healthwatch Sandwell

A conversation about health and care services for people with Sickle Cell

October 2021

Introduction

Healthwatch Sandwell (HWS) bid and were selected for a commissioned piece of work by the Care Quality Commission (CQC). The brief from the CQC was:

Create a portrait/case studies that represent a local seldom heard community with protected characteristics that have barriers to engaging with health and care services and the Care Quality Commission.

The CQC specified what they wanted to know about the chosen group:

- Which health and care services are used and how frequently
- Challenges faced engaging with services and the CQC
- Hopes and fears for health and social care services
- What they would like to see change in the health and social care system

The CQC asked for the report to include:

- Write ups of each engagement, with some direct quotes from people engaged with
- Any previous reports HWS have written on these specific groups
- Recommendations to CQC on how they can empower, engage and work with the group
- HWS to make recommendations, including specifically to the Public Insight Team, and detail how HWS could work with CQC to facilitate these recommendations

HWS proposed to engage with people with Sickle Cell (an inherited blood disorder, which predominantly affects people of African and African Caribbean ethnicity)

Overview of People with Sickle Cell

A Sickle Cell "crisis" can feel **"like your bones are shattering, being hit by a sledgehammer!"**

Sickle Cell is an inherited blood disorder which can cause lifelong health complications, and for many people regular hospitalisation due to Sickle Cell "crisis" episodes - which can present risk to vital organs and require strong prescription pain management, including morphine.

In Sandwell there are estimated to be about 85 people affected by Sickle Cell. The Midlands region has the highest number of people with Sickle Cell outside of London, estimated to be around 600. More than 15,000 people in the UK have Sickle Cell disorder with around 300 babies born with Sickle Cell each year in the UK.[1] Sickle Cell disorder can also affect families multi-generationally.

The Sickle Cell and Thalassaemia Centre at Birmingham City Hospital supports patients with day treatment services, including regular blood transfusions for some. It also provides specialist support service links, including hemoglobinopathy to hospitals in the Black Country and West Birmingham NHS Trust and within the Midlands region.

[1] https://www.sicklecellsociety.org/about-sickle-cell/

Conversations with people with Sickle Cell

HWS have been actively engaging, listening, guiding and signposting people with Sickle Cell in Sandwell over the past 2 years in regard to health and care services. HWS have worked with OSCAR Sandwell (a local support organisation for people with Sickle Cell and Thalassaemia) to encourage and empower patient voices in services and to develop working relationships with health and care service providers.

HWS invited 6 people with Sickle Cell, who were representative of the community, to join conversations to support the CQC project brief. 5 people attended a virtual meeting and an individual telephone conversation was had with one young adult. Representation was:

Males (3), Females (3), 18-20 yrs old (1), 30-50 yrs old (3), 65+ yrs old (2) African Caribbean (6)

Awareness of Care Quality Commission

HWS showed the Focus Group the Care Quality Commission (CQC) logo and asked whether they were aware of the CQC and if they knew what the CQC role was.

4 people had not heard of the CQC, 2 others said they were aware but unsure what the CQC did but thought it was **"to do with health"** and **" in charge of setting protocols and reviewing services"**.

HWS presented information to the group explaining the role of the CQC and that their role was related to all of the health and care services that people with Sickle Cell access.

Health and Care Services used

HWS asked the group to confirm which health and care services they used, how frequently, and how the services were accessed?

The group identified using the following services:

- G.P. Surgeries
- Ambulance service
- Sickle Cell & Thalassaemia Centre (SCaT) - City Hospital, Birmingham
- Hospitals
- Social Services - care and support

Sickle Cell - health and care services used

G.P. Surgeries

The participant group only referred to use of G.P. Surgeries for issue of prescription medications related to their Sickle Cell condition.

Sickle Cell and Thalassaemia Centre (ScaT) - City Hospital, Birmingham

Patients attend the Sickle Cell & Thalassaemia Centre (SCaT) centre for planned treatments including blood exchange transfusions dependent on the patients level of treatment needs. Thalassaemia patients require life long regular blood transfusions, this report includes reference to people with Thalassaemia but does not explore specifically. Patients may choose to use the SCaT centre during a Sickle Cell "crisis", when accessible, i.e. during opening hours. The effects of Sickle Cell on people with the disorder vary, some people may have a Sickle Cell "crisis" a few times in their life whereas others may spend a lot of their life within hospital.

