Invitations to the focus group and links to the online surveys were sent to all our users and then sent out through wider networks on Facebook. This makes it difficult to identify sample frame but our base number from the database was 135.

Vaibhav Kalamdani

Social Media Specialist | Digital Marketer | HubSpot Inbound Marketing Certified | Google Analytics & AdWords Certified

“For any given post on a brand’s Facebook Page, there are 3 visible interactive elements on Facebook – reactions, comments and shares. Taking these into consideration, the formula for average Facebook post engagement rate is derived as the total number of Reactions, Comments and Shares for a particular period to the total reach derived for the posts considered. This figure is then multiplied by 100 to arrive at the average Facebook post engagement rate.”

Using this crude calculation

Post engagement rate = Number of reactions +Comments+shares on a given day / Total reach of the posts on a given day. X 100.

The algorithm is built into Facebook and our page tells us that:

- The focus group invite was seen by 430 people
- the first survey was seen by 979 people and
- the cross checking survey was seen by 1171 people.

Focus group Sample frame = Database + Facebook engagement = **565**

First Survey Sample frame = Database+ Facebook engagement = **714**

Cross Checking Sample frame = Database + Facebook engagement = **1306**

## 2.5 Data Collection

The focus group was conducted by an independent consultant who recorded the hour long discussion and analysed the content through a coding frame which in turn highlighted issues and themes.

Both surveys were designed on Survey Monkey an online tool that collects and present the data. The free text was analysed by the same consultant who then presented all the data in through this report.

## 2.6 Data Analysis

An Excel coding frame was deigned to capture comments made both positive and negative about services and experiences. The focus group recording was analysed audibly and every mention of a service or experience was entered into the appropriate section of the coding fame. The approach is called the Framework Method and it sits within a broad family of analysis methods often termed thematic analysis or qualitative content analysis. These approaches identify commonalities and differences in qualitative data, before focusing on relationships between different parts of the data, thereby seeking to draw descriptive and/or explanatory conclusions clustered around themes. The Framework Method was developed by researchers, Jane Ritchie and Liz Spencer, from the Qualitative Research Unit at the National Centre for Social Research in the United Kingdom in the late 1980s.

Both surveys were analysed within the online Survey Monkey tool. The free text that came from the surveys was added to the matrix spreadsheet relating to the coding frame.

## 2.7 Limitations

Time and budget are always against us and the engagement results presented in this report were achieved within both constraints. This meant our sample size had to be small with an emphasis on qualitative information. A smaller sample size means that more bias is introduced and fewer assumptions can be made due to non-response. The channels we had access to, to recruit participants were limited too, which also introduces voluntary response bias. You could only have taken part in the engagement if you had internet access and a Facebook account or were notified by a friend or family member. The focus group was held at the Kath Lock Centre at 6:00clock pm. This could have been a barrier to those just finishing work or for families as this time often reflects peak home activity. Findings from smaller samples are still useful as suggested by Catherine Cassell, Gillian Symon (2004) “ For a quantitative researcher, generalization is achieved through such techniques as sample size, sampling frame and so on. The idea is to be able to sample cases (respondents,

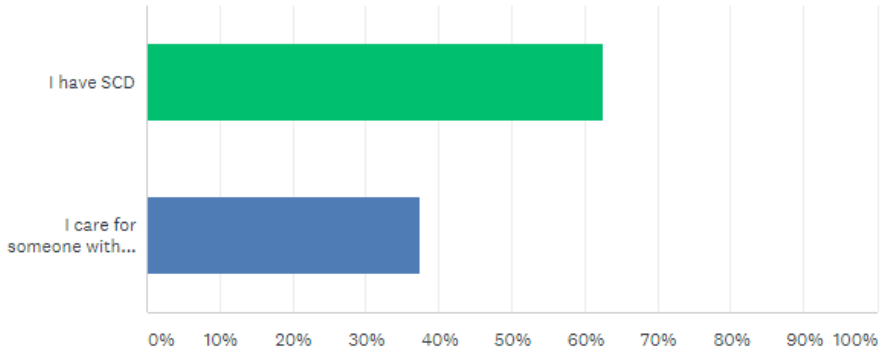
organizations) which are typical (in specified ways) of the population. If the sample is correctly drawn, then the results are deemed to be applicable (generalizable) to the specified population" This is statistical generalization (Yin, 1994).

# 3 Results

## 3.1 SCD Survey

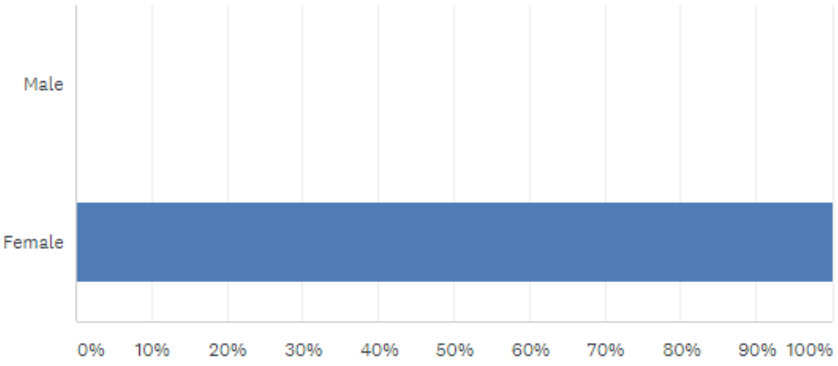
Are you a SCD Sufferer or are you a carer?

