

Unheard carers from minority groups in North Somerset

September 2022

healthwatch North Somerset

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About Healthwatch North Somerset

Healthwatch North Somerset has a statutory duty and remit to provide a voice for people who use health and adult social care services. We give people an opportunity to have a say about their care or the care of their family members, including those who are not usually heard.

We ensure that their views are taken to the people who make the decisions about services. Our expertise in engagement and coproduction means that during this project we have been able to provide detailed experiential evidence to local statutory authorities and commissioners.

We share feedback with national stakeholders Healthwatch England, NHS England and the Care Quality Commission (CQC) to ensure that the community's voice is heard. We make all findings public.

Our vision is that Healthwatch North Somerset is a place where peoples experiences improve health and care. Healthwatch is committed to promoting equality and diversity, and tackling social exclusion in all our activities. We aim to ensure equitable access to our initiatives and projects, and work to tackle health inequalities.

Introduction

This report explores the needs of carers from minority communities in North Somerset. We aim to provide a platform for their experiences and feedback in order to inform North Somerset Council's (NSC) refreshed Carers Strategy, a live document anticipated in 2022.

Minority communities include people from Black, Asian, and minority ethnic communities; refugees and asylum seekers; Gypsy, Roma and Traveller people; and disabled people. We looked at how carers from these communities see their role, what their health and social care needs are, and how these needs make them vulnerable and require support from services.

Executive Summary

Eight unpaid carers were engaged from the Syrian refugee community, the Gypsy, Roma and Traveller community, the Asian community, and the disabled community. Each person shared their experiences of caring with us.

Although most of the participants come from distinct cultural backgrounds and have unique stories about providing care for their loved ones, there were shared experiences.

Most of the unpaid carers did not identify themselves as a carer, but instead referred to themselves as someone looking after a family member or loved one. All eight respondents when asked, felt that being told about rights and entitlements, and information about where or how to access public services, was ineffective. None were supported by their GP or GP surgeries, and no health or social care professional had ever discussed with them their role as a carer.

Language and cultural differences present barriers for the refugee carers, and they lack the support of extended families that local residents often have.

Refugee carers expressed a particular need for emotional support.

These findings provide a glimpse of the experiences of carers. Further research would provide in-depth evidence, filling gaps in the data and providing much-needed understanding of the needs of carers from minority groups. These projects should include carers from the LGBTQ+ communities and the armed forces Veteran community.

In summary we found:

- Participants do not identify themselves as unpaid carers. They felt unacknowledged by GPs and other frontline health and social care services.
- The lack of information or communication directed at them from health and social care services is the main barrier to accessing the support these carers need.
- Carers would like training so that they can better support the cared-for person, and emotional support for themselves. This was especially true for the refugee carers.
- The carers wanted peer support groups with other carers who face similar barriers or provide a similar type of care.
- Uptake of services by diverse communities (and better health outcomes)
 would be improved by gaining a better understanding of the key issues
 relating to culture and how this may influence use of health and support
 services.

Background information

NSC have been working to refresh their Carers Strategy and ran a public consultation to gather a range of views and experiences from the unpaid carers in North Somerset. In early 2021 we co-produced a piece of engagement with North Somerset Parent Carers Working Together. During that project, we spoke in-depth to 31 people through focus groups and telephone interviews. Our report in April 2021, 'Listening and learning from unpaid carers', made evidence-based recommendations to help inform the 2021-24 Carers Strategy. 'However, during the public engagement stage and consultation, there was very low participation of carers from minority communities or carers with a disability. Healthwatch North Somerset (HWNS) agreed to utilise our engagement expertise with vulnerable communities of carers. In late 2021 we began targeted work with these 'seldom heard' groups to build trust and understanding with carers who have disabilities and those from established and new minority ethnic communities.

Our report represents the experiences of eight unpaid carers. Three refugees from Syria, two from local minority ethnic communities with roots in Asia, one carer from the Gypsy, Roma, and Traveller community, and two carers who have physical disabilities themselves.

Our work was limited by the number of COVID-19 cases among the contacted groups during early 2022. We initially engaged with three carers within the Gypsy, Roma, and Traveller communities, but two were unable to participate fully due to COVID-19 and family bereavement.