Ambulance

During a "crisis" patients will be transported to hospital or will call an ambulance. The ambulance policy is to take patients to the hospital nearest to where they live. The SCaT centre links with the regional hospitals to support and enable treatment of Sickle Cell patients.

Other hospitals

The participant group live across the Black Country and West Birmingham area so several hospitals were referred to— "City" - Birmingham, "Sandwell" - Sandwell, "Manor" - Walsall and "New Cross" - Wolverhampton.

Social Services—care and support

People with Sickle Cell have a higher risk of stroke, including in childhood. 2 of the participant group spoke of having had a stroke in early adulthood and had received social services follow up care at home and reablement services. HWS have found that less than 10% of people with Sickle Cell in Sandwell are accessing or receiving social services care or support or have applied for assessment of their, or their family carers, needs. Patients have told HWS that conversations about care and support needs post hospitalisation are not occurring. The position in other local authority areas is not known. ***HWS, OSCAR Sandwell and patient representatives have worked positively with Sandwell Council to seek to improve access and uptake of care and support services within Sandwell***. However it appears the operating links between hospital and social services need to be reviewed to ensure service connections occur.

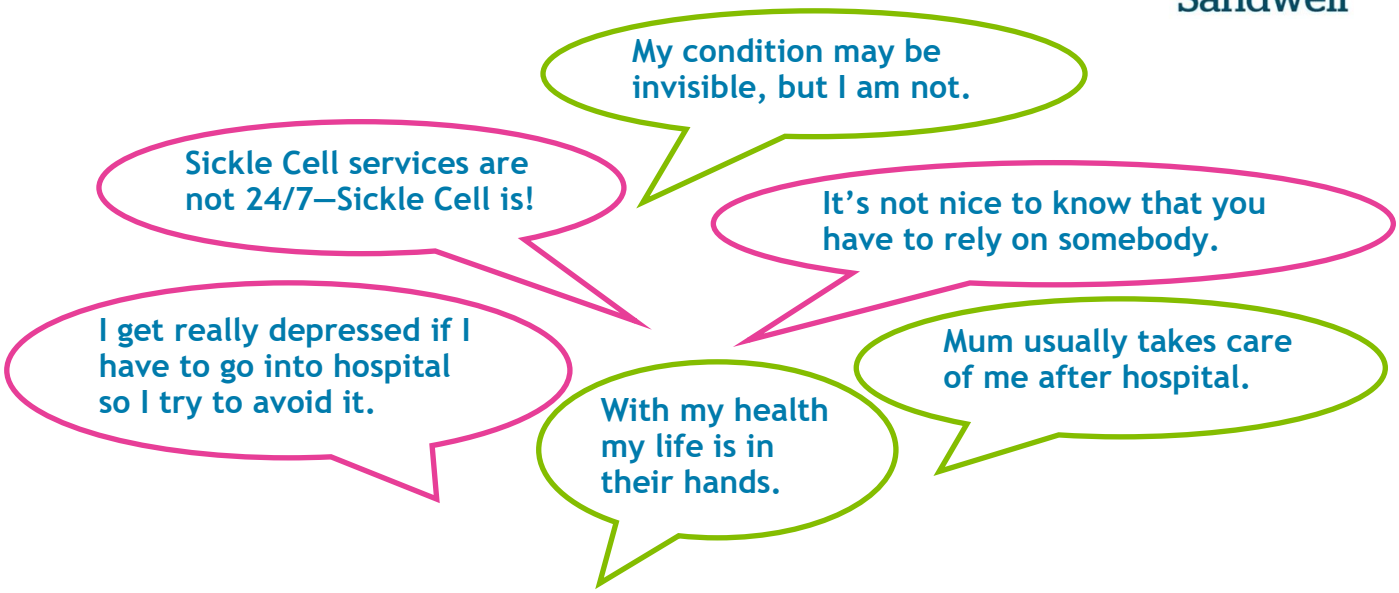
Engaging with health and care services

HWS asked the group about their overall experience of health and care services and whether there were any challenges with accessing or engaging with services.

An underlying issue is lack of awareness and understanding of Sickle Cell, it's impact on individuals lives and, during a Sickle Cell "crisis", adhering to treatment protocols on medication administration timeframes.