Answered: 8 Skipped: 1



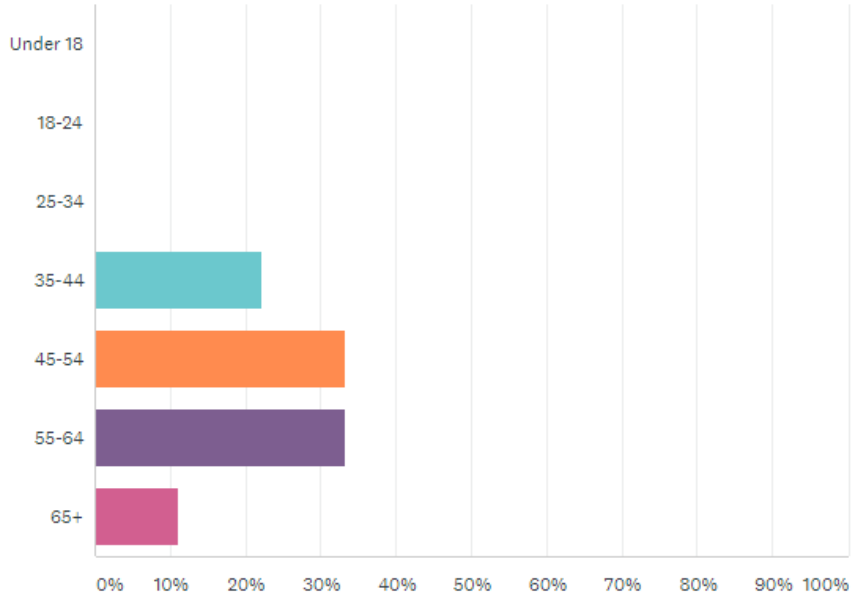

Are you Male or Female?

Answered: 9 Skipped: 0



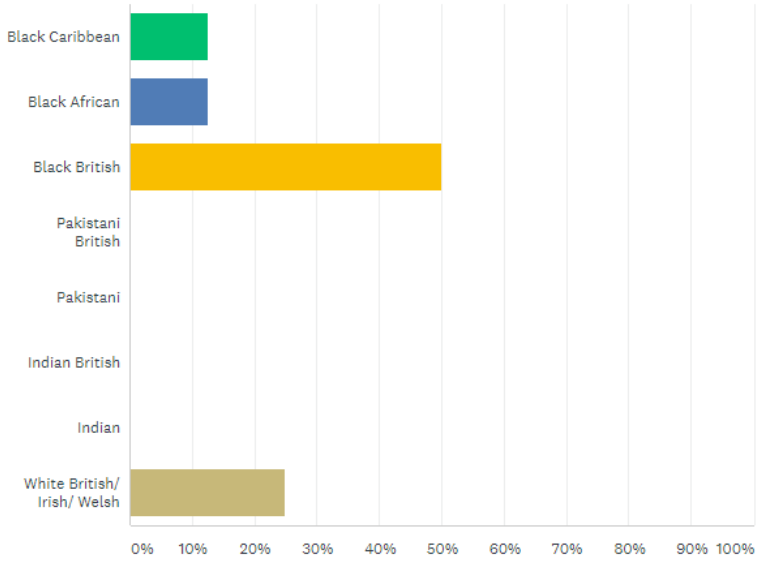
## What age group do you fit in?

