



Experiences of health and care - Perspectives of people living in Foleshill Coventry

Summary report



July 2024

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Introduction

Healthwatch Coventry is the independent champion for NHS and social care.

The Healthwatch Coventry mission is to hear the experience of NHS and social care services from those in Coventry who do not have a strong voice or are ignored. Healthwatch are committed to reaching new people by trying different ways of hearing experiences.

Healthwatch Coventry have long established links with voluntary and community groups in Coventry and are hosted by a local charity. We advertised a small grants application programme for community research projects to gather experiences of health and care or of barriers to health and care from less heard groups of the local population. This was the second round of small grants. This time the focus was on hearing from:

- Young people
- Men from socially disadvantaged neighbourhoods
- People from diverse communities experiencing health inequality

This piece of work was carried out by Coventry Independent Advice Service through their connections with communities in Foleshill Coventry to reveal the experiences of communities with long term health conditions or disabilities about accessing the help they need, including financial support.

We wanted to gather their stories, good or bad, about the support they receive from health or social care services.

Coventry Independent Advice Service

Coventry Independent Advice Service (CIAS) is a local charity which offers free, confidential, community-based advice in Coventry. They hold the Advice Quality Standard, a nationally recognised quality mark for organisations providing free, independent advice to members of the public. Coventry Independent Advice Service, deliver several services in the Foleshill area of the city, an area with a high level of deprivation and high proportion of new communities. Over 40% of clients are from global majority communities, over 60% are women and most live in the most deprived neighbourhoods. They work closely with a range of community partners to ensure our service is targeted at the people who need us most. More than 10% of CIAS clients experience health challenges and as a result, have experience of using health and social care services.

More information about Coventry independent Advice Service is available on their website - <https://covadvice.org.uk/>

How we did the work

CIAS focused this project on four community locations in Foleshill, where they deliver our services:

1. Foleshill Community Centre – CIAS deliver an outreach service, to deliver expert advice, information and support for complex debt and benefit enquiries
2. Foleshill Family Hub – CIAS deliver an outreach service, as above.
3. Foleshill Library – CIAS deliver community digital sessions, helping the public to use technology and find the help that they need online.
4. Ekta Unity, a support group for the South Asian Community in Foleshill and the wider community.

The method used a combination of:

- Online survey
- Face to face survey
- Group activities and discussions at seven community events, we asked people about their experiences of health and social care, focusing on what service was important to them, and how they thought they could be improved.

A questionnaire to help people in the community collate information from friends, families, and the wider community was produced in community languages, using existing volunteers with language skills and included Gujarati, Polish, Punjabi, Romanian, and Tamil.

Volunteer support

CIAS had support from two volunteers. Feedback from one volunteer:

- *“To be involved with this project has been an eye-opening experience. To find out how many individuals are unable to access the health care they need when they have been ill is shocking and unbelievable. I personally, have never had an issue getting doctor's appointments when needed and I have always been very happy with the level of care I have received, for myself and for my children. It has been difficult for me to hear that some individuals are unable to even get through to their doctor's surgeries and have been unable to get an appointment for themselves or for their children”.*

Who took part

25 people completed online survey responses and 20 of these filled out the equality information.

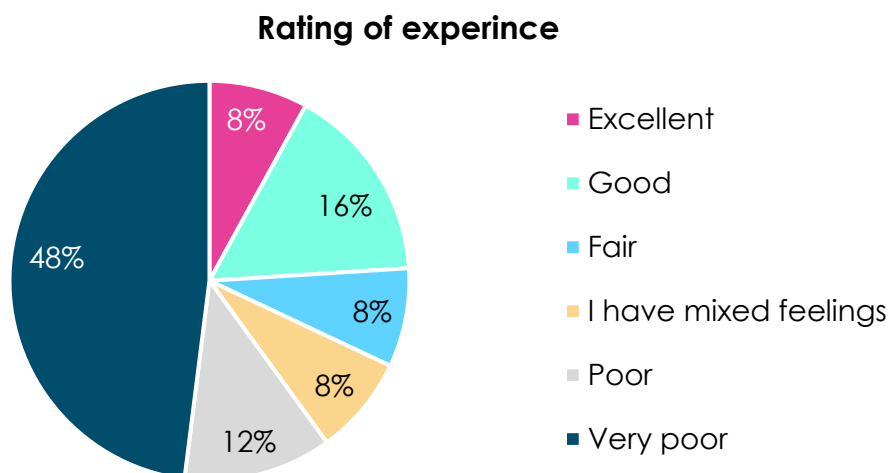
The majority were from a global majority background¹, were women, had access to the Internet and lived in the Foleshill area of the city.