A literature review shows that unpaid carers from minority communities face inequity because of their caring role. They are twice as likely to experience poor health compared to the non-carer population. Throughout the COVID-19 pandemic, most carers had to provide even more care than usual, often because the help from family and friends diminished, and due to limited or no support from local services. ²

The 2011 census provides the most recent data for carers, as multivariate data from the 2021 census is not expected until winter 2022. In 2021, one in eight of the population in England were carers, and around 10% of them were carers from

ethnic minority groups. ² These numbers have increased, especially since the beginning of the COVID-19 pandemic. A report by Carers UK shows that Black, Asian, and minority ethnic carers provide more care than average, which puts them at greater risk of ill-health, loss of paid employment and social exclusion. ² They also face several additional difficulties such as language, cultural barriers, and stereotypes.

Evidence shows that these barriers impact on the health and wellbeing of carers, increasing their chances of experiencing poverty and social exclusion². They are more likely to struggle financially and provide more than the average hours of care. According to the NHS Information Centre, they are more likely than majority white carers to care for twenty or more hours a week, 56% compared to 47% in the white population ³. Despite this greater need for support, they are less likely to access and engage with formal services. ³

The NHS England's (10-year) Long Term Plan, launched in 2019, makes clear the need to tackle health inequalities by identifying and supporting carers from 'least-heard' groups and communities, including members of the Gypsy, Roma, and Traveller community, Asian carers, and refugees and asylum seekers. One of the Long-Term Plan's aims is to "understand what would ensure more carers from vulnerable communities access support so that they can maintain their own wellbeing." ⁴

The 2011 census shows there were 22,313 carers in North Somerset, representing 11% of the total population. ⁵ However, there isn't any local data available about carers from so-called 'vulnerable communities' and, according to North Somerset Council, there is a gap in identifying and engaging with those carers. According to the 2021 census, the population in North Somerset increased 7% since 2011. However, the breakdown of percentage of ethnic minority residents and the numbers of carers were not available when this report was written.

Gypsy, Roma, and Traveller population

A leading national Traveller-led charity in a briefing report on health inequalities claims Gypsy, Roma, and Traveller communities "face some of the most severe health inequalities and poor life outcomes amongst the population in the UK, even when compared with other groups experiencing exclusion, and other ethnic minorities". ⁷ The 2011 census recorded 176 people from the Gypsy, Roma and Traveller communities in North Somerset, but difficulties of obtaining a precise number may mean the actual figure is much higher. ⁸

Gypsy, Roma, and Traveller families mostly live in large trailers or caravans on one of several designated sites in North Somerset, containing an amenity building with kitchen facilities.

There is very limited data on the number of unpaid carers within these communities. Studies show that members of the Gypsy, Roma, and Traveller communities much prefer to care for unwell members of families and their wider relatives at home. 8 There may be a significant number of people carrying out unpaid caring roles within these communities.



Refugees and asylum seekers

In the last ten years, North Somerset has received refugee families from a number of countries. In 2016, North Somerset Council took part in the national Syrian Vulnerable Persons Relocation Scheme (VPRS), accommodating 14 families. These families were supported by the council to settle here. There are refugees from other countries, including other Syrian families, that live in North Somerset which are not part of the Vulnerable Persons Relocation Scheme.

The number of unpaid carers among the refugees is high. This may be because the VPR scheme prioritises those refugees "in desperate need of assistance who cannot be supported effectively in their region of origin. This includes women and children at risk, people in severe need of medical care and survivors of torture and violence, amongst others". 9



Black, Asian and minority ethnic communities

Based on the 2011 census, around 3% of the population in North Somerset are considered non-white British. Recent data suggests this population has increased in the last decade. Of those from a Black or minority ethnic group, 44% classified themselves as Asian and a further 37% classified themselves as mixed race. 6

The two main voluntary community organisations that support and promote activities for people from ethnic minorities are North Somerset BME Network (recently renamed Race Equality North Somerset) and The Multicultural Friendship Association. There are some additional faith and language-based groups that support this population.

