

Experiences of Healthcare in The Black Country



Bridging the gap between
communities and
healthcare systems

Insight Report

People's Voice Media
November 2024



“Every time you go into a GP surgery you are seeing someone different. Which is never great for anyone, but for an autistic individual to actually open-up and talk about what’s wrong, you know, it’s clear that you have to have a relationship with your doctor, that’s the whole point of the GP, and it’s not like its rocket science is it?”

Black Country Resident

People’s Voice Media partnered with the Black Country Integrated Care System (ICS), the Voluntary, Community and Social Enterprise (VCSE) network and Wolverhampton Voluntary and Community Action (WCVA) to start the Black Country Integrated Care System REND Project. This work took place between August 2023 and July 2024.

Funded by Research Engagement Network Development (REND), the project aimed to:

1. **Build capacity:** Enhancing the capacity of the VCSE Engagement and Partnership Team and Involvement Team to support a three-year programme focused on research within the VCSE.
2. **Gather qualitative insights:** Increasing qualitative insight in formal research to capture the diverse views within the community, specifically regarding access to healthcare services in the Black Country.
3. **Build community-led intelligence:** Supporting the creation of a library/data bank of community-led intelligence that can inform strategic decision-making.

To achieve the aims set out above, a key aspect of the project was to implement the Community Reporting method as a tool in targeted areas to undertake research into health inequalities. The project looked specifically at how people access health services (GP’s, hospitals, mental health services) across the Black Country. Through gathering lived experiences from residents of the Black Country about topics pertinent to health inequalities and access to services, Community Reporting approaches supported the collation and analysis of qualitative, community-based insights. These insights were then used to support strategic direction, service improvement and resident engagement in decision-making across the area and in the ICS.

The result of this work is the basis of this insight report. It covers key topics that emerged from the stories, including:

- Technology and accessibility
- Communication between healthcare professionals and the people they support
- Person-centred approaches

It also presents a set of recommendations that have emerged from the work, which are:

- **Improve communication and training**
- **Address digital Inequities**
- **Champion a person-centred approach**

Method

Originating in 2007, Community Reporting has been developed across Europe as a mixed methodological approach for enhancing citizen participation in research, policymaking, service development, and decision-making processes. It uses digital, portable technologies to support people to tell their own stories, in their own ways via peer-to-peer approaches. It then connects these stories with the people, groups and organisations who can use the insights within them to make positive social change. This approach to lived experience storytelling as a changemaking tool has three phases, loosely based on the Cynefin framework for decision-making in complex environments (Snowden and Boone, 2008).



To achieve the project aims, we employed a three-stage methodology rooted in the Community Reporting framework developed by People's Voice Media.

Proof of Concept' programme (August 23 – February 2024)

A 'Proof of Concept' programme was started to 'test the water' and to get initial engagement and interest going. There were 3 sessions in the areas of Sandwell, Wolverhampton and Dudley spread over the month of August 2023. 7 organisations took part and 8 People were trained in story gathering. 9 stories were gathered during this period.

This initial taster in Community Reporting helped people to decide on the most effective open question to use by trying out different questions. The original and first prioritised research question was chosen by the BCICS and VSCE was:

'What are the barriers to accessing healthcare and other services for our most vulnerable communities and how can we support them to remove these barriers?'

However, the question was changed to:

'What is your experience of health care in the Black Country?'

The second question is and open and less leading. This question worked and a wide range of responses were recorded.

The 8 participants came back together in February 2024 to take part in online story curation activity in which they looked across the stories for key themes and insights.

Community Reporting Programmes (March 2024 – July 2024)

In 2024, two full programmes of Community Reporting were delivered. One in Dudley and one in Wolverhampton. These areas were determined by engagement during the previous phase. These training programmes were more in-depth than previous activities, and participants were able to try out other techniques such as dialogue interviews and personal monologues. They also learned more about responsible storytelling practice, including ethics and consent, how to review and curate their stories, and how to mobilise their stories by uploading them to the Community reporter website.

Programme one took place March – April 2024 in Dudley. 14 organisations took part and 17 people were trained in story gathering. 14 stories were gathered during this period. Programme two took place April – June 2024 in Wolverhampton. Here 6 organisations took part and 11 people were trained in story gathering. 15 stories were gathered during this period. After these programmes, the participants took part in online story curation activities for each location. Here the participants looked across all the stories collected to identify the key insights and the learning from them. 8 people from the Dudley group and 4 from Wolverhampton took part in these curation activities. We also held a 'Conversation of Change Event' in Wolverhampton in July 2024. This event brought together members of the BCICS, wider stakeholders and local people to explore the findings from the stories and identify practical ways in which the learning can be put into practice and shared within the system. The results of which have informed this insight report. 15 people attended this event.

38 stories were collected and 51 people engaged with the training

Key Insights

“Technology has its place but face to face contact, as a nurse, myself, it’s very hard to do a good assessment via technology because it’s about looking at the patient, seeing what’s happening.”

Black Country Healthcare Worker

Several key barriers to accessing healthcare services emerged from the stories. These included (1) the time it takes to get an appointment, (2) telephone appointments and online assessments and (3) the general increase in adoption of technologies as part the service. These barriers are leading to frustration amongst residents in the Black Country.

In terms of the time, it takes to get an appointment with a GP or relevant health services, people's stories detailed long waits on the phone and sometimes not being able to get through to anyone. It was also common that appointments were being made weeks after the initial contact and this wait felt too long for residents. One storyteller expressed feeling that appropriate care in terms of getting an appointment was only provided under extreme circumstances, stating:

"I don't think they're giving an appropriate service in a timely fashion unless you lie and just pretend, you're dying and exaggerate your issue."

