

Putting a Face to Unmet Need

Published: May 2023

Contents

Contents	2
Executive Summary	3
Background	5
Methodology.....	8
Key Findings.....	10
Conclusions.....	13
Recommendations.....	14
Next Steps	16
Appendices.....	17

Executive Summary

Following contact from a member of the public about their father's experience of health and social care services, Healthwatch East Sussex undertook a project to further explore people's social care needs and how they were being met.

Working in collaboration with three partner organisations, Citizens Advice in Eastbourne, Diversity Resource International (DRI) and Care for the Carers, fifteen people were identified and interviewed. They were asked about their experience of social care and the impact of needed social care. People were drawn from three groups, namely unpaid carers, individuals from an ethnic minority background and people on low incomes.

The case studies developed from people's experiences describe:

- The significant impact on unpaid carers in terms of their health and well-being and their relationships and lives.
- Their difficulties in understanding and navigating adult social care systems and the lack of support available to carers from that system. These difficulties were mentioned by those from an ethnic minority background but also highlighted as an experience also shared by others.
- A desire for closer joint working across agencies in order to effectively support people with multiple needs that may cut across multiple service boundaries and responsibilities such as health, social services, housing and financial.

In writing this report HWES has adopted a broad definition of social care proposed by the social movement *Social Care Future*:

"We all want to live in the place we call home, with the people and things we love, in communities where we look out for one another, doing what matters to us." Some people might need support to do these things, whether because they have a disability or because they have developed a health condition as they aged. Social care provides this support. This definition implies that when it works at its best, social care helps create a web of relationships and support that people can draw on to live their life with meaning, purpose and connection, regardless of their age or disability. "

HWES has made a series of recommendations from our findings, which take into account the constraints placed upon East Sussex Adult Social Care by the national system and the financial constraints under which it operates.

Summary of Recommendations

- 1.** Adult Social (ASC), working with local voluntary, community and social enterprise (VCSE) organisations, should develop and implement a plan to better educate the public about what social care is, who is responsible for providing social care and how to access it online or in person.

2. ASC should work with partners and in particular the Safeguarding Adults Board to develop and implement a plan to improve public awareness of safeguarding and who to contact with a concern.
3. Health and social care system partners including ASC, NHS and VCSE organisations should develop a plan to provide information, advice and emotional support for unpaid carers and people arranging for the care of a family member.
4. All health and care services, including ASC and the NHS should ensure that interpretation and translation services are provided for people whose first language is not English at all points in their support journey.
5. ASC need to ensure that individual's assessments are done in a timely manner and seek to progressively reduce wait times in East Sussex.
6. Health and care strategies and delivery programmes should identify and focus resources on preventative measures, rather than just crisis management.
7. System partners including ASC, the NHS and VCSE organisations should consider putting in more robust processes for people with issues and challenges illustrated in our case studies, such as identifying people with memory loss/learning disabilities/mental health issues and supporting them appropriately.
8. System partners including NHS, ASC and VCSE organisations should invest in finding ways in which to create stronger, more joined up positive relationships.

Summary of Next Steps

1. This report should be considered by the East Sussex Health and Care Partnership Board to address the issues raised involving closer working with more than one agency in an integrated way.
2. Adult Social Care (ASC) should review the way it engages with its service users, making sure a diverse range of the population are given a voice to tell ASC directly what they need.
3. Create a way in which people who need social care services are able to not only access information, but guidance.
4. NHS and ASC staff need to be more informed of what integrated health and care support is available to individuals in their local communities. Primary Care Networks (PCNs) can be a primary vehicle for building a support knowledge bank.
5. Healthwatch East Sussex to work closely with NHS and ASC partners over the next 12 months to develop an evaluation framework for monitoring changes to be made by health and care partners, to be based upon user experience, with key milestones included.

Background

In September 2021, an individual contacted the Healthwatch East Sussex (HWES) Information and Signposting service with a harrowing story of how they felt that their father had been let down by the public bodies involved with his care which had left him in a very vulnerable position.



“This gentleman is not unwell, and was 100% independent 5.5 – 6 weeks ago, and is now stuck in bed, being lifted out with a hoist, and is having to wear incontinence pads for bowel and bladder movements. Where is the dignity?”



There was a thorough investigation into this family’s account of events which identified that whilst the correct procedures were followed, and appropriate responses were made, the family’s account clearly showed that Adult Social Care and NHS services were not joined up in this case¹.