Answered: 9 Skipped: 0



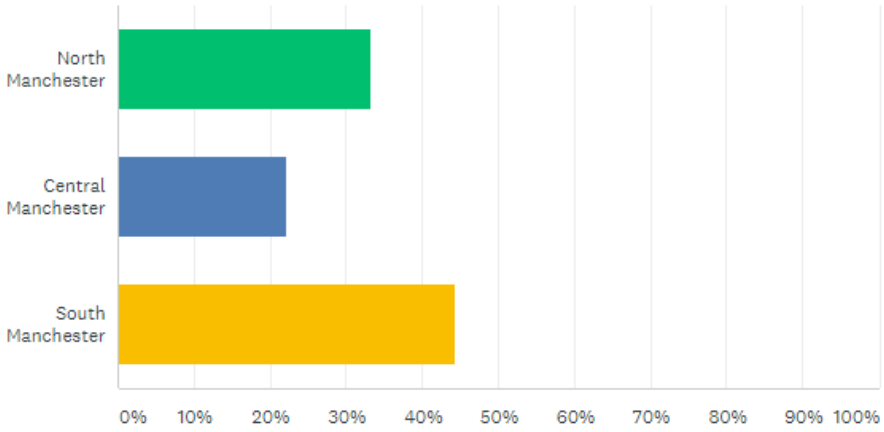

## What Ethnicity are you?

Answered: 8 Skipped: 1



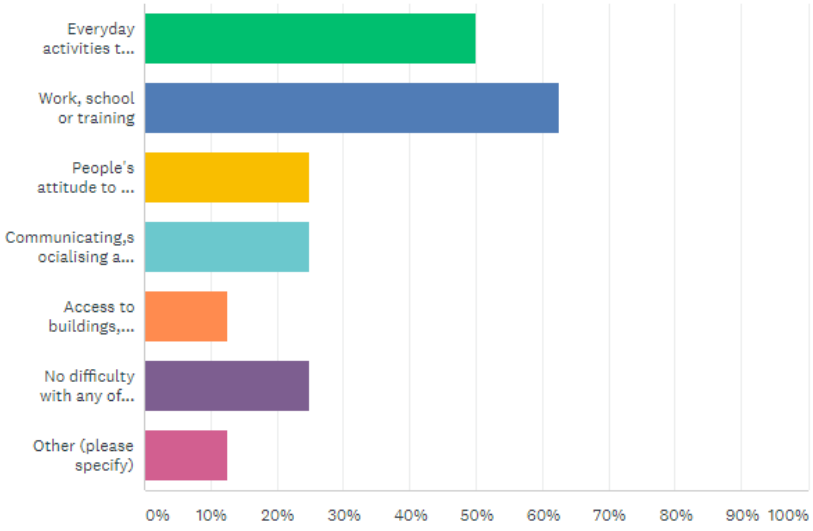
## Which part of the city do you live?

Answered: 9 Skipped: 0



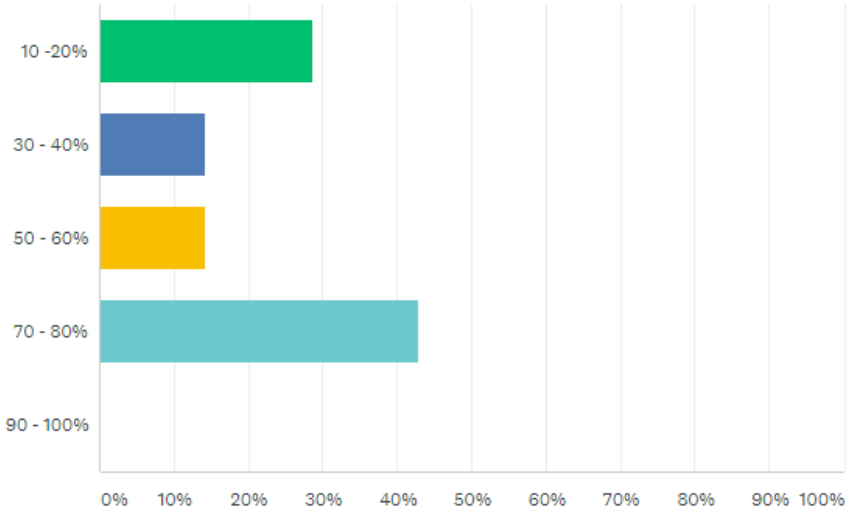

## Does SIckle Cell cause you (or the person you care for) difficulty with any of the following?

Answered: 8 Skipped: 1



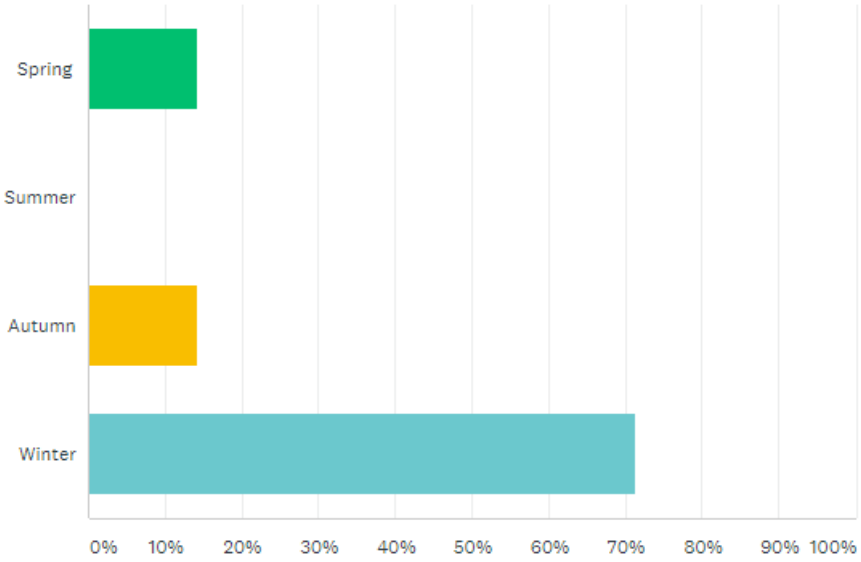
## Across an average month, how much of the time are you in pain?