Some patients have told HWS about lack of awareness of Sickle Cell by some "frontline" health professionals, generally ambulance, Accident and Emergency or hospital ward services. This does not relate to all patients experiences or all health staff but it does appear to be the root cause of issues for some patients and has a high impact on patients confidence in services. ***The SCaT Centre provides some awareness training and is responsive to feedback on issues arising but this may be an area that would benefit from review***.

Connections with adult social services care and support is generally not in place, including following a hospital stay or if an individual has transitioned from children's social services.



Experiences and challenges of accessing or engaging with services

G.P. Surgeries

Some of the group spoke about delays in medication prescription issue, communication problems between G.P. Surgeries and the SCaT centre and patients having to chase up prescriptions when they are unwell. One expressed their experience as **"A push back and forth between G.P. & ScaT"** another said that their G.P. understands them quite well but it had been a **"bit of a struggle"** to get to that point, they explained that now they can get "Oramorph" prescribed to manage pain at home. Another expressed that they felt **"G.P.'s do not have the time to deal with Sickle Cell"**

Ambulance service

The ambulance service policy is to take patients to the hospital nearest to where they live. The participant group expressed positive and negative feelings about this policy and experiences in their local hospitals. However one participant spoke about having had a stroke during a Sickle Cell "crisis" in a particular hospital and not wishing to return to it. They said they had subsequently obtained a letter from their consultant to show to the ambulance crew and inform to take direct to City Hospital if in a Sickle Cell "crisis". Another expressed that for them the letter had proved to be ineffectual and **"not worth the paper it is written on"** their understanding was the reason was that their local hospital was deemed a capable hospital.

One participant stated that for them **"Ambulance is the first port of call in a Sickle Cell "crisis""** and that **"111 is not fit for purpose to be honest"** they explained:

"I will stay on the phone for ages and when I finally get to speak with someone, I will have to wait for ages for a clinician to ring me back. I've had to get a taxi to the hospital once because I had to wait too long. When I get to speak to a clinician, they will just tell me to take paracetamol. For these reasons, I never bother to call them again."

Sickle Cell & Thalassaemia Centre (SCaT) - City Hospital, Birmingham

The group talked about the SCaT centre, which several participants attend for blood exchange transfusions or during a Sickle Cell "crisis". Concerns were expressed about the SCaT centre operating hours being limited to day time only. HWS has heard about patients choosing to go home during a Sickle Cell "crisis" and revisit the next day for continued treatment rather than be admitted to hospital overnight. Participants said there were not enough day beds available, 2 participants spoke of being asked to move from a bed during treatment to meet another patients needs. Another participant said **"New Cross Hospital has day care treatment facilities which have longer opening times and more beds available"**.

Hospitals

The group spoke about the anxieties of needing hospital treatment during a "crisis", concern about possible struggles with admission process and ensuring their condition was understood during treatment, including protocol timeframes being met for medications to manage the pain. Fears were expressed about risk to organs or of a stroke with Sickle Cell, 2 of the group shared that they had previously had a stroke while in hospital with a "crisis". Some people have expressed that they feel they may be seen as challenging patients.

The Manager of the SCaT centre has recently informed HWS ***"Outreach cover started on the 4th of September, this was following patient's feedback around timely administration of analgesia and also utilising this time to teach the members of the wider team"***.

Covid-19 has added to anxieties - people with Sickle Cell fall into the shielded category but may still need admission to hospital. 1 participant spoke of fear of contracting Covid while in hospital and explained that it had heightened concerns about hospitalisation **"I try by all possible means not to get admitted to hospital"** another participant echoed the same sentiment while others in the group cautioned against the risks involved of not attending hospital.

1 participant spoke of previously receiving blood as well as pain medication in their local hospital during a "crisis" but said the policy had now changed between the hospital and SCaT centre. 1 participant mentioned having a port in their vein for ease of access during treatment but said it was frustrating if health professionals did not use it or were not trained to do so.

The group spoke of concerns about the possibility of tolerance or dependency risks with strong treatment medications, such as morphine, and particularly about anxiety in this regard when returning home after long stays in hospital. Some of the group also expressed a concern that they felt they may be misunderstood and perceived as drug addicts during treatment.