13 of the participants were from Southeast Asian heritage (India and Pakistan). The participants were between 18 and 80 years old. Nearly half of the people interviewed had a long-term health condition.

Foleshill is an area of high deprivation with a population of 24,383, where there are 44.8% Asian /Asian British and 12% Black/African/Caribbean/Black British.²

Experience overall

We asked how people would describe their experience of the service(s) they had used. 60% thought this was very poor or poor; 32% said it was either excellent, good or fair and 8% had mixed feelings.



¹ Global majority is a shortened version of the term 'people of the global majority'. We use it to refer to all ethnic groups except white British and other white groups, including white minorities. This includes people from black, Asian, mixed, and other ethnic groups who are often racialised as 'ethnic minorities'.

² <https://www.coventry.gov.uk/facts-coventry/population-demographics/3> as of 04/07/24

GP Services

14 people commented on GP services. Nine respondents rated their experience 'Very Poor' or 'Poor'. Two rated excellent, one rated fair and one rated 'mixed feeling'.

They highlighted issues around difficulties in accessing appointments, including face to face appointments and then receiving poor service, or a negative attitude from the staff when they got an appointment. Patients struggled to access medication or were unable to make a complaint effectively.

There were also positive comments around people's experiences with their GP where they had historical and ongoing support from their GP for their mental health.

Some of the comments were:

“My child has an autism diagnosis and complained of a sore throat and stopped eating because they said it hurt. I was unable to get a doctor's appointment for days, being kept on hold only to receive automated message to say no appointments available.

“The recent changes in booking appointments make me very uneasy. Previously I had to call at 8 am hang on the call for an hour to know whether I can get an appointment. The new process is even harder. I have to do everything online but not after 6 pm. Secondly, I have been all over the place. Start with NHS site and been taken over to PATCHs and ended up that I cannot access my records as it is not been linked. So have to call the surgery again. Today I called my surgery but cannot reach anyone as they were all in staff training.”

“I am end of life care and feel let down by everyone. Can't get an appointment when needed and they just seem to pass me from one person to the next person and no one is helping me.”

🗨️ I asked for complaints procedure at my surgery and was directed to the website to fill in form. When I visited website there was no form and no complaints procedure, but you are asked to write to the clinic manager”.

🗨️ “GP was very rude didn't put in referral that was important - until I made repeated phone calls”.

🗨️ Doctor has helped with my depression for many years. Very caring and provided support and medicines.

Feedback from informal conversations with South Asian women from Ekta Unity

These people did not want to complete a survey form. But spoke about their experiences with their GPs and getting an appointment.

- 🗨️ *It's really hard to get an appointment*
- 🗨️ *The Dr doesn't really listen to what I am saying*
- 🗨️ *You can only talk about one thing*
- 🗨️ *The Dr is always in a hurry*
- 🗨️ *I feel frightened to tell them everything I am feeling*
- 🗨️ *We get treated differently*
- 🗨️ *I don't like going to the Dr it feels like I am wasting their time*
- 🗨️ *They don't like to help us*
- 🗨️ *The Drs are terrible, and it is frightening to have to go to see them*
- 🗨️ *I am elderly and in a lot of pain, it is very hard for me to get an appointment*
- 🗨️ *I have to keep calling to get through*

Feedback from our volunteer who attended Ekta:

Our volunteer attended a group discussion with Gujarati women, 5 of whom, completed a monitoring and survey form. He recorded the general themes from what the women said about accessing a GP appointment, his comments are as follows:

“The main achievement in this exercise that shines through is the need for urgent medical doctor appointments by quite elderly members of the community and the difficulties they encountered in getting urgent appointments were quite painful to hear... They were left to call and call and call again.

Pharmacists very not a problem for any of them.

However, the Dentistry profession again was questioned on the appointments issue where getting an appointment was troublesome. We can help them I think.”

Pharmacies

People were positive about their experience of community pharmacy services and happy about the services they received.

“Chemist good and I get help with collecting medicine”.

Dental Care

Two people were concerned about access to dental care

“Dentist is a problem; appointments take a long time.

Mental health support services and access

Three respondents rated their experience as very poor in relation to mental health services.

The two case studies below describe people's experiences of trying to access mental health services which they found were not meeting their needs, or their family needs over a long period of time. They also showed their difficult experiences of accessing and using services and getting the support needed for them as people with complex needs.