Healthwatch East Sussex and its volunteer-led Social Care Task Group wished to establish if this family’s experience was a one off, or if there was a wider issue within East Sussex. In particular, whether other families and individuals felt that their health and social care needs were not being adequately met by the NHS, Adult Social Care and other services.

This prompted HWES to undertake a county-wide project initially aiming to:

- Collect and share the stories of people (including unpaid carers) who feel that they may not be receiving sufficient care for their needs from Adult Social Care and other services.
- Better understand *why* these people’s needs were not being sufficiently met; and
- Create a set of recommendations on what changes could be made to ensure that more people’s needs are better met in the future.

Both Healthwatch England and Healthwatch East Sussex have made looking at social care post-pandemic a key priority.

Healthwatch England have also produced a video case study which can be found on YouTube [here](#).

¹ It is important to recall that Adult Social Care is not responsible for meeting a person’s need for services if those services are required to be provided as part of the National Health Service under the National Health Service Act 2006.

Subsequent to HWES conducting its interviews, the House of Lords Adult Social Care Committee published in December 2022 its report on the adult social care [*called A “gloriously ordinary life”*](#): spot light on adult social care”

The Committee heard the voices of unpaid carers and how exhausted carers are by the pressure to provide care that is placed on them by the assumption, held by our society and policy makers, that social care happens first and foremost in the family circle. One significant problem which the Committee heard many times was that there is little support for carers to navigate the system, which means that they often find themselves endlessly searching for advice and information, despite the very little time that they have to do so.

In many cases, neither carers nor the individuals themselves are signposted to information, which makes navigating the social care system especially difficult in a time of crisis. The Committee were also advised that frontline professionals, particularly in primary care, community settings and hospitals, should themselves have the knowledge, skills and training to signpost unpaid carers to the best and clearest pathways to resources and support. Too often they did not. Supporting carers involves multidisciplinary input from the health and social care services and the voluntary sector, and the support of primary healthcare professionals can make a significant difference to carers’ health and wellbeing.

Unmet Need and Safeguarding

This report looks at unmet social care needs in a broad way. We asked people about their lived experience of the social care system. Based on what we heard, the public appear to know relatively little about who oversees adult social care, how it works, how it is paid for and what help they might get.

The complexities of what is a health need or a housing need or a social care need and who might (if anyone) help or be responsible for helping was reflected in the interviews that were conducted.

Whilst the Care Act 2014 talks of eligible need for social care, which a local authority is legally responsible for meeting, people were not asked in this research about whether or not they had eligible needs and whether these needs were being met by Adult Social Care. Eligible needs are around basic personal care. Instead people were asked to talk about their lives and their experiences and feelings in circumstances where they or their family member had social care needs.

The aim of this project was not to examine whether or not Adult Social Care were meeting its legal obligations under the Care Act 2014, but for HWES to understand in a broader way the needs and experiences of people whose lives were impacted by the adult social care system.

It is possible to take a wider definition of social care. One such definition has been proposed by the social movement [*Social Care Future*](#): *“We all want to live in the place we call home, with the people and things we love, in communities where we look out for one another, doing what matters to us.”*

Some people might need support to do these things, whether because they have a disability or because they have developed a health condition as they aged. Social care provides this support. This definition implies that when it works at its

best, social care helps create a web of relationships and support that people can draw on to live their life with meaning, purpose, and connection, regardless of their age or disability.

Unmet social care needs should also encompass people with multiple needs for example, people with a learning disability or mental health condition experiencing difficulties accessing or using health services or with housing, debt, or benefit problems. Also, adults at risk of abuse or harm or those raising concerns of self-neglect. Multiple agencies may be involved, and their intervention may be under different pieces of legislation or government policy – for example, the Mental Capacity Act 2005, the Care Act 2014 or under NHS legislation or the Mental Health Act.

The Social Care Future definition of social care and its aims would equally apply to these cases, with the aspiration of social care helping to create a web of relationships and support that people can draw on to live their life with meaning, purpose and connection, regardless of their age or disability.

Methodology

HWES seeks to give a voice to people using health and social care services. As part of this objective HWES conducts interviews with people willing to share their experience with us. This subjective and qualitative approach can add value to data by drawing out a common core of experience to inform conclusions and make recommendations based upon people's lived experiences.