Hospital discharge and care and support services

The group spoke about there being no "after-care" following a "crisis", of being left to look after themselves or going home to family or friends providing care or support **"they just kick you out"** and **"for people who don't have a family it's quite a challenge".** From wider engagement and conversations with people with Sickle Cell and family carers HWS understand that the hospital discharge process is not properly working for the patient group, that conversations about care and support post hospital are not generally occurring. The SCaT centre advise that the hospital liaison team attend to these processes and consider that things are working. HWS are unable to clarify the position further but there appear to be some missing links between hospital discharge functions and social services care and support services.

As previously referred to it appears most people with Sickle Cell are not connected up with adult social services for their care and support needs. There appear to be gaps in transition from children's to adult's social services, a lack of awareness and knowledge of services available by people with Sickle Cell and some reticence and distrust of the services. ***HWS, OSCAR Sandwell and Sandwell Council Adult Social Services have worked together to raise awareness and break down the barriers to access with people with Sickle Cell, including recruiting ambassador representatives to help spread the messages***. Sandwell Council Adult Social Services have recommended that people with Sickle Cell should apply for assessment of their care and support needs while they are well i.e. not during a Sickle Cell "crisis" and discuss and plan for the services they may need when "crisis" occur. OSCAR Sandwell plans to help support some people through the application and assessment process to "test" the system and help encourage more uptake.

1 participant said of health and care services **"They don't want to join the dots!"**

A young adults story

Healthwatch Sandwell wanted to ensure representation of the experiences of young adults transitioning from Children's services to adults within the commissioned work. An individual telephone interview was held with a 19 year old with Sickle Cell.

The young adult is a student whose education is affected by their Sickle Cell disorder and the impacts of the need for a hip replacement as a consequence of Sickle Cell. The hip hurts on a daily basis. At the time of the interview the young adult was not receiving any treatment for the hip, no longer takes codeine and use crutches when needed. Consultations have been held with orthopaedic services, a steroid injection was given at 17 years old but the benefit had not lasted long, plans for a hip replacement are being delayed to allow for developmental growth due to age. The family moved to a more suitable property but adult social services were not able to fit a stair lift, however some aids had been provided. An assessment of any other care and support needs had not been undertaken.

HWS asked about the transition from children's to adults services and were told: At 16 years old the Children's hospital Doctors and Nurses start to talk about transition to adult services and the SCaT centre had offered some introduction events at their City hospital base but the young adult had not attended. A letter was received from the Children's hospital about moving on to adults services and at the last appointment at 17 years old the patient was discharged from children's services **"I felt a bit sad, children's hospital services had been amazing, kind and caring"**.

The young adult's first experience of adult hospital was during a Sickle Cell "crisis" they felt that at first staff appeared to not have knowledge of Sickle Cell **"It was my first time in an adult ward - I felt lost"**. In the Children's hospital the patient's Mother had been able to be a long stay visitor and sleep over, the change within adults services was distressing to the patient but the SCaT centre linked up with the ward about the patients needs and the matter was resolved.

The young adult spoke about a stay on an adult ward **"I thought I would see people around my age on the ward but I was the only teen there with older people"** and staying in hospital for treatment **"I was a bit confused at first but now it's a good thing sometimes"**. They also spoke of having visited the SCaT centre for treatment and the perception of having to go home when not feeling ready to do so as the SCaT centre was closing for the day. The SCaT centre have allocated bed spaces within City Hospital that patients can be transferred to if necessary. This was not something the patient felt fully aware of at the time so they returned home to parent care and support with medication, cooking and bathroom assistance. The patient said they felt **"Gloomy"** when returning home after a Sickle Cell "crisis".

Hopes and fears for health and care services

HWS asked the group about their concerns, hopes and fears for health and care services.

Participants in the group expressed concerns about sufficient resources being invested in services for people with Sickle Cell and Thalassaemia especially the SCaT centre facilities and about care and support services becoming joined up. It was felt a holistic offer would include investment in organisations, such as OSCAR Sandwell, to help support people with Sickle Cell to be able to live their lives with the disorder fully and independently —for example eligibility for the state benefits of Personal Independence Payment (P.I.P.) was raised as being inconsistent.

All the group participants expressed the same fear - that the challenges reflected in this report would not change and that they would continue to have to battle to raise awareness.