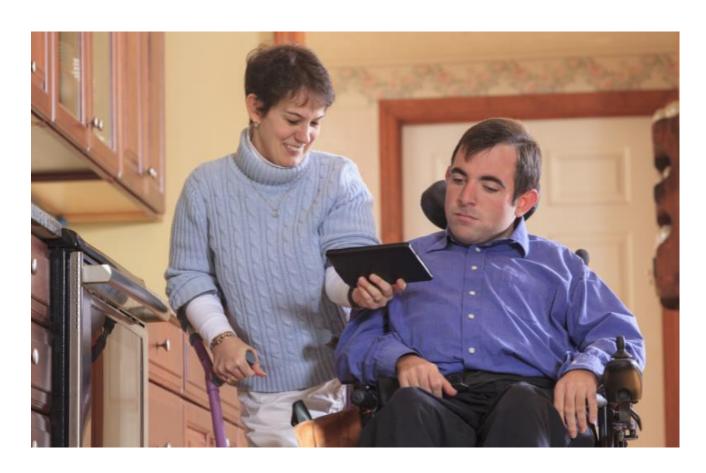


Carers with disabilities

Many people with existing disabilities or long-term conditions take on the role of caring for others. According to Carers UK, the 2019 GP Patient Survey found that carers are more likely to report having a long-term condition, disability, or illness than non-carers – 63% of carers compared to 51% of non-carers. ²

Based on a survey of carers in households, run by the NHS Information Centre, 27% of carers were in receipt of the Disability Living Allowance because of their own disability or ill health.

In North Somerset, there is limited data on carers with a disability, but of the total (2011 census) population of just over 200,000 people, 8.6% (17,335) have a disability that they describe as limiting their day-to-day activities a lot and 10.6% (21,405) have a disability that affects their day-to-day activities a little. ⁶



Methodology

To identify carers from Black, Asian and minority ethnic communities, HWNS contacted and worked with the following voluntary, statutory and community organisations, as well as accessing networks known to them from previous work:

- North Somerset BME Network (now Race Equality North Somerset)
- Multicultural Friendship Association
- North Somerset Vulnerable Person Resettlement Scheme
- Traveller Advisory Teacher and Reintegration Worker from North Somerset Council
- Alliance Homes Carers Support Service
- Refugees Welcome North Somerset

Information about this project was shared on social media by these organisations. Eight carers were identified, and they agreed to take part in individual face-to-face, in-depth, semi-structured interviews. An interpreter was engaged for the Syrian refugee carers, giving them full access to information, and enabling accessible communication during this project.

Most of the interviews were carried out at carers' homes. Participants signed a consent form (see Appendix 1). Before the interviews, HWNS had several contacts with the carers face-to-face or by phone to explain the aims of this project and ensure that they were happy to take part in the interviews.

A semi-structured interview schedule (see Appendix 2) was used. It consisted of several open-ended and closed questions. The project outputs included qualitative thematic analysis of the interviewee responses.

Demographic data

Demographic data of participants	
Female	7
Male	1
Age	30-60
Ethnicity	Arab (3); Asian (2), British (2); Gypsy, Roma, and Travellers (1)
Demographic data of participants	
Female	7
Male	1
Age	30-60
Ethnicity	Arab (3); Asian (2), British (2); Gypsy, Roma, and Travellers (1)

Caring roles

Refugee carers:

Three Syrian refugees were interviewed.

One person cares for his wife, who has limited mobility and is in a wheelchair.

One person cares for their bedridden parent.

One person cares for a non-verbal autistic child.

Asian carers:

One person cares for a seriously ill parent who does not speak English.

One person cares for a child born with a serious hearing impairment.

Carers with disability:

One person suffers with Long-Covid fatigue and cares for her husband, who is a wheelchair user.

One person has several health issues including Fibromyalgia and cares for an autistic child who suffers from severe social anxiety.

Gypsy/Roma/Traveller carer:

This person cares for a child who is a wheelchair user.

Findings

Not recognising themselves as a carer

When asked if they identified themselves as a carer, all eight participants said no. They see their role as looking after someone in the family who they love, and for most, there is no single word to define what they do. Those who care for a child were emphatic with their answer, saying that they were mothers, not the carers of their children.



"I don't see myself as a carer for my daughter. I am her mother, and she is part of my heart. I don't identify myself as a carer". (Syrian refugee carer)



"I am the mother. I can't separate that and have another word to define what I do. I look after my child" (Traveller carer)

For the Syrian and Asian carers it was first necessary to explain the term unpaid carer. While they have in their native languages the concept of a duty to look after a relative or friend, as exists in English, they do not have the concept of a carer based on an understanding of the UK social care system.

"I see myself as helping a human being, and she is my wife. I would care for anyone who needs help." (Syrian refugee)

The term 'carer' can also be confusing as the word is used within health and social care settings to describe those who provide paid care workers. 10 Based on a survey carried out by Carers UK, the majority of unpaid carers within the general population take years to recognise their caring role, and many simply do not see themselves as carers. 10

For the two carers with a disability, who are White British, it also took years to recognise that they were carers.