How we identified and selected the participants in the case studies.

We followed a research methodology developed and employed by Healthwatch England for its investigation into care needs.

This involved working with organisations in the community that were closest to the people we were keen to hear from. We also wanted to work with organisations with whom we had pre-existing relationships and who had strong connections within the communities they worked with.

These partners identified participants, interviewed them, and produced case studies from their stories. The findings from this process are set out later.

Our partner organisations were:

- **Diversity Resource International** (<https://driorg.com/>) created 5 case studies from individuals from diverse ethnic and cultural backgrounds.
- **Citizens Advice Bureau Eastbourne** (<http://www.eastbournecab.co.uk/>) created 5 case studies from individuals living on a low income.
- **Care for the Carers** (<https://www.cftc.org.uk/>) created 5 case studies from individuals who identified as unpaid carers.

Participant Demographics

We were keen to hear about the experiences of people from seldom heard or under-represented groups or communities living in East Sussex, as they may be less likely to be heard by social care and health professionals and decision-makers.

We decided to focus on three key demographics to ensure that we gathered stories from people from a wide range of backgrounds: unpaid carers, individuals from an ethnic minority background and people on low incomes.

It is important to recognise that many of the participants who provided us with case studies fell into more than one of these categories.

Consent

All participants were required to sign consent forms before participating in the project. The consent forms clearly stated the reason why we were collecting the information, as well as how we would use it (See Appendix A).

Suggested Interview Questions

To ensure that the various case studies gathered all the information we needed, we provided our partners with a list of interview questions to use as a guide when conducting interviews.

Along with these suggested questions we provided information on our rationale behind these questions.

These questions and the rationale were provided to Healthwatch East Sussex by Healthwatch England (See Appendix B).

Accessibility

Healthwatch East Sussex chose to closely follow the accessibility guidance provided by Healthwatch England in their Unmet Need Research Methodology Discussion Guide.

The guidance indicates that as these interviews were likely to touch on sensitive topics and face-to-face interviews would be the preferred approach. However, we recognised that face-to-face engagement might not be possible given the ongoing levels of COVID-19 infections locally. Interviews, therefore, took place online using Teams, Zoom, or another video-conferencing platform or over the telephone where participants were not comfortable meeting face to face or when it was considered unsafe to do so.

Participants were welcome to have a friend, family member, support worker or advocate present when undertaking their interviews to ensure that they felt comfortable and safe sharing their stories.

Also, to ensure that the interviews were as accessible as possible to people from diverse ethnic backgrounds, we provided additional funding for partners to provide translators where necessary.

We chose our target communities as it also links into our wider work at Healthwatch East Sussex which focuses on working with and for a wide range of diverse communities and people as part of our Equalities, Diversity, and Inclusion commitment.

Key Findings

The fifteen interviews conducted for this project all describe human suffering, hardship, and isolation. They highlight unmet social care need, gaps in wider health and care services and the needs of vulnerable people, including safeguarding.

Those interviewed included three main groups (some people fell within more than one group):

- Unpaid carers
- Individuals from an ethnic minority background
- People on low income approaching the Citizen Advice for advice on financial matters

Unpaid carers told of the enormous impact of caring on their lives, health and well-being. They spoke of anxiety and depression, of being tired and run down, of losing relationships and losing their sense of themselves, of losing time for themselves and some of suicidal thoughts.

“If it hadn’t been for a Care for the Carer Support worker’s help, I would have gone under.”

People spoke about their experiences of applying for or being referred to a carer’s assessment. Referrals were typically made by Care for the Carers. Some unpaid carers had been referred to or informed about Care for the Carers.

For example, the outcome of one assessment was not positive. As a result of her husband receiving a greater care package, his carer wife lost her respite care. Another person said the carer’s assessment had made no difference. This sentiment was echoed in another interview.

A further respondent gave up and didn’t pursue another carer’s assessment application until years later. One person was left confused and lacking in confidence about what future help might be received from Adult Social Care.

People with an ethnic minority background spoke of difficulties in communicating with those providing health and social care services and other services such as housing. They spoke of problems in understanding the adult social care system. They spoke of a lack of trust in the system. The impact is that support is not sought leading to unsupported caring and to anxiety and depression.

“My mother and I are afraid to ask for help”.