"A lot of words have been said here, for 20 years we have been saying the same things"

"My daughter will be moving to adults services in 4 years time, I don't want her to be going through the same challenges with services"

"There has been a lot of frustration over time, different groups, different platforms—it's becoming very repetitive"

A new hospital for Sandwell and West Birmingham is currently being built. The **Midland Metropolitan University Hospital (MMUH)** will provide a single site for acute care and the Sickle Cell and Thalassaemia (SCaT) centre will be relocating there in 2023. The hope is that the challenges in health and care services outlined in this report will have been resolved before the opening of the new hospital which will provide good, joined up care and support services for people with Sickle Cell and Thalassaemia.

The Director of System Transformation, Sandwell and West Birmingham NHS Trust recently informed HWS:

"We have more information now on our 7 day medical model and have allocated a bed hub for Sickle Cell patient admissions in MMUH so we can consider how we can enhance experience in the new environment as part of our work."

Thank You!

The group wished to express their gratitude for the services provided by the NHS and stated

"Things have improved tremendously,without the NHS some of us would not be alive today"

Changes in health and care services

HWS asked the group what GOOD health and care services would look like?

The participants agreed that GOOD health and care services would be:

These aims meet the 5 key questions that the CQC ask of all health and care services:
Are the services—safe, effective, caring, responsive, well led?

HWS also asked the group how access to and engagement with health and care services would best work for them?

"We are born with Sickle Cell - so we know how to manage it more than anybody else"

"Remember—this is a job for you, but this is a life for me"

The group agreed that they would like to see the following:

- To be well informed and included in decisions about their health and care
- Joined up health, care and support services with a clearly communicated structure
- Agreed treatment protocols met
- Smooth transition from Children's to Adult's health and care services resulting in well prepared, informed and empowered young adults
- Engaged with, listened to and views respected

One of the group participants shared service agreement cards that were created during an engagement event with the SCaT centre on World Sickle Cell Day.

How can the Care Quality Commission help?

HWS asked the group what they would like from the Care Quality Commission (CQC) and how could they best engage and support people with Sickle Cell and Thalassaemia?

"For 20 years we have been saying the same things" , "We are tired"

"We want to see some form of change, some sort of middle person that has the power to empower and ensure change"

People with Sickle Cell or Thalassaemia and carers and supporting organisations continue to be willing to engage, to use their voices and share their experiences, to help inform and improve health and care services. However significant improvements in health and care services that are joined up and patient centred are not currently visible.

The group felt the CQC could be an organisation with the power to effect change.

"I'd love for the CQC to be a fly on the wall, unannounced, and just come and see what's going on, because it really is something that you need to see for yourself"

The participant group felt patients, carers and community support organisations such as OSCAR Sandwell should not be having to work so hard to raise awareness of Sickle Cell and battle to achieve improvements in health and care services.

The group highlighted that the picture for people with Sickle Cell and associated health and care services was national and they felt some areas of the country may be receiving better services. Reference was made to the Sickle Cell Society All Party Parliamentary Group on Sickle Cell and Thalassaemia[2]—comment was made that the organisation and work going on appeared to be London focused and not benefitting local services.

The group felt that there is something missing, that there is a need for a service to advocate for people with Sickle Cell and Thalassaemia and carers, to hold to account and ensure that health, care and support services meet all patient needs and provide consistently good service.

HWS spoke with OSCAR Sandwell (who provide support to people with Sickle Cell and Thalassaemia) to explore thoughts on what good support group functions would look like:

OSCAR Sandwell explained that the Clinical Commissioning Group (CCG) had previously funded the organisation to provide an advocacy and support role including advice, guidance and welfare. Funding had later reduced to cover a service to new born or newly moved to the area people with Sickle Cell and currently the CCG is not funding any service. Despite the financial resource challenges OSCAR Sandwell continues to offer advice, guidance and support to all people with Sickle Cell and Thalassaemia in Sandwell. Where necessary individual cases are signposted to Powher advocacy services.

OSCAR Sandwell suggested a supporting service offer to people with Sickle Cell would include:

- Peer support, socialising, events - including culturally appropriate opportunities.
- A focus on advice, guidance and support underpinned by health, care and support services connecting with the community support organisations.
- Information, consultation and engagement events using a variety of forums to engage with the patient groups and carers.

2 https://www.sicklecellsociety.org/sctappg/

Conclusion

HWS welcomed the opportunity to bring together the voices of people with Sickle Cell and reflect their messages within this CQC commissioned report. Sickle Cell and Thalassaemia disorder affects people as individuals so experiences differ. This report does not reflect all peoples voices or experiences but does highlight some common challenges encountered within services. Equally staff in health and care services are individuals, doing their best in very challenging circumstances. This report is not seeking to spotlight individuals or particular services but aims to provide an overall picture and suggest that a fully integrated health, care and support system for people with Sickle Cell and Thalassaemia is what is needed.