Case study- Access to mental health services case studies

🗨️ I tried to access mental health services, I was put on the waiting list - so far it's been 7 years, and I was told I'm not on the waiting list, they just chuck pills at you. I want to be able to get to the root of the problem. I didn't get any help from GP. I told my GP what I was feeling, they just tried to give me pills. They did not make a referral.

I've got no support with mental health now. Some days I just want to stay in bed but I can't. They don't even take into consideration your feelings; they just want to chuck pills at ya [sic]. I've tried other charity CBT over the phone. It doesn't help like that I need to be in the room with the person. Finished all the sessions, (6 x 1 hours sessions) not good enough. Not get to the route of the problem.

Case Study - A family carer's experience

"I support my sibling with their hospital appointments. I also support my parent with their appointments, I also work full time. I also have to attend my own appointments. I have tried to book appointments on my day off but end up having to book most of my holidays on appointments. I have tried to explain but feel that this is not taken into consideration. The responsibilities of a carer and how difficult it can be to get time off work is not taken into consideration. I have mentioned on many occasions of appointments can be booked when it is also easier and convenient for me.

My sibling has mental health issues, and I am a mental health support worker, when attending clinics, I have observed the lack of patience and understanding of mental health with other patients too from reception staff. In my capacity of support worker there are many issues with our clients being able to access services too, they face many barriers and are often pushed from pillar to post when trying to book appointments.

Advice and Information on Menopause within the south Asian communities is rare, there is a great need for this too."

Cancer services, community support services and financial support

The case studies below around people's experiences of cancer services show how people have had positive experiences where healthcare has been delivered to meet their needs and help their situation, giving them access to the services they feel they require. There are also fewer negative comments and feelings where people were frustrated by their experiences: feelings that health staff do not listen to them or take their views into account. Their experience also shows that it takes time to make contact and appointments with health and community services.

The case studies show the difficulties people face to access services. For the services it shows their challenges when delivering services to meet people's needs, especially when people are isolated or immobile due to their condition and are unable to physically access resources.

Caran

I am getting cancer treatment at the moment: Chemo. I suffer from a brain tumour.

My Discretionary Housing Payment (DHP) is due to stop, and I will be paying a large amount out of my Personal Independent Payments (PIP) to remain in my house. Previously I have contacted the Council for help with dressing and washing, I contacted the Disabled Facilities people and occupation health, who said this care has to be paid for and that they would charge for all services. They wanted to charge £20 per week, and for cleaning services and another charge for shopping services. Every time I ask for something they can't help. I became disillusioned with them when I lived in my old house (and they didn't help) I didn't try again in this house.

A family member takes me shopping. I am really struggling, and I rely on my family.

The social prescribing lady didn't turn up. She is telling me to call lots of different people. I don't have the energy to keep trying to get through to people. I am doing her job for her. I have been a client of CIAS, and they helped with getting DHP £82.00 per week. I started a claim 16th August, I had not heard anything, and I called the council - they still hadn't processed my claim. They skipped all finance checks, answered all questions.

I receive no professional help with day-to-day care. There isn't any help available. I don't receive a cold weather payment. I was locked away through

COVID. My life has not changed since COVID. The team at the Arden Centre, I can't fault them at all.

Madaline – cancer care experiences

In the early part of 2022, I was diagnosed with cancer. I had no outward symptoms, and it was discovered after a routine test.

During chemotherapy treatment, I developed complications, and I was advised to start injections to help but due to the chemotherapy that caused pain, I found this impossible and had to rely on district nurses and friends to help.

Then on 3rd January 2024, I had another operation, and I am waiting for more treatment.

As of March 2024, I am still waiting for more treatment, which I desperately need.

I purchased a lightweight electric wheelchair as I can't walk very far without assistance and I have received some equipment from occupational therapy, that assist me with my daily living. I pay for a weekly cleaner using my benefit payments, as I am unable to do this myself. My husband is now the only wage earner as I have been unable to return to work due to my declining health.

Having cancer has been incredibly isolating and I have also struggled with my loss of independence.

What went well

The scan saved my life and the oncology team (including chemo and radio staff and receptionists) have all been fantastic.

I feel that the team at the MacMillan office at UHCW have been "fantastic" and all staff (support workers, receptionists, even the cleaners and volunteer staff) at the Arden centre have worked well together and have been very competent and caring.

I attended the HOPE group, which is a 6-week course run by the MacMillan Cancer Support, aimed at cancer patients who have finished their treatment and need support to rebuild their life. I feel that they have been really supportive.

I was referred to Coventry Citizens Advice from the MacMillan team, who helped my claim for PIP (Personal Independence Payment) which has been an absolute god send.