There were cases studies which highlighted vulnerable adults with multiple needs including health, money and housing problems struggling to deal with these problems. These cases were relayed by Citizens Advice as the organisation approached by those facing financial or housing difficulties. These cases often

required involvement not just of adult social care, but the health services, DWP and housing bodies.

Citizens Advice noted that over the past year it had been helping clients with greater levels of vulnerability and has ended up co-ordinating the client contacts with other agencies to ensure there are effective referrals which bring about necessary changes and improvements to a client's situation. They commented that:

“Strictly speaking, this isn't within [the Citizens Advice] remit as it goes beyond ‘advice’. However, it appears to be increasingly necessary to ensure clients receive the service from other agencies that they so badly need.”

The case studies provided by the Citizens Advice included adults with learning disability, memory loss or mental health conditions and outlined the difficulties for Adult Social Care in intervening in these cases. In particular, where a person does not want the involvement of Adult Social Care perhaps because of a lack of trust, or a referral being made when it hasn't been requested.

It appears from four of the case studies that the difficulties that clients faced were left unresolved. Some people who are vulnerable or who have diminished capacity to advocate for themselves reported not feeling sufficiently supported by Adult Social Care, despite advocates being available from ESCC for people without capacity and no representative. This is leaving people in vulnerable positions for long periods of time, which can have a negative impact on their physical and emotional wellbeing, as well as cause them significant problems in managing their affairs.

Two case studies described people living in isolation and in pain and with anxiety and depression and struggling to lead a fulfilling life. Neither person had been in contact with Adult Social Care (ASC), but their stories came via Citizens Advice as people seeking help for a housing or financial problem, but both spoke of the difficulties they were having with getting what they thought was appropriate medical treatment. One person said:

“I do not think this is what I would consider to be ‘life’.”

Our case studies suggest that there is scope to improve joined up working between agencies and voluntary, community and social enterprise organisations. In relation to unpaid carers, some people were referred to Care for the Carers by their GP or district nurse and Care for the Carers were able to refer to ASC or the NHS. For Citizens Advice case studies, it appears that it was forced to take on a role as co-ordinator to some extent, and those case studies outline the need for improved mechanisms for joint working.

Overall, the case studies revealed how many people struggle with a lack of knowledge of how the Adult Social Care system works, its relationship with other services and knowing who to turn to, for which services at what point and how to do so. However, people spoke positively of the guidance and support that they had received from Care for the Carers who are funded by Adult Social Care to provide information, advice and support to unpaid carers.

“Shirley expressed her appreciation for Care for the Carers for all the support they provided during her carer journey. They advocated for her, advised her, explained her rights, linked her up with other carers and enabled a Continuing Health Care assessment. They supported her to apply for a grant for ‘treats’ for her (like the first hair cut for two years) which boosted her morale and self-esteem and helped her get her identity back.”

The Case Studies

Of the 15 case studies collected, eight individuals gave consent for their story to be published and used to ‘shine a light’ on unmet need. All the case studies tell a ‘back story’ and conclude with an impact statement.

The published case studies can be viewed here:

1. [Case study one](#)
2. [Case study two](#)
3. [Case study three](#)
4. [Case study four](#)
5. [Case study five](#)
6. [Case study six](#)
7. [Case study seven](#)
8. [Case study eight](#)

Please note that where case studies have been provided anonymously, NHS and Adult Social Care are not able to comment on the specific circumstances of what people in these case studies describe and propose.

Conclusions

We have concluded that changes need to be made to minimise the risk of health and social care services failing to meet the needs of people, particularly those who face additional barriers in accessing services and support. We also conclude that health and care services need to find a way to integrate and work more effectively together.

Our case studies describe unmet social care need and reveal human suffering, hardship and isolation. The lived experience of the people interviewed chimes with the experiences given to the House of Lord's Adult Social Care Committee in its [report](#) published in December 2022.

The Committee wants to see a system that is not based on the assumption that families will automatically provide care and support for each other because no other choice is open to them. It argues that unpaid carers must get access to more short breaks from caring and better help to navigate the system. The Committee endorsed a broader definition of social care and said there should be an appropriate and funding settlement to support delivery.

HWES is aware of the constraints under which East Sussex County Council provides adult social care and the recommendations in this report take account of these constraints.

More positive, joined up working with other statutory organisations and the voluntary, community and social enterprise sector could have a positive impact for people with health and social care needs, some of whom also face financial and housing problems.