"I never saw myself as a carer, but as the mother, especially when my son was a child. Only after some friends told me that I was a carer, that I realised that apart of being a mother, I am also his carer." (Carer with disability)

"They should say if you look after someone from your family." (Traveller carer)

"At the beginning I would not identify myself as a carer, but as the wife. Only after I read a lot about it, I realised I was a carer." (Carer with disability)

When asked how they should be identified if the word "carer" is not the right term for them, some suggested simply being called mother or parent.

"Mother or parent, because I am her mother." (Syrian refugee carer)

Participants suggested using of the term 'Looking after someone'.

Not being recognised as a carer by GP surgeries and other health professionals

Carers UK say that if unpaid carers do not recognise their caring role, they may struggle without the support they need which leads to poor health outcomes for themselves.

GPs, social workers, and other frontline professionals within health and social care play a vital role in identifying and guiding carers as early as possible, so they can access the help and support available to them. ¹⁰

However, none of the carers interviewed for this project said that their GPs, or any other health or social care professional, has discussed with them their caring role.

"No, no one has discussed my role as a carer. It's difficult because of language barriers." (Syrian refugee carer)

"No, they don't talk or ask anything about carers and the support available. They only ask to tick a box on a form, and that's it. Nothing happens." (Carer with disability)

HWNS emailed a sample of eight GP surgeries in North Somerset among the four Primary Care Network groups (Tyntesfield, Pier Health, Gordano and Mendip

Vale), asking if and how the practice proactively identify carers. Two surgeries sent their responses:

"We have a question on our registration form asking if a patient is a carer. We also identify through patients who might need a carer (who is supporting them). We then code them as such and send out a carer's pack. The Practice has a Carer's Champion." (Haywood Family Practice)

"We encourage carers to self-identify. This is by posters in the practice and on our registration forms. We encourage the Patient Participation Group to be involved in carers week". (Winscombe & Banwell Family Practice).

When asked if their GPs supported them with their caring role, the participants said that they did not feel supported by their doctors.

"No, I don't feel that my GP support(s) me or know(s) my situation." (Asian carer)

"The GP knows I care for my wife, but he has never mentioned it to me, and they have never asked me about it at the surgery. They see us only as husband and wife." (Syrian refugee carer)

Information and communication

When asked what the main barriers for them were to access support with their caring role, all participants felt that the main barrier was due to a lack of information and communication from health and social care services.

For the refugee and Asian carers, there are multiple challenges around information and communication. Apart from the immediate language barriers, they find it hard to understand the health and social care options available to them and the services they are entitled to access as a carer.

Carers UK say that translating information into multiple languages is an initial step. They also suggest that outreach services are developed to ensure that minority ethnic communities know what services are available. 11

Anyone who provides regular care is entitled to have an assessment of their own wellbeing and how caring has affected them, and to explore what help and support they might need in their caring role. This is in the North Somerset Carers Strategy but none of the interviewed carers were aware of this strategy. The Syrian carers are given support by the VPRS workers to claim Carers' Allowance, but they are not informed about other help or support. Syrian carers and the carers from Asia were unaware that they were entitled to have a carers' assessment.

The information relating to local support services for unpaid carers is only available in English, and only online. There was a consensus from all the carers we spoke to, including those with English as their first language, that information about social care and support on the council's website was difficult to find and understand.

"The information needs to be simpler and in plain English that suits everyone." (Traveller carer)

"I would prefer to receive any information via [text] messages or through the post, as the internet is difficult for us because of language barriers and facilities to access it". (Refugee carer)

"The information at NSC's website is terrible, it is not clear. It takes time to find any information. They have to realise that we don't have time to look for things, especially when you have your own health issues. It's very distressing". (Carer with disability)

All participants reported that the communication they received from health and social care services was inadequate. This was more evident during the COVID-19 pandemic, when many community and public services limited face-to-face access.

"We need more communication. During COVID-19, we had only one phone call from the council and that was after two years". (Traveller carer)

"We don't receive any information from the council. More communication and to have access to support groups." (Refugee carer)

"During the lockdown, no one from the council contacted me to see if I needed something, or to say that we had priority shopping, for example, or any other support. There is no way to find out about carers and the support available". (Carer with a disability)

"We need better communication and information about the rights of carers. The Council and GPs need to work together, inform the parents because they know who are disabled or have any other problems and need support". (Asian carer)

Their needs arising as a carer

When asked what their needs arising from being a carer were, most of the participants said that their needs are mostly for help so that they can meet the needs of the person they care for.