Answered: 7 Skipped: 2



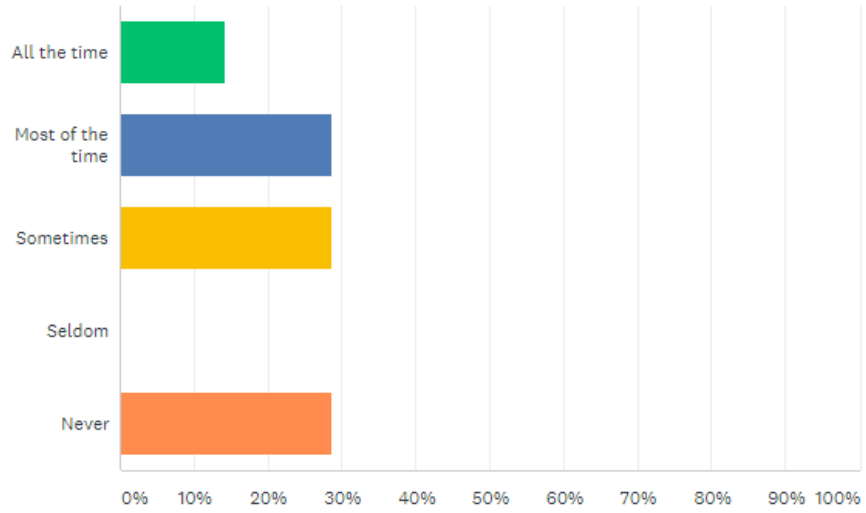

## Which season would you say you experience the most pain?

Answered: 7 Skipped: 2



## Does the condition impact on your wellbeing and outlook on life?

Answered: 7 Skipped: 2




## Please use this space to tell us how NHS services can improve naming the service your response relates too. (e.g. MRI )

MRI, do a wonderful job caring for sickle cell patients. Easy access to clinics, specialist nurses meeting us in A&E, meetings and conferences put on for us. Counsellors available to talk to

3/8/2019 8:23 AM Add tags – View respondent's answers

Vaccinations and prescriptions

2/21/2019 1:40 PM Add tags – View respondent's answers

I tried my best to be a friend but it was difficult

2/20/2019 9:15 PM Add tags – View respondent's answers

Manchester Foundation Trust could stop charging patients and visitors for parking and also penalties for staying in car parks for over 3 hours. In Emergency situations you need to be able to park without fear of getting Parking Charge penalties.

2/17/2019 11:47 PM Add tags – View respondent's answers

Acting more promptly, listening and take the patients more seriously about the ongoing chronic problems, they are fasting.do more test, and more examination,ensuring it's nothing g serious that could be life threatening to health,and keeping closer eye on them.

2/17/2019 3:22 PM Add tags – View respondent's answers

Accident and emergency There should be protocol to give painkiller as soon as sickle cell patient comes in with crisis.

2/7/2019 9:07 AM Add tags – View respondent's answers

They can provide centres closer to where i live

2/7/2019 8:20 AM

## 3.2 Focus Group

The following questions were used to generate discussion in the focus group. Themes that emerged were used to generate the Cross Checking Survey.

How would you describe having SCD or its impact on your life?

Which services do you use in Manchester?

Which ones are good?

Which one needs improving?

What needs happen for health services to improve for SCD sufferers?

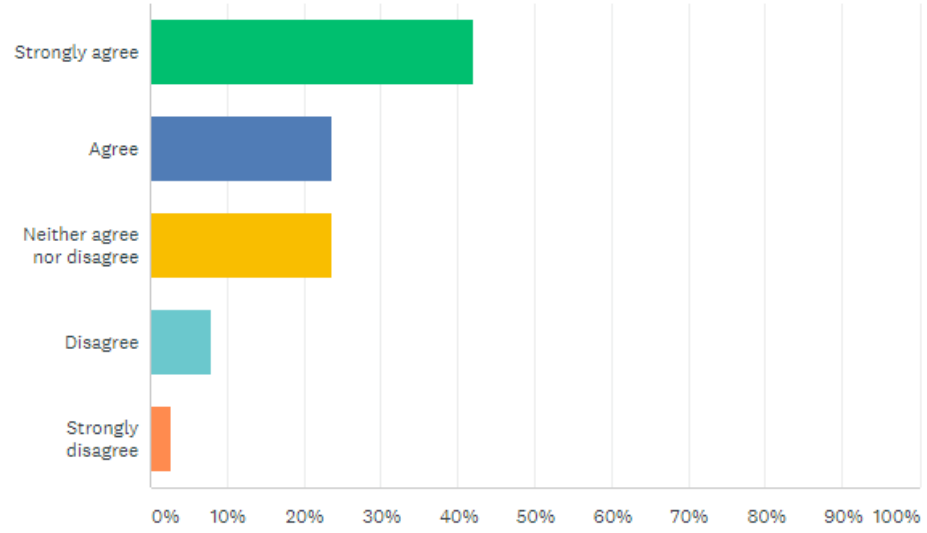
Do you think there is enough awareness of SCD in Manchester?

What advice you would offer someone newly diagnosed with SCD?