HWS appreciates the time and efforts given over the past 18 months by key people across health and care services. In particular Sandwell Council in seeking to improve engagement, information and uptake of adult social care and support services and the SCaT Centre for being responsive to patient feedback and in starting the process of consultation and engagement about service change plans with the planned move to the MMUH in 2023.

However progress has not been smooth or easy. Certain individual professionals within health and care services and supporting organisations, such as HWS and OSCAR Sandwell, and patient and carer representatives have extended themselves to achieve these results. However none of these individuals are responsible for the overall shape or delivery of health, care and support services for people with Sickle Cell or Thalassaemia and this appears to be the missing gap in the picture.

Regionally the Clinical Commissioning Groups have gone through recent merger changes and are now in the stages of further structural change. This and operating within Covid-19 restricted times may account for some recent aspects of challenge presenting with bringing health, care and support services together. But the picture of experiences of health and care services for the patient group has a longer history.

The development of an Integrated Care System for the Black Country and West Birmingham NHS Trust and local place based partnerships should give the opportunity to enable efficient change over time. Recently key senior roles have been appointed - HWS appreciate that the individuals concerned have been attentive to the challenges presenting for the patient group and have actively supported processes.

It is hoped that the contents of this commissioned report will be helpful in identifying and structuring fully integrated health, care and support services for Sickle Cell and Thalassaemia going forwards. The additional oversight of the Care Quality Commission could be beneficial for health and care services and in supporting people with Sickle Cell and Thalassaemia to engage with and be an involved part of the processes of development of services.

Recommendations

HWS function is to champion the patient voice in health and care services. HWS are not medically qualified. The recommendations proposed are based on the CQC commissioned engagement project and previous conversations and feedback from people with Sickle Cell, Thalassaemia, carers and community support organisations.

HWS recommends that the CQC consider the contents of this report and:

- Respond to the report, including comment on any need for review of the overall offer of health, care and support services for people with Sickle Cell and Thalassaemia in the Black Country and West Birmingham to ensure a holistic, integrated, comprehensive, quality service and that any gaps in service are commissioned.

HWS also recommends that the CQC:

- Be an interested and "critical" friend during the change processes and development of integrated health, care and support services for people with Sickle Cell, Thalassaemia and carers in the Black Country and West Birmingham region.
- Consider and propose solutions to the patient group proposal of a service that can empower patients and help hold health and care services to account.
- Consider and comment on opportunities for awareness raising of Sickle Cell and Thalassaemia, as appropriate, at regional and national level.
- Consider how to ensure any best practise learning in health, care and support service delivery and patient and carer engagement for people with Sickle Cell and Thalassaemia can be shared to ensure a consistent, quality service and patient experience nationally.

Healthwatch offer

The CQC asked HWS to confirm how they can work with the CQC to facilitate recommendations, including recommendations specifically to the public insight team of CQC

HWS can:

- Provide supplementary information, including contact details, to support the CQC in any work undertaken as a result of this report and recommendations.
- Assist in engagement with people with Sickle Cell, Thalassaemia, carers and community support organisations.
- Continue to be a "constructive" friend to local health, care and support services for people with Sickle Cell and Thalassaemia and carers.
- Engage with and support, as appropriate, any service that is developed to empower patients and help hold health and care services to account.
- Ensure the final report is shared with people with Sickle Cell and Thalassemia, carers, supporting organisations and key health and care service stakeholders and encourage joint working on developing health, care and support services for the patient group.

Acknowledgements

HWS greatly appreciate the time effort and commitment of the people with Sickle Cell who agreed to contribute their views in order to inform and create this report. **Thank YOU.**

HWS value the collaborative working relationship with OSCAR Sandwell that has served to ensure that the voices of people with Sickle Cell and Thalassaemia in Sandwell are heard within health and care services. It could not have happened without you Rachel McFee C.E.O.

HWS appreciate the open ears and minds of key people in Sandwell Council Adult Social Care, the Sickle Cell and Thalassaemia centre and within the Black Country and West Birmingham NHS Trust Integrated Care System who have responded positively to information received and stepped towards making improvements in services. We look forward to the journey continuing.

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