Home adjustment:

"I think Social Services should have a better understanding about disabled children or people among the Traveller's communities. Our needs are their needs. My child needs some adjustment in the house to meet his needs, but because we live in a caravan, that's sometimes difficult. If we lived in a normal house, that would probably be different". (Traveller carer)

Training:

"I need some kind of training around safety that helps me to support my child. Someone who can help me to look at my house and tell me what I should do to keep my child safe. It's not safe to go out with my child, so I also need help to do some risk assessment before I go out." (Refugee carer)

Language translation at appointments:

The Asian carer who supports an older parent said one of their main needs was to have language support for the cared-for person when dealing with health professionals.

The time the carer needs to spend helping her parent, has meant she has to work part-time, which has affected her financial circumstances.

Mental and physical health;

Caring for someone over a long period without support negatively affects a carer's health and wellbeing, and this is likely to be exacerbated in minority communities.

Carers from these communities are less likely to be identified as a carer or access the local support services. Studies show that even when carers from these groups are identified, they face numerous barriers. This is in addition to communication difficulties, isolation, and a lack of understanding by services about how best to support them with few culturally competent services to access. ¹²

These barriers were especially evident among the Syrian refugees, who do not have support from extended family or community, and are not familiar with the range of services available or their rights to health and social care.

"I have no one to help me. When I had COVID-19 I had to carry on looking after her. I feel under pressure because I don't have time for myself. One day I had to

go out, but I had to come back to change her because no one else can do it. Sometimes I feel depressed."

"I am having a lot of back problems because I need to carry my wife upstairs to have a shower. We do not have the facilities we need, and this is also affecting my mental health."

"I also feel lonely, and I would like to have someone who could listen to me, someone who could understand my situation. I can't go out and I can't leave my child with anybody else."

The carers with disabilities mentioned that due to their physical health problems, their needs were mainly around more practical support such as helping with completing forms and jobs around the house.

The support they would like to have

When asked what support they needed and what the council could do to help them, there was a consensus among the refugee carers of the need for groups and emotional support.

"More group support with other parents with children with the same needs as mine, so we can share and talk about our situation. I also need someone who could listen to my emotions and help me with my mental health".

"More communication and have access to support groups".

"Offer some emotional support, such as having someone who I can talk about how I feel."

Four participants also commented that some training would help them with their caring role:

"More training on how to support my child." (Refugee carer)

"The council could offer some training to help us to look after our children such as sign language". (Traveller carer)

"Training about support and how to get help for the cared-for person and for yourself". (Carer with a disability)

"The council could help with or train [us] about the benefits forms and assessment paperwork. I can't work it out, and it is very tiring when you have your own health issues". (Carer with a disability)

One of the participants raised the issue of recognising unpaid carers at the same level as foster carers and offering similar support.

"The unpaid carers are not recognised. For example, if you are a foster carer, you get much more support than us, and they are recognised better than unpaid carers. We also need a card that says, "I am a carer!", and not only an emergency card." (Carer with disability)

Recommendations

- 1. Health and social care services build cultural understanding to achieve strong and positive networks with minority community, language-based and faith-based groups in North Somerset in order to engage and identify carers from vulnerable communities and groups. This should be based on outreach engagement together with data collection.
- 2. A specific chapter be included in the Health and Social Care Joint Strategic Needs Assessment of carers from minority groups, aiming to tackle the health inequality among these communities.
- 3. The local authority works together in co-production with community groups to develop sufficient and appropriate information packs about support and carers' rights that are easy to understand, in different formats and languages. The word "carer" should accompany an explanation such as 'If you look after someone in your family or a friend who couldn't manage without your help, you are a CARER and you have rights to get support for yourself.'
- 4. The local authority to work together with the Integrated Care System (ICS, which has replaced the CCG) to encourage GP surgeries to adopt the Framework of Quality Makers developed by NHS England. ¹³ This aims to improve the identification of carers of all ages at general practices. ICS should monitor how this framework is adopted by each GP surgery.
- 5. Carers' support should include access or signposting to appropriate emotional support especially the Syrian refugee carers, with the assistance of an interpreter. This could be through peer support groups and/or counselling sessions.