More resources should be invested in preventative measures with Adult Social Care, the NHS and the voluntary, community and social enterprise organisations working more closely together to stop people reaching crisis point.

Improving people's understanding and ability to navigate the adult social care systems is an essential element in making change for the better and is a change that can greatly assist people now even before any wider reform of social care takes place. Knowing who might help you and how is vital even if it is to find out that help will not come from Adult Social Care and that another form of support may be available and more appropriate in meeting people's needs.

Recommendations

As with the Key Findings, the following recommendations have been put together by a combination of Healthwatch East Sussex staff and volunteers and representatives of partner organisations contributing to this report.

1. There is a general lack of public awareness about Adult Social Care (ASC), what it is, who is responsible for providing services and how to access advice and services. We recommend that ASC, working with local voluntary, community and social enterprise organisations, should develop and implement a plan to better educate the public about what social care is, who is responsible for providing social care and how to access it online or in person. Implementation of the plan should be independently evaluated for its impact on the public, and then regularly monitored.
2. Adult Social Care should work with partners and in particular the Safeguarding Adults Board to develop and implement a plan to improve public awareness of safeguarding and who to contact with a concern. This plan should include raising awareness within the NHS and voluntary, community and social enterprise organisations likely to come into contact with adults who may need to raise safeguarding concerns. Implementation of the plan should be independently evaluated and regularly monitored.
3. Health and social care partners including ASC, NHS and VCSE organisations should develop a plan to provide information, advice and emotional support for Unpaid carers and people arranging for the care of a family member. This could consider funding a range of providers of advice, guidance and emotional support to unpaid carers, including peer groups. The plan should include how such services are publicised and ensure that Health and Social Care Connect can offer guidance, advice and support and to signpost effectively for those who ask for or need more support.
4. All health and care services, including Adult Social Care and the NHS should ensure that interpretation and translation services are provided for people whose first language is not English at all points in their support journey. This should include translatable web pages, forms and paper information in multiple languages, with sufficient interpreters available at all times and easily accessible. *We welcome Adult Social Care's offer to explore with us why local authority and NHS interpretation and translation services are not reaching people and whether this is worse in East Sussex than the rest of Sussex.*
5. Adult Social Care need to ensure that individual's assessments are done in a timely manner and seek to progressively reduce wait times in East Sussex². Assessments are prioritised based upon the level of risk and need resulting in many individuals, with lower-level needs having to wait months for an assessment with no support. This is having a real negative impact on peoples physical and mental health and causing financial hardship.

² A recent report from the Association of [Directors of Adult Social Care \(ADASS\)](#) showed that, nationally, as of 28th February 2022, 254,537 people were waiting for an ASC assessment, with 64,772 of those people waiting 6 months or more.

6. Health and care strategies and delivery programmes should identify and focus resources on preventative measures, rather than just crisis management. If ASC, NHS services and voluntary, community and social enterprise (VCSE) organisations can help to stop people reaching crisis point, this will in turn reduce demand and improve outcomes. We welcome collective discussions to look at more focus on prevention in the ASC and wider NHS strategies to improve understanding on appropriate pathways for prevention support.
7. System partners including Adult Social Care, the NHS and VCSE should consider putting in more robust processes for people with issues and challenges illustrated in our case studies, such as identifying people with memory loss/learning disabilities/mental health issues and supporting them appropriately. These needs should be flagged properly at the referral stage and followed through consistently.
8. System partners including NHS, Adult Social Care and voluntary, community and social enterprise organisations should invest in finding ways in which to create stronger, more joined up positive relationships. Better link-up and information sharing could improve the handling of multi-organisation cases and help remove barriers to people receiving the help they need.

Next Steps

In order to start putting the above recommendations into practice, Healthwatch East Sussex suggests the following next steps could be taken by Adult Social Care, the NHS and other services locally.