The MacMillan team also referred me to The Hope Group (as mentioned above) who also helped her apply for a disabled bus pass, a cinema CEA card (enables a disabled cinema guest to receive a complimentary ticket for someone to go with them when they visit a participating cinema. They also contacted all my utility providers and requested for me to be placed on the vulnerable users register.

What went less well

When I was diagnosed with the complications, I felt that the nurse was not listening to me, in regard to the injections and my inability to administer the injections myself. After talking with my oncology nurse, I was switched to tablets.

I feel that when I need to contact my nurse, that I have to leave a message and wait for a call back, which can take too long.

I had a follow-up appointment with the oncology team in August 2023 and feel that they have been lacking. During one appointment, which was with a junior doctor, I felt that he ignored all the things that I said, especially regarding my symptoms which were all symptoms that would occur when the cancer has spread. He also advised me to lose weight and did not take into account, that my weight has only increased due to being prescribed certain medication. I later mentioned this to my oncologist, and she arranged for me to have four PET scans a year.

I had to fight to get the equipment I needed from occupational therapy.

Audio accounts are available to listen to on our YouTube channel - <http://www.youtube.com/@covadvice>

Conclusions

This small survey gathered some in depth stories that revealed useful insight and case studies of experiences.

The comments made about GP practices highlight issues which people experience within this area of Coventry and indicate how people feel about the challenges of accessing GP care along with the positives they see from continuity of support for example related to mental health.

Issues were raised were about accessing GP practices by phone, and difficulties getting to see the GP face to face, especially if the person has a mobility issue and cannot get to the surgery.

The case studies show some of the difficulties people face and their experiences of health and care services when confronted by multiple and complex issues, such as ill health and finance.

Someone who received support from multiple sources from the NHS, from Macmillan nurses and CIAS, among others felt that their issues could be resolved effectively.

People living in complex situations and are struggling with multiple challenging situations including poverty, insecure housing, and multiple health issues, may need joined up thinking and additional support.

For more information about our learning from the research process, see Appendix B.

The key asks

The key asks from people are:

- For GPs and other health professionals to take time to listen to people's concerns particularly when they have multiple and complex needs.
- For GPs and other health professionals to respond in a timely manner to patients in Foleshill
- For GPs and other health and care organisations, both statutory and voluntary to work together holistically to help people to manage and overcome their health and other difficulties.
- More information to help make people aware of the mental health and other services available to them, including Healthwatch Coventry.
- Explore how to make sure people from this community get access to information about health issues e.g. menopause.

Acknowledgments

Our thanks to all the people who helped with our research, this includes our staff, volunteers, survey respondents and people who gave us extended time to help us write their case studies.

We would also like to thank the following community organisations and services for supporting this work; Foleshill Community Centre, Foleshill Family Hub and Ekta



Appendices

A) Services people had used and rating of services

We asked what area of care people would like to share their story about? They could identify multiple services. The most frequent were GP services and mental health support.

Type of service	Frequency
A&E	1
Hospital inpatient	2
Hospital outpatient	3
Mental health support	6
GP services	14
Dentist	4
Pharmacist	3
Social care	1

Excellent	2
GP services	1
GP services; Pharmacist; Dentist	1
Fair	2
GP services; Pharmacist	1
Hospital outpatient; Mental Health support	1
Good	4
GP services; Dentist	1
Hospital outpatient	2
I have mixed feelings	2
GP services	1
Mental Health support	1
Poor	3
GP services	1
GP services; Mental Health support	1
GP services; Pharmacist; Dentist	1
Very poor	12
A&E	1
GP services	5
GP services; Dentist; Mental Health support	1
Hospital inpatient	2
Mental Health support	2
Social care	1

B) CIAS reflections

We conducted this research in less than 3 months, which also coincided with the Easter holidays, and whilst we have collected some insightful information and accounts, we would recommend at least 6 months to complete this type of research.

Engaging with the public on issues around health is difficult, creating a safe space where people can carry out an unrelated or creative activity that puts them at ease and allows the conversation to flow has been effective for us.

1. Working with our partners in the community has been successful and engaging with people who already attend community services is an effective way to reach people.
2. Writing to our clients or calling them has not been successful and we have had limited success in engaging with our target group on social media.
3. We have been able to confirm what we already know about engaging with communities who live in Foleshill, namely that working with partners, building trust over time and investing time and resources to create safe place for people to talk about what they have experienced is an effective engagement model.

CIAS makes the following suggestions.

- Further research into the extent of the issues of access challenges for people from a global majority background to health professionals in Foleshill; including GP access.



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