Stakeholder Responses

Shane Devlin, Chief Executive Officer, Bristol, North Somerset and South Gloucestershire Integrated Care Board

"We welcome the report's findings and recommendations. Tackling inequalities in health outcomes, experience, and access to services across the whole of Bristol, North Somerset and South Gloucestershire is a key priority for the Integrated Care System (ICS); and as part of this, it is important we look at how we can improve the experience of carers, particularly those from minority communities.

This summer (July 1 – September 25), we have been running a 12-week period of public and partner engagement to inform the development of the new Integrated Care System strategy. To date, 17% of the responses from North Somerset have come from carers, who are a key stakeholder for this work. We will also use Healthwatch's report findings to inform the development of this strategy, which will set out a population-level vision for the future (2, 5, 10 and 20 years' time).

We will continue to work closely with North Somerset Council and other partners to tackle inequalities and support communities at a local level. We will share the report with North Somerset – and other – Locality Partnerships so that we can build on the great work Healthwatch is doing to develop relationships with carers and unheard communities.

We are committed to provide the best health and care for people across our area, and we encourage people's feedback to help us get it right. We look forward to continuing to work with you to embed the voice of carers at the heart of our future plans."

Kathryn Benjamin, North Somerset Council Strategy and Policy Development Officer, Adult Social Services. Author of the NSC Carers Strategy 2021-24

"North Somerset Council welcomes the Healthwatch report, 'Unheard carers from minority groups in North Somerset'. This is an important piece of research detailing the experiences and needs of carers in these groups. It is a valuable contribution to understanding how we can better support them, building on our own previous engagement with carers. It is notable that some of the experiences identified in this report are shared with other carers in our community, for example, the impact of looking after a loved one on their own health, but that others are specific to those from minority groups, such as language barriers and how cultural issues impact on uptake of support and services.

We note the clear recommendations of the report and will use these to inform the action plan for the multi-agency North Somerset Carers Strategy. We will also share these recommendations within the council and work with the Integrated Care System and other partners, as their implementation requires an integrated approach which spans across health, social care, and the voluntary sector, to improve outcomes for these carers in our community."

References

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Appendices

Appendix 1

Consent form

These are used to record a person's agreement to take part in the project. Consent form for the use of your data

Please tick all appropriate boxes

rease tien an appropriate boxes		
	Yes	No
I have read and understood the study information about the project. I		
have been able to ask questions about the project and my questions have		
been answered to my satisfaction.		
I consent to be a participant in this project and understand that I can		
refuse to answer questions and withdraw from the study at any time,		
without having to give a reason.		
I understand that information I provide will be used for a published		
report.		
I agree that my information including my ethnic background and my		
nationality can be quoted in research outputs.		
I understand that any other personal information such as my name or		
address will not be shared beyond the project team.		
I am happy to participate in a video or voice recording to express my		
views and opinions.		
I give permission for the information that I provide to be archived and re-		
used.		

Name of Participant [IN CAPITALS]

Signature

Date

Name of Researcher

I confirm that all the information relating to this research was provided prior to consent Signature

Date

Appendix 2

Interview questions

- 1. How do see your role as a carer? Do identify yourself as a carer?
- 2. Do you know or have you heard that the local Council has a document called Carer's Strategy?
- 3. Has anyone, a professional, such as your GP, ever discussed with you about your caring roles?
- 4. If you saw a poster or flyer at your GP surgery, for example, saying "We would like to invite all unpaid carers to participate on this event/survey", would you think that is for you as well, or would you pay attention to it?
- 5. What words do you think the Council should use to reach you instead of "carer"?
- 6. What are your needs arising from being a carer and what support can public/community services offer to you that would help you?
- 7. Do you feel that your GP supports you?
- 8. What barriers do you feel there are for you to access any support?
- 9. What can the local Council do to help you with your role as a carer?
- 10. How would you like to be contacted by the local services?

Appendix 3

Logic Model – to view or download this project planning tool, please visit www.healthwatchnorthsomerset.co.uk/unheard-carers-minority-groups-north-somerset-august-2022

Appendix 4

Equality Impact Assessment – to view or download this project planning tool, please visit www.healthwatchnorthsomerset.co.uk/unheard-carers-minority-groups-north-somerset-august-2022

If you require this information in an alternative format, please email helen@healthwatchbnssg.co.uk.

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