1. This report should be considered by the East Sussex Health and Care Partnership Board to address the issues raised involving closer working with more than one agency in an integrated way.
2. Adult Social Care should review the way it engages with its service users, making sure a diverse range of the population are given a voice to tell Adult Social Care directly what they need. Existing forums and groups that provide feedback to ASC need to regularly refresh their membership to ensure diverse representation. It would also be helpful if feedback received this way is published so learning across support agencies can be shared.
3. Create a way in which people who need social care services are able to not only access information, but guidance. This could be achieved by building upon the work of Health & Social Care Connect (HSCC) and ensuring advisors who work with individuals better understand what they are eligible for, how they can apply for it and how to manage while they are awaiting support.
4. NHS and Adult Social Care staff need to be more informed of what integrated health and care support is available to individuals in their local communities. Primary Care Networks (PCNs) can be a primary vehicle for building a support knowledge bank. This may allow them to signpost individuals more efficiently to services which can improve their wellbeing.
5. Healthwatch East Sussex to work closely with NHS and ASC partners over the next 12 months to develop an evaluation framework for monitoring changes to be made by health and care partners, to be based upon user experience, with key milestones included. Healthwatch will publish a report on progress made from a service user perspective in 2024.

Appendices

Appendix A

East Sussex Community Voice asked all project participants to sign a consent form (see image below). At the time of publishing, 8 of the 15 participants had consented to have their full case studies shared in the public domain. These case studies can be accessed via our website (www.healthwatcheastsussex.com) or by contacting our team directly (info@healthwatcheastsussex.co.uk).



East Sussex Community Voice Consent Form

These are used to record the consent process and a person's agreement to take part in the project.

The individual should be given a copy of the form and the researcher should retain the signed original. The original consent forms can be digitised and stored securely, permitting the original copies are destroyed securely.

A digital copy of this consent form must be provided to East Sussex Community Voice.

Consent form for the use of your data

Please tick all 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.	<input type="checkbox"/>	<input type="checkbox"/>
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.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to my interview being recorded, and a transcript being written and sent to Healthwatch East Sussex.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that information I provide will be used for producing research reports and blogs.	<input type="checkbox"/>	<input type="checkbox"/>
I agree that my information can be quoted in research outputs.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that any personal information that can identify me, such as my name or where I live, will not be shared beyond the project team, unless I separately consent to this.	<input type="checkbox"/>	<input type="checkbox"/>
I give permission for the information that I provide to be archived and re-used.	<input type="checkbox"/>	<input type="checkbox"/>
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		

Appendix B

It is important to remember that the questions below are meant to be a **discussion guide** and not all the questions would be relevant for every single participant. We have included a rationale after every theme so that it is clear why we are asking these questions. Remember, the questions should help you to start and steer the conversation with the interviewees in the right direction. Please avoid using them as a survey questionnaire, as you might miss out on nuanced rich data if you simply adhere to asking these questions and writing down their answers. If an interviewee says something that you think is worth exploring, **please do dive deep** and explore what they are saying in more detail.

Note: it is likely that the people you interview will share experiences or questions that require further information. In order not to disrupt the flow of the interview, we recommend you answer any questions and offer signposting information at the end of an interview. You can always follow up with the participants after the interview with more information.

For service users

Background:

- 1) What is the nature of your condition, the thing that causes you to feel you need support?
- 2) What are the things in your life that you are no longer able to do because of your condition, but which you would like to be able to do, with the right support? These could be day-to-day tasks around the house, or the social and leisure activities you enjoy.
- 3) What support would help you to achieve these?

***Rationale:** These questions will help give some background into the nature of the person's condition, what their expectations of social care support are, and what they would like to be able to do with the right support.*

Experiences of social care:

- 4) Looking back, what led you to ask for extra support from the social care system? Did you make the decision, or did someone else, such as a friend or family member, or did someone else? This could be a referral from your doctor, or advice from someone in the voluntary sector.
- 5) When was this?
- 6) What were your next steps after realising you needed formal support?
 - a) Where did you look for information and advice?
 - b) Who did you contact?
 - c) How long did it take you to formally apply for something, and what did you apply for?
 - d) What services were you using during this period? E.g., GPs, A&E, other hospital services, patient transport services, social prescribing, care from local charities or support groups?

e) While you were waiting for help, did you need support from friends and family? What kind of support did you need?

f) How long did it take you to get help? And what was the impact of this waiting period?

7) When you decided to ask for help, what did you expect social care would be able to help you with?

8) And, did the social care support you were provided with meet those expectations?

a) How personal was the care? Did you feel involved in deciding what social care you needed/could get?