## 3.3 Cross Checking Survey

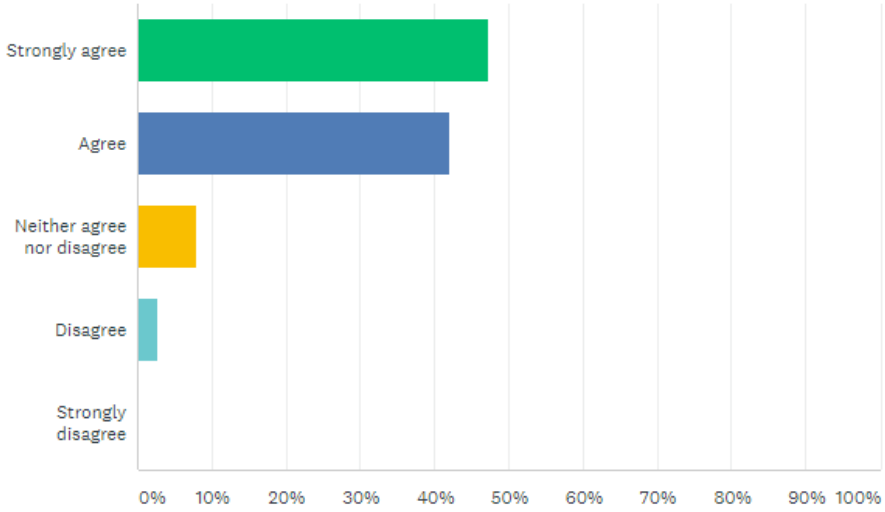
Sickle Cell Disease has a negative impact on my mental health

Answered: 38 Skipped: 0



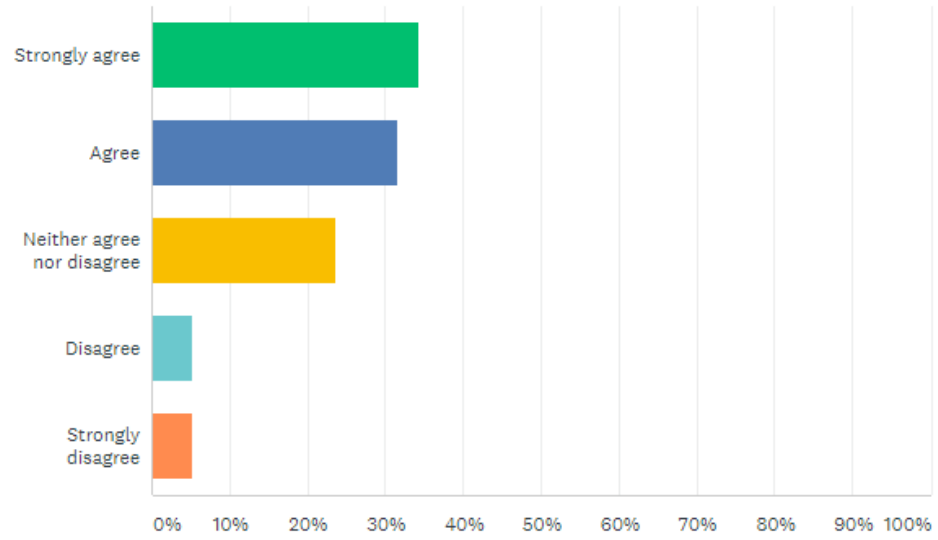

Sickle Cell DIsease has a negative impact on working

Answered: 38 Skipped: 0



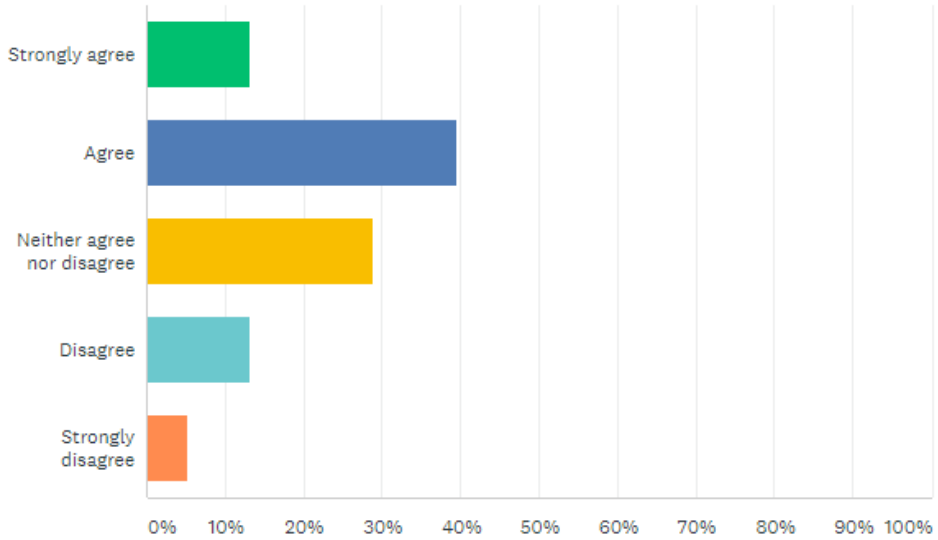
## Sickle Cell disease has a negative impact on my relationships