The stories also highlighted that they couldn't access or effectively use the technology required to do online assessments, pre or during appointments. For example, some appointments required photographing the ailment and/or using WhatsApp. The stories highlighted that for some people, they didn't have the knowledge, experience or technology to do this.

An attendee who is Deaf shared that they cannot use the telephone for appointments and that their GP surgery has an intercom system, so they need to have someone to go with otherwise they cannot enter the building. Experiences like this undermines people's independence and makes accessing services even more difficult. However, some people did state that they preferred the telephone assessments because they didn't have to physically go somewhere to access support. For these people, telephone consultations were either more convenient, and in some instances more accessible. What we can decipher from this, is that a 'one size fits all' approach is not appropriate and thus a blended approach to healthcare appointments – with the option for in-person or remote support always being offered. A healthcare worker involved in the storytelling activities, echoed this sentiment: "Technology has its place but face to face contact, as a nurse, myself, it's very hard to do a good assessment via technology because it's about looking at the patient, seeing what's happening."

"There doesn't seem to be any specialist autism support or learning disability that I have ever met in hospital, particularly when I was going through my breakdown. There was lot of professional's to-ing and fro-ing but no one who really understood."

Black Country Resident

Another common theme that came up throughout the stories was that healthcare workers lacked awareness and training about certain conditions. This was particularly felt by people who have learning disabilities or who are neurodivergent. One resident shared with us that "there doesn't seem to be any specialist autism support or learning disability that I have ever met in hospital, particularly when I was going through my breakdown. There was lot of professional's to-ing and fro-ing but no one who really understood." This lack of awareness and understanding created communication barriers and an overall bad experience, which often resulted in people not wanting to go back to the doctors, dentist, hospital etc. One person said:

“A lot of people with autism end up in crisis and go to hospital as a result and it’s not a good experience at all. They try to medicalise it and sometimes the crisis isn’t about that.”

However, there were some practical solutions identified during the project. For example, one person used a hospital passport and had a dedicated Learning Disability nurse at their GP surgery which they found extremely helpful. The hospital passport is a relatively simple tool that can be used by people who have learning disabilities or are neurodivergent. The passport is a document written by the person that states the practical things that will help the healthcare worker find out more about them. This includes things like how the person likes to communicate, what medications they take, what makes them anxious, etc. The Learning Disability nurse offers patients support when they interact with other healthcare practitioners. This works as an advocate for the patient. This requires them to have prior knowledge of the person and how they like to interact, communicate, what makes them anxious, etc.

There was also reference made to Oliver MacGowan training. In 2022, the Health and Care Act brought in a legal requirement that regulated service providers must ensure their staff are ‘*trained to provide appropriately adjusted care for people with a learning disability and autistic people to reduce health inequality.*’ Some of the trainees felt that this training would be very effective at helping to make health care more accessible, reassuring and a better all-round experience.

Ref: <https://www.hee.nhs.uk/our-work/learning-disability/current-projects/oliver-mcgowan-mandatory-training-learning-disability-autism>

“I told them I couldn’t take the tablets anymore, they would say, if you can’t take the tablets then we can’t offer you anymore help.”
Black Country Resident

Other challenges to accessing support and information for health that emerged through the storytelling included a lack of person-centredness to support and an environment of time poverty. For example, one storyteller noted that they felt “rushed out” during GP appointments, and because of this they felt unable to communicate their concerns effectively. Another person described how they were told they’d be denied support if they didn’t follow the medical advice - “I told them I couldn’t take the tablets anymore, they would say, if you can’t take the tablets then we can’t offer you anymore help.” Experiences such as this exclude people from healthcare provision.

Time and space need to be allocated to healthcare workers to enable them to understand the people they are supporting. As one storyteller put it; they need to find out what “makes the patients tick”. From discussions around the stories, this time and space needs to include better awareness and use of accessibility standards including British Sign Language (BSL), Makaton, awareness of neurodivergence and cultural competence. This type of approach to working with people takes into consideration the whole person, holistically.

Summary of core challenges to accessing healthcare services

- **Communication barriers:** This included language, digital exclusion, seeing different doctors and health care workers so no consistent care
- **First point of access barriers:** Not being able to make an appointment to see a doctor – long phone queues, no capacity to answer phone
- **Quality of care:** A significant concern raised was the perceived lack of adequate service delivery that resulted in frustration and stress when dealing with healthcare workers and demonstrated the need for specialised training in terms of working with Disabled people and people who have neurodivergences.

- **Technology and the digital divide:** Digital systems mean that many people are excluded due to a lack of access or familiarity with technology, although some individuals appreciated using the NHS App for managing appointments and accessing records.

Recommendations

Improve communication and training: There is a need for better, specialised training and development for healthcare professionals on communication skills and cultural competences to ensure all residents are heard and understood within health settings. One person said that having English as a second language with no translators on hand and needing to fill out forms written in English created barriers for his family and community members. Moreover, opening conversations with residents with the question – What reasonable adjustment will help you access relevant support? – would support the creation and implementation of more inclusive and equitable health services.

Address digital Inequities: Healthcare providers need to focus on bridging the digital divide by providing support for those with limited internet access or digital literacy. This could include simplifying the appointment booking process or involve offering alternative ways to book appointments. In-person assistance in navigating online systems should also be considered.

Champion a person-centred approach: Encourage continuous community engagement through initiatives like Community Reporting that can help capture ongoing feedback from diverse populations. This will ensure that healthcare services evolve based on the community's needs. This type of work should not be 'ad-hoc' or 'one-off' projects, but instead mainstreamed and embedded into the system as a continuous approach in the Black Country.

For further details about our work:

Visit: <https://peoplesvoicemedia.co.uk>

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