***Rationale:** these questions will help to show the person's journey through the social care system, how and why they first entered the system. If they had to wait for support, we'd like to know what the impact of this waiting time was, including if they had to access other services or ask for help from loved ones. If the person received social care, we'd like to know whether this met their expectations/needs. Are they able to do the things they wanted to when they asked for support?*

Impact of needing social care:

9) Are you in employment, either full or part time?

a) How easy or difficult have you found it to get into work?

b) How has your condition impacted your experience of working?

10) Are you on any benefits?

a) Are any benefits you're on due to your condition?

b) Do you feel you are on the right benefits?

c) Have you ever received any support and guidance on what benefits you should be on, how much you should receive and how to apply?

11) Has your condition impacted where you live?

a) Does your housing meet your needs?

b) If not, have you been able to make any changes to the housing that you need, or has something prevented you from doing this?

***Rationale:** these questions will show the wider impact of social care support. Does not receiving support have a knock-on effect on people's ability to work, their benefits status, and/or their housing?*

For unpaid carers

*Please note: we'd like you to interview **unpaid carers**, not care workers.*

Background:

1) Do you consider yourself to be a carer?

2) What is your relationship to the person for whom you care?

3) What is the condition of the person for whom you care? How high is their level of need?

4) How long have you had caring responsibilities?

5) Are you a full-time unpaid carer?

a) If not, roughly how many hours per-week?

6) Has the amount of time you spend on caring been constant at its current level, or increased/decreased from a lower level?

a) If it has increased or decreased, from what level? Was this change gradual or sudden?

***Rationale:** these questions will give background about the person's views about caring, their responsibilities as an unpaid carer and if these have changed over time, and the relationship with the person for whom they care.*

Impact of being an unpaid carer – daily life:

7) How has being an unpaid carer impacted your day-to-day life?

8) Have your caring responsibilities impacted your ability to work?

a) If so, has this led to a reduction in income, or worsening of your overall financial position, or have benefits covered this?

***Rationale:** these questions will show the impact of being a carer on the person's day to day life, and ability to work. This is a broad question. We'd like to know about the impact of caring responsibilities on a carer's average day – are they able to sit down for a cup of tea? Has being a carer had a knock-on effect on their other responsibilities, or their finances?*

Impact of being an unpaid carer – wellbeing:

9) How is your physical and mental health generally?

a) Do you think having caring responsibilities has negatively impacted your health?

10) Do you ever feel that your physical or mental wellbeing is limiting the quality or amount of care you can provide?

a) If yes, how so?

11) How has being a carer impacted your emotional wellbeing?

a) Has this changed over time?

b) Is there any support you think you need which would improve your emotional wellbeing?

***Rationale:** these questions should uncover the impact of being an unpaid carer on a person's physical, mental, and emotional wellbeing. We'd also like to know what support people would like in order to improve their wellbeing.*

Impact of being an unpaid carer – relationships:

12) How have your caring responsibilities impacted other relationships in your life?

a) Has your social interaction become more limited?

b) What about your relationships with friends or family?

13) Do you think being an unpaid carer has changed your relationship with the person for whom you care? This could be both positive and negative.

a) If yes, how so?

b) If for the worse, would some level of social care help?

***Rationale:** these questions will show the impact of caring responsibilities on a person's relationships. These could be wider relationships with friends and family, general social interaction, and/or the relationship with the person for whom they care. Note that changes could be positive as well as negative. If there are benefits to caring responsibilities, we'd like to hear them!*

Further Support:

14) Is there any practical or financial support you think you need which would improve the quality or extent of the care you are able to provide? a) If you were able to access support, what would you like to be able to do?

15) Have you ever asked for a 'carers assessment' from your local authority (council)?

a) If yes, were you given an assessment?

b) Were you given more practical support? Were you provided with information on financial support? Were you provided information on respite services, or day care opportunities for the person you care for? Were you happy with the support provided?

c) If no, have you sought information from other places to help you support the person you care for?

16) If the person for whom you care were able to access social care, would you reduce the hours you spend as an unpaid carer, or maintain them? In other words, is your expectation for social care to reduce the time you spend caring, or to add extra support alongside the caring you already do? a) If you were to reduce the time you spend caring, what would you like to use the time to do? For example, would you work, volunteer, increase social interaction with friends and family, use it as respite time etc.

***Rationale:** we'd like to know what support the social care system could offer to unpaid carers in order to improve both their quality of life, and the care they are able to give. We'd also like to know whether current support that is on offer meets their needs.*