Answered: 38 Skipped: 0



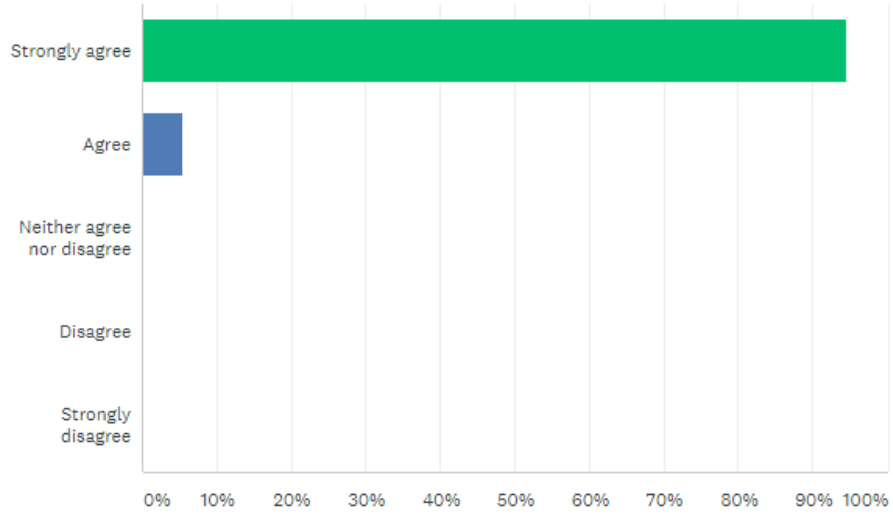

## When i'm not in crisis i try to forget i have Sickle Cell Disease

Answered: 38 Skipped: 0



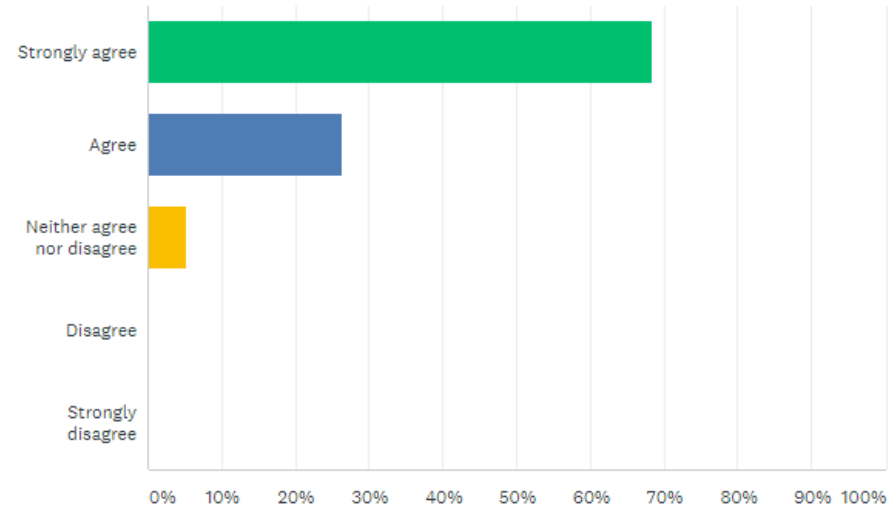
## There should be access to Counselling for SCD sufferes and their families/carers

Answered: 37 Skipped: 1



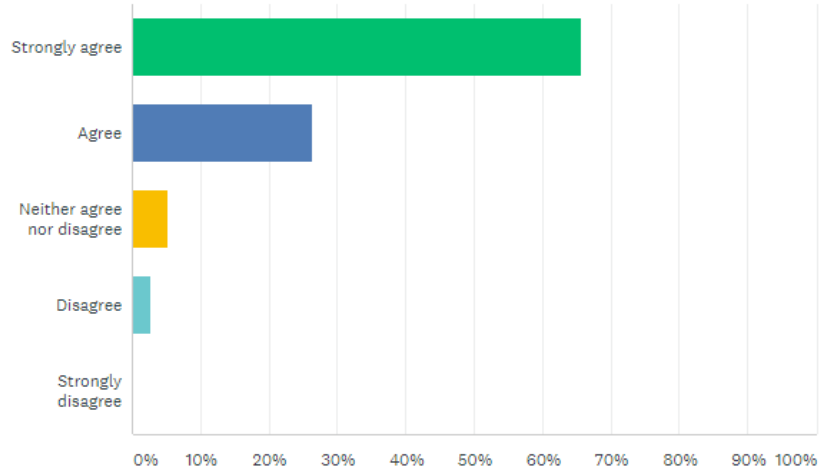

## Health Professionals do not know enough about Sickle Cell Disease

Answered: 38 Skipped: 0



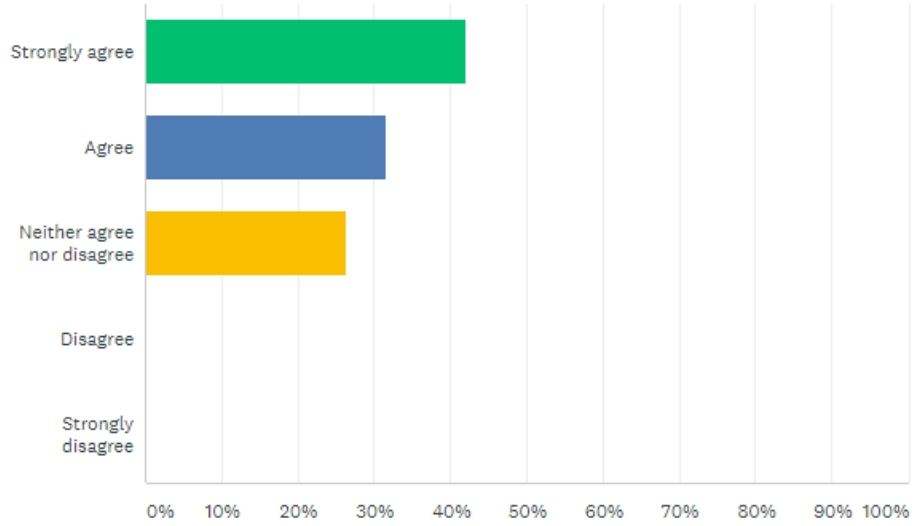
## The quality of care you get at the hospital is dependent on who is on duty.

Answered: 38 Skipped: 0



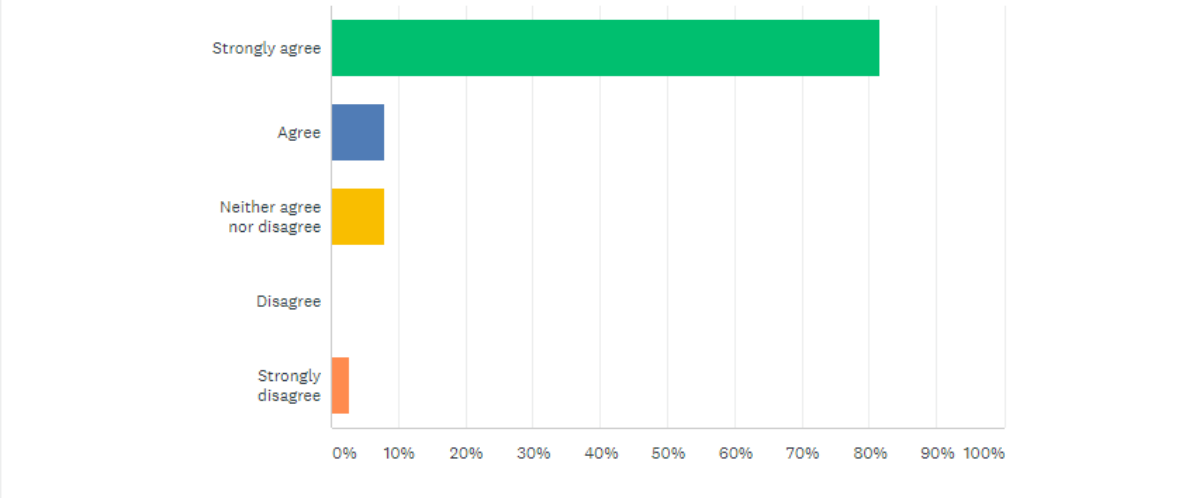

## Weekend care at the hospital is worse than care during the week

Answered: 38 Skipped: 0



Sickle Cell Disease doesn't get the same recognition and support as other conditions like diabetes, dementia etc.

Answered: 38 Skipped: 0




# Is there anything else you would like to say?

Thanks for all your support and promoting your service. Female - 25 years old

3/13/2019 10:14 AM Add tags – View respondent's answers

I think the wording "Sickle Cell Disease has a negative impact on.." can be confusing as negative could mean nothing or no impact. I think it should just say "Sickle Cell Disease has an impact on..." or "Sickle Cell Disease has a big impact on..." kind regards Matthew

3/11/2019 10:14 AM Add tags – View respondent's answers

The older suffers should mentor the younger suffers. The long term families should mentor the new suffers, practical videos based on experience in best practices, Andy Powell.

3/8/2019 7:49 AM Add tags – View respondent's answers

I do not suffer SCD but have family member who does. My answers of neither agree or not are based off of this

3/7/2019 1:13 PM Add tags – View respondent's answers

Hard to understand how SCD sufferers have to pay for prescriptions, while other conditions where medication is needed for life as well gets exempted.

3/6/2019 8:12 PM Add tags – View respondent's answers

Prescription charges should be free for people with sickle cell disease

3/6/2019 6:08 PM Add tags – View respondent's answers

This is a devastating disease and nowhere near enough is being done to help suffers and carers and this needs to be addressed as a matter of urgency.h

3/6/2019 1:07 AM Add tags – View respondent's answers

Careers of sickle cell patients like parents should be listened to and be informed and involved with the care of there children. Thank you.

3/5/2019 11:51 PM Add tags – View respondent's answers

No

3/5/2019 3:28 PM Add tags – View respondent's answers

There is a need to raise more awareness amongst medical professionals , employers , and tbe UK, community at large there is also a need to have a standardised care procedure on handling siclke especially in accident and emergency rooms and local hospitals. I look forward to a day when sickle cell anemia would be given the recognition as other life threatening conditions. People living with SCD go through thesame or even more stress on their daily lives as cancer or diabetes and they are at risk of suffering stroke , and heart attacks just because their heart undergoes a lot of stress on a daily basis .

3/5/2019 11:38 AM Add tags – View respondent's answers

Pain Killers like paracetamol and ibuprofen should be free for people with SCD. They would not need as much if not for the SCD

3/4/2019 10:37 PM Add tags – View respondent's answers

I hope the National Health Service will run mandatory training for not just medical staff but also receptionist who will come into contact with pexpletives who have sickle Cell disease.

3/4/2019 4:10 PM Add tags – View respondent's answers

Unfortunately because it affects mainly Black people we are not getting enough support

3/4/2019 3:09 PM Add tags – View respondent's answers

SCD does not get free prescription like other conditions.

# 4 Discussion

SCD clearly has an impact on the lives of those who suffer with it. The majority of the results from the survey and focus group highlight that it affects both relationships and work. We can assume using conversations from the focus groups that this trend relates to performing as a spouse, worrying about a loved one and having too much time off due to crisis and pain but more research would need to be carried out to conclude this.

It was quite evident in the focus group discussion that there is an element of avoidance/avoidant coping or escape coping when it comes to dealing with SCD out of crisis. This is a maladaptive coping mechanism characterised by the effort to avoid dealing with a stressor. Gordon (1957) introduced the term Repression Sensitisation to describe the type pf defence mechanism someone employs to cope with anxiety arousing circumstances. Clearly the consensus was that when a SCD sufferer was not in crisis it was out of sight and out of mind which would offer some insight into the low uptake of this engagement. This was not confirmed at the cross-checking stage however, with over 50% of the responses ranging from neither agree nor disagree to strongly disagree.

It was generally agreed that SCD has a negative impact on sufferer's mental health although again due to sample size and the fact that around 40% of the responses fell in the range of neither agree nor disagree to strongly disagree makes it hard to draw conclusions. In contrast, 100% of the responses agreed that there should be Counselling services highlighting that they all recognise there is a need for support understanding and coping with SCD. This conflicting evidence may be explored further using the Repression Sensitisation theory.

Health professionals and frontline staff clearly need more training on SCD, how it affects sufferers and what they can do to assist them when in crisis. The few who have an understanding make a huge difference to the well-being of SCD sufferers. The only service that was named even when prompted across all three engagement settings was Manchester Royal Infirmary. This highlights that we have a crisis management service as SCD only use health services for emergencies. As suggested in the focus group, this may contribute to any DNA figures for routine care. There was also a belief that weekend care is substandard to care during the week. The fact that the report only mentions one service could again be a result of using a small sample but this makes setting targets for improvements easy as efforts in the first instance can be focused on one site (MRI).

SCD sufferers, their carers and family do not feel that the condition is taken seriously or given the same attention and support as other long-term conditions. Results even go as far as suggesting that this is due to the fact that the condition is mostly prevalent in BAMER communities. The engagement results across all settings highlight that there is a general belief that people with the condition should get free prescriptions.

# 5 Recommendations

Based on the results from the engagement the following recommendations are made:

- Further research should be conducted over a longer period and gathered through a variety of engagement methods.
- Conversations should be facilitated between MRI staff and SCD sufferers. This will help develop a natural understanding between both parties.
- Access to counselling for SCD sufferers, their families and carers should be explored.

# 6 References

Repression-sensitization (Bell & Byrne, 1978; Byrne, 1964)

Essential guide to Qualitative Methods in Organisational Research, Catherine Cassell and Gillian Symon. 2004.

https://smpncilebak2011.files.wordpress.com/2011/11/essential-guide-to-qualitative-in-organizational-research.pdf

Qualitative Research practice, JAN E RITCHI E AN D JAN E LEWI S
https://mthoyibi.files.wordpress.com/2011/10/qualitative-research-practice_a-guide-for-social-science-students-and-researchers_jane-ritchie-and-jane-lewis-eds_20031.pdf

https://www.linkedin.com/pulse/20140711022232-33996286-here-s-the-correct-formula-to-calculate-your-facebook-post-engagement-rate

# 7 Appendices

## 7.1 Focus Group Questions

How would you describe having SCD or its impact on your life?

Which services do you use in Manchester?

Which ones are good?

Which one needs improving?

What needs happen for health services to improve for SCD sufferers?

Do you think there is enough awareness of SCD in Manchester?

What advice you would offer someone newly diagnosed with SCD?

## 7.2 Survey Questions

Are you a SCD Sufferer or are you a carer?

Are you male or female?

What age group do you fit in?

What ethnicity are you?

Which part of the city do you live?

Does Sickle Cell cause you (or the person you care for) difficulty with any of the following?

- Everyday activities that people your /their age can usually do
- Work, school or training
- People's attitude to you or the person you care for because of the condition
- Communicating, socialising and mixing with others
- Access to buildings, streets or vehicles

- No difficulty with any of these
- Other (please specify)

Across an average month, how much of the time are you in pain?

- 10 – 20%
- 30 – 40%
- 50 – 60%
- 70 – 80%
- 90 – 100%

Which season would you say you experience the most pain?

- Spring
- Summer
- Autumn
- Winter

Does the condition impact on your wellbeing and outlook on life?

- All of the time
- Most of the time
- Sometimes
- Seldom
- Never

Please use this space to tell us how NHS services can improve naming the service your response relates too. (e.g. MRI )

## 7.3 Cross Checking Survey Questions

Sickle Cell Disease has a negative impact on my mental health

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

Sickle Cell Disease has a negative impact on working

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

Sickle Cell disease has a negative impact on my relationships

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

When I’m not in crisis I try to forget I have Sickle Cell Disease

- Strongly Agree

- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

There should be access to Counselling for SCD suffers and their families/carers

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

Health Professionals do not know enough about Sickle Cell Disease

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

The quality of care you get at the hospital is dependent on who is on duty.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

Weekend care at the hospital is worse than care during the week

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

Sickle Cell Disease doesn't get the same recognition and support as other conditions like diabetes, dementia etc.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

Is there anything else you